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How do older people negotiate social care support? A study of the perspectives of older people, their families and other stakeholders

by

Kathryn Margaret Wicks

Thesis for the degree of Doctor in Philosophy

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ABSTRACT

FACULTY OF SOCIAL SCIENCES

Gerontology

Thesis for the degree of Doctor of Philosophy

HOW DO OLDER PEOPLE NEGOTIATE SOCIAL CARE SUPPORT? A STUDY OF THE PERSPECTIVES OF OLDER PEOPLE, THEIR FAMILIES AND OTHER STAKEHOLDERS

Kathryn Margaret Wicks

Current English social care policy advocates 'active ageing', 'ageing-in-place' and 'independence', whilst promoting 'choice and control'. Yet research has shown that these competing policy agendas relay mixed messages to older people. Latest figures show that over half of older people aged 65+ live with two or more health conditions, which affect their ability to carry out activities of daily living (ADLs) and instrumental activities of daily living (IADLs) in and around their home environment. Older people face an increasing risk of being left unsupported, owing to ongoing consequences of austerity measures affecting formal social care provision in recent years.

Many studies have focused on *who* provides support, but little is known about *how* older people arrange support. This thesis aims to understand how older people who are living in the community negotiate arrangements for support and assistance with ADLs and IADLs from formal and informal sources, using a qualitative research approach. Semi-structured interviews were conducted with older people aged 65+ (n=8) and members of their formal and informal support network (n=19). Data were analysed by combining thematic analysis with a symbolic interactionist approach. The findings indicate that older people tend not to adopt a direct approach for help with ADLs and IADLs from informal members, preferring to adopt 'hinting' to highlight unmet need. Older people usually adopt a direct approach when negotiating with formal members, or with informal members if recent reciprocity is evident. Importantly, older people accept help if it is offered. The findings have two main policy implications: First, to highlight awareness to formal support members about the language used by older people to draw attention to unmet need. Second, to ensure that older Personal Budget holders receive advice and support to make contingency support arrangements in emergency situations.

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DECLARATION OF AUTHORSHIP

I, Kathryn Margaret Wicks declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

How do older people negotiate social care support? A study of the perspectives of older people, their families and other stakeholders

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission.

Signed:

Date:

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Definitions and Abbreviations

ADL	Activity of Daily Living
CLC	Care Life Cycle project
IADL	Instrumental Activity of Daily Living
HA	Housing Association
ONS	Office for National Statistics
PA	Personal Assistant
PB	Personal Budget

Chapter 1 Introduction

It is widely accepted that people are living longer than their counterparts a century ago. According to the 2011 Census data, older people aged sixty-five and above numbered 9.2 million in England and Wales, comprising 16% of the overall population (ONS 2013). Males aged 65 living in England in 2016 are likely to live for another 18.70 years and females for a further 21.10 years (ONS 2017a). People are generally living for longer because of advancements in medical treatments and access to better standards of living (ONS 2017b). Provided the status quo remains, recent life expectancy figures suggest that a male born in England in 2016 is likely to live until the age of 79.5 and a female until the age of 83.1 (ONS 2017). Hence, barring a human orchestrated or natural disaster, the trend for people to die much later in life is likely to continue into the foreseeable future (ONS 2014; Mortimer and Green 2016).

However, there is no guarantee that the extra years of life will be spent in good health (Mortimer and Green 2016). Whether a person is healthy in later life is largely dependent on choices made earlier in the life course, which part of the country they live in, the education they have received and their financial status (Marmot 2010). In 2012, 58% of older people over the age of 60 were living with chronic diseases such as arthritis, diabetes and high blood pressure (Ham *et al* 2012), affecting the extent to which they can carry out everyday tasks in and around the home by themselves. More people are expected to be living with three or more chronic diseases by 2018, and the percentage of older people requiring social care support is predicted to increase by 61% within the next fifteen years or so (ibid.). Recent figures indicate that 24% of males and 31% of females who are aged 65 and older required assistance with one or more activities of daily living (National Statistics 2017).

An accurate number of older people in England receiving some form of help with everyday tasks is unknown, mainly because members of older people's own support networks, such as family, friends or neighbours, provide it, often on an ad hoc and informal basis (McNeil and Hunter 2014). Help is also obtainable through a variety of other sources: Older people can pay privately for services needed by, for example engaging a cleaner or gardener. Less wealthy individuals may qualify for publicly funded support with everyday tasks, usually paid via a Personal Budget (PB) from their local

Council. It is not uncommon for older people to arrange help from a combination of different sources to meet their support needs (Dunér and Nordström 2006). Most research has focused on what support is provided or who has provided it. However, there is a general lack of research investigating how older people negotiate support which they receive at home in England (Porter 2005).

1.1 Rationale and policy relevance

1.1.1 Rationale

This thesis explores how older people arrange or negotiate the care and support which they receive in their home environment. Little research has been carried out in England since the late 1980s and early 1990s investigating how older people arrange social care support (Qureshi and Walker 1989; Finch and Mason 1990; Finch and Mason 1993). Have the factors affecting negotiation of social care support altered over the intervening years? Understanding how and when older people choose to negotiate support (and when they choose not to) is crucial for policy-makers to ensure that policy measures are directed towards older people with greater care and support needs and to provide support to prevent those with lower levels of support needs from becoming critical.

Research indicates older people choose not to contemplate the possibility of what might happen if they need help with everyday activities unexpectedly (Price *et al* 2014). In addition, few older people anticipate what future support arrangements should be in place if their health deteriorates in the future (Samsi and Manthorpe 2011). Yet older people report better overall health outcomes when they become involved in their own support planning process (Wall and Spira 2012). The setting where social care support takes place is another key consideration, as evidence suggests that it is beneficial for older people to remain in familiar surroundings for as long as possible (Hwang *et al* 2011; Sixsmith *et al* 2014; Consultus Care and Nursing 2014). In addition, research has suggested that receiving treatment and advice from the same doctor or healthcare team is important to one's long term health and well-being (Stokes *et al* 2005). Yet older people receiving visits from formal state care and support staff are invariably visited by different people. Little appears to have altered in this trend within the last twenty years

(Ware *et al* 2003; Francis and Netten 2004; Glasby and Littlechild 2009; Lewis and West 2014).

Most research conducted about social care support and older people in England has focused on <u>who</u> provides support, rather <u>how</u> support is negotiated or arranged (Silverstein *et al* 2006; van Gaalen *et al* 2008; Willyard *et al* 2008; Lashewicz and Keating 2009; Sims-Gould and Martin-Matthews 2010; Grundy and Read 2012). This thesis investigates how older people in England negotiate the support which they need with everyday tasks in and around the home. In particular, the thesis explores strategies which older people adopt when negotiating support from others. The emphasis is to uncover older people's "theories of negotiation" (Strauss 1978: 237) to gain a deeper understanding of how and when they arrange support to meet their support needs.

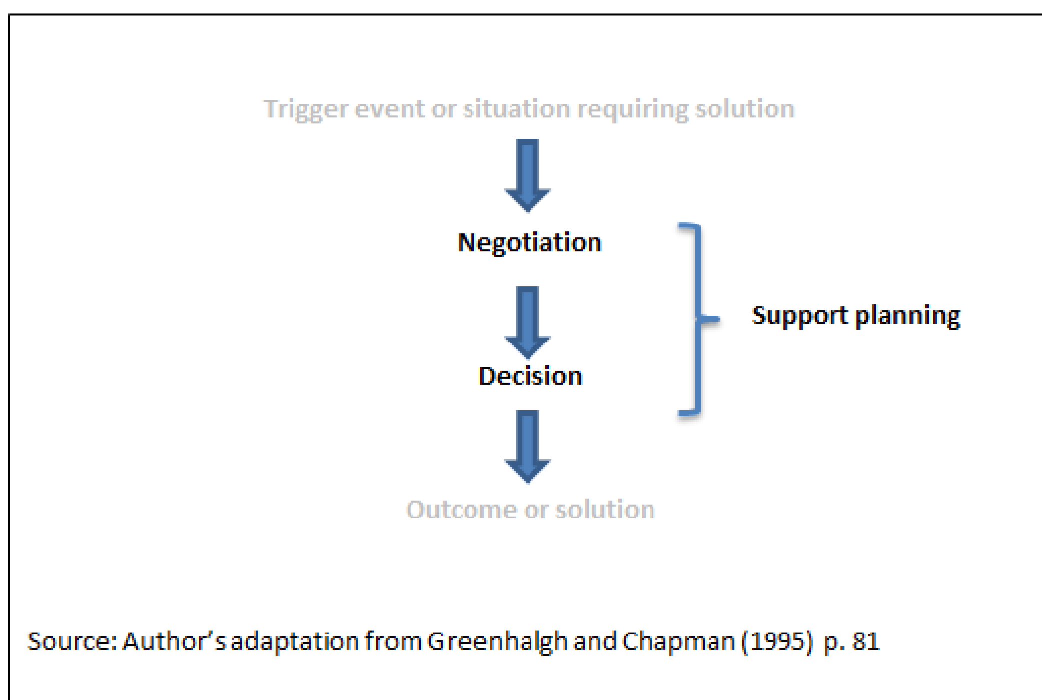


Figure 1: Support Negotiation Process (adapted from Greenhalgh and Chapman1995:81)

Figure 1 shows, in its simplest form, a conceptualisation of four steps in the support negotiation process: first, a 'trigger event' or situation arising which requires resolution; secondly, negotiation of support; third, a decision is made; fourth, an outcome or solution. The 'trigger event' refers to a support needs-based situation which precipitates the requirement of support. The next step is where negotiation of support takes place: an older person appraises the situation and may (or may not) interact with others to

negotiate support. A decision about what to do is then made (accepting support offered, rejecting support offered, negotiating a different solution, doing nothing). The outcome or solution is where needs are either met or unmet. This conceptualisation of support negotiation has been adapted from Greenhalgh and Chapman (1995), as the focus of the present research is on the process of how older people negotiate support that they receive to meet their needs, rather than simply reporting the outcome of negotiations. Other models of care and support decision-making were considered, in particular, the model used by Levkoff *et al* (1999), which conceptualised the steps which informal carers of older people with dementia took to obtain assistance from formal sources of support. However, Levkoff's model (ibid.) was not considered appropriate in the current research because its focus was on health outcomes rather than negotiation of social care support.

Most closely aligned research carried out in England has either investigated 'trigger events' or situations requiring a solution, with the main focus on health-related events resulting in hospital treatments and discharge (Glasby *et al* 2007), or the solution itself, such as investigating who provides support to older people, what type or how effective such support was (Silverstein *et al*, 2006; van Gaalen *et al* 2008; Willyard *et al* 2008; Lashewicz and Keating 2009; Sims-Gould and Martin-Matthews 2010; Grundy and Read 2012). The social support decision-making process has been investigated to some extent, mainly using qualitative data (Jenkins 2000; Tetley *et al* 2009; Tetley 2013).

However, little research has been conducted in England which investigates how social care support has been negotiated by older people. Most research focusing on aspects of support negotiation was conducted in the late 1980s, 1990s and 2000s (Qureshi and Walker 1989; Finch and Mason 1990; Finch and Mason 1993; Matthews 2002; Horton and Arber 2004). One reason suggested for the lack of research relating to the negotiation process itself is because the people involved in the planning process are "…assumed to be synonymous with helping networks" (Smerglia *et al* 1988:308). In other words, the individuals who carry out social care support tasks are presumed to have also been involved in the negotiation process (Matthews 2002). Additionally, the outcome of the negotiation process, that is, the support solution that emerges as a result, is considered much easier to identify, capture and evaluate, rather than constructing a representation of the negotiation process itself (Thompson *et al* 1995). It is important for policy-makers to understand how older people negotiate the support they need to carry out tasks in and

around their home and to identify how current policy might be adapted or introduced to facilitate the support negotiation process.

1.1.2 Policy relevance

Social care policy for older people in England is currently under review. In November 2017, the present Government ordered a comprehensive investigation into social care, in particular, how an older person pays for it over their lifetime and to identify possible areas to be reformed (HM Government 2017). The findings will be disseminated in a Green Paper which is due to become available by July 2018 (Parliament. House of Commons (2018)). Currently, state support arranged and delivered by adult social care departments of local Councils is means-tested, as individuals in England are not automatically entitled to receive free state support (ADASS 2014). Eligibility depends on a combination of the older person's level of support need, as well as their financial circumstances (ibid.), which is further explicated in Chapter Three. Local Councils are funded in part by central Government and partly by their electorate (National Audit Office 2014). Since 2007, successive Governments have maintained promoting 'choice and control' for service users of state social care support as part of the personalisation policy agenda (Her Majesty's Government 2012; Department of Health 2015; Department of Health and Social Care 2018). Another policy emphasis is to enable older people to continue to live in their home environment for as long as possible (ibid.). Since 2007, it has been possible to receive state social care support as a personal budget (National Audit Office 2014). However, in practical terms, older service users' personal budgets are more often managed on their behalf, rather than received as direct payments (Carr 2011; Age UK 2013; Baxter *et al* 2013; Routledge and Carr 2013). In addition, evidence shows that older people tend to receive smaller personal budgets than other service users (Forder 2008; Carr 2011). Yet older people are the largest group of recipients of formal social care (ADASS 2017). Since 2010, social care funding levels have decreased by 31%, which has had a significant impact on how local Councils have chosen to deliver care and support to service users (ibid.). Since 2012, there have been significant changes to the criteria to assess whether an individual is eligible to receive state social care support, which are adopted by local Councils and a greater focus on individuals with 'severe' as opposed to 'mild' or 'moderate' needs have resulted in fewer older people qualifying for state support (ibid.). The combined effect is many older people are now ineligible to

receive state support in cases where their needs are less severe, which has led to higher admissions of older people to hospitals via Accident and Emergency departments (National Audit Office 2014; Age UK 2014). Against this background, an examination of how older people negotiate social care support is both timely and has clear policy relevance.

Little is known about how older people negotiate support needs when arranging personal budgets or help from other sources, particularly from privately funded sources or informal sources. This qualitative, longitudinal research investigates how older people negotiate social care support from the sources available to them. The outcome of the research highlights practical issues faced by older people and to influence future policy direction by identifying challenges faced by older people in negotiating social care support. In addition, the findings of this research informed the Engineering and Physical Sciences Research Council-funded research project "The Care Life Cycle: Responding to the Health and Social Care Needs of Ageing Society" (CLC Project), which investigated and modelled the supply and demand of social care within the ambit of an ageing society (University of Southampton 2015).

1.2 Research questions

The overall question this thesis examined was "How do older people in England negotiate social care support?". The reason for undertaking this investigation is because little is currently known about what influences older people to seek assistance from particular avenues of support, whether from private, voluntary, state or informal sources. To provide deeper insight into the thesis enquiry, four sub-questions are addressed:

1. How is social care support from different sources negotiated by older people?

The main aim of this thesis is to understand how older people approach negotiating support with everyday tasks which they can only achieve with assistance from others. The thesis explores different negotiation tactics employed by older people with different members of their support network and the effect, if any, that those strategies had on the relationship dynamic and fulfilling the task.

2. To what extent do support arrangements change over time?

This thesis also sought to uncover the extent to which support arrangements are renegotiated by older people over time: do older people seek support from the same individuals over time? Research has tended not to provide a longitudinal approach to care and support and this thesis aims to provide a better understanding of the factors underpinning changes in support provision.

3. What barriers or facilitators are available which influence older people to negotiate support from different sources?

Another aspect of this thesis enquiry is to understand issues which might pose a barrier to older people seeking support from one source over another, and what might provoke negotiation of support from a particular source.

4. How do older people negotiate arrangements within a personal budget and what factors influence that choice?

Little is known about how older people negotiate support within a personal budget. This thesis aims to uncover the experiences of older service users who receive state support as direct payments and who negotiate their own care and support arrangements.

These thesis sub-questions were shaped by an initial investigation of existing studies which focused wholly or partly on social care support received by older people within their home environment. Qualitative research, in the shape of a longitudinal case-study approach was chosen to elicit the data needed to address the overall thesis enquiry. The rationale behind, explanation of and reflection on the methods chosen are explained in depth in Chapter Five.

1.3 Structure of the thesis

Chapter Two to follow provides definitions of the key concepts used within this thesis, namely, older people, social care support, sources of social care support, types of social care support and the concept of negotiation. Chapter Two also discusses the theoretical bases of the research. Social care policy relevant to the time of the data collection is critically examined in Chapter Three.

Chapter Four comprises a critical study of literature surrounding negotiation within the context of social care support, in particular, types of negotiation, negotiation strategies, research surrounding who provides support and older people and support networks. Chapter Four concludes by highlighting the gaps in knowledge which have been discussed within the critical literature review.

Chapter Five then provides a comprehensive explanation and justification of the methodology adopted within the thesis: in particular, an analysis of the structure of the research, its methods, sampling and recruitment strategies, how the research questions were answered, how the data were collected and analysed and consideration of ethical issues present in the research.

Chapters Six presents the findings from the first stage of the field research which took place between 2013-2014. Participant profiles are presented, followed by the results from thematically analysing cross-sectional reports from the case studies of three participants.

Chapter Seven presents the descriptive findings from the second stage of the research, which took place between January 2015 and July 2015. Profiles of the participants are presented, together with the types of support provided by the older people's support network.

Chapters Eight and Nine provide an analysis of the case study interview data. A discussion of these findings is presented in Chapter Ten, where the research results are contextualised within relevant literature, together with a critical assessment of the contribution of the research conclusion and recommendations for policy-makers and future research direction based on the thesis findings.

Chapter 2 Concepts and Theoretical Context

2.1 Overview of the chapter

This Chapter provides a narrative literature review to define key concepts which are integral to the main thesis enquiry and research sub-questions, which have been outlined in sub-section 1.2 above. A discussion will follow about theoretical underpinnings and considerations in relation to this thesis. Finally, a conceptual framework of social care support negotiation will be presented.

2.2 Definition of key concepts

The main thesis enquiry is "How do older people living at home negotiate social care support?". It is important to be clear about the key concepts used in this thesis to provide credibility to the research findings (Berg and Lune 2012). These key concepts have been identified as: older people, social care support, need and its measurement and the concept of negotiation. Each will be defined in turn.

2.2.1 Older people

The focus of this research is to find out how older people negotiate social care support at home from others. The reasons for choosing older people as main research participants are twofold. First, the outcome of the research informed the CLC project (see sub-section 1.1.2) which examined the supply and demand and health and social care within the ambit of an ageing society. In addition, this research is being conducted in fulfilment of a doctorate in Gerontology, which is "…the science concerned with the study of ageing" (Victor 2005:1).

It is important to classify who older people are for the purposes of this thesis to introduce an element of conceptual rigour (Bryman 2008). Older people are defined as those aged 65 and over because by this age, almost a million individuals will find it hard to perform one or more ADL (Age UK 2014) and therefore are likely to experience some form of "unmet need for social care" (Vlachantoni 2017:1). In addition, the thesis explores the ways in which older people negotiate social support from their support network, which is

based on the extent to which they are able to find a way to meet their needs. Both older males and females are included as participants. In England in 2013-14, figures suggested that at the age of 65, males were projected to live to the age of 83.8 and females to 86.2. Both sexes were projected to experience about 50% of the intervening years in "good health" although females were projected to have a slighter shorter healthy life expectancy than males (ONS 2016:3)

2.2.2 Defining social care support

The legal definition of social care is used to define support received with social care tasks which is found in Part 1 of the Health and Social Care Act (2008), Section 9(3) which:

> "…includes all forms of personal care and other practical assistance provided for individuals who by reason of age, illness, disability…or any other similar circumstances, are in need of such care or other assistance"

The social care activities appearing within the legal definition are broad. For the purposes of this thesis, 'personal care' includes support with activities of daily living (ADLs). 'Practical assistance' means support with instrumental activities of daily living (IADLs). ADLs are classed as essential tasks which an individual performs as a part of their everyday routine, such as bathing and showering, using the toilet and continence, dressing, eating and general movement (Vlachantoni *et al* 2011; Whitehead *et al* 2013). IADLs are tasks which facilitate living self-sufficiency, such as laundry, housework, changing bed linen, gardening, grocery shopping, travelling, making telephone calls, taking medication and managing finances (ibid.; ibid). For the purposes of this research, these definitions of ADLs and IADLs will be adopted to include any and all tasks that older people negotiate support arrangements with others to fulfil and help with these tasks will be referred to as 'support'. It is usual for an older person to carry out some or all of these tasks themselves and to negotiate support to perform from a combination of different sources in order to meet their needs (Alcock 2008; Whitehead *et al*, 2013; Consultus Care and Nursing 2014; Brennan-Ing *et al* 2014). Different sources of support are defined in section 2.2.3 below.

2.2.3 Social care support activities

Informal support is generally provided via an individual's unique support network (Qureshi and Walker 1989; Antonucci *et al* 2013; Brennan-Ing *et al* 2014). Informal support means unpaid help with ADLs and IADLs. Informal support members are individuals within an older person's support network who are known to an older person, whether a relative, friend or neighbour (ibid.). Informal support can also be provided from other sources, such as by volunteers, unpaid helpers or members of community groups affiliated with charities, churches or community groups (Qureshi and Walker 1989). An individual's support network is established throughout their lifetime and is dynamic in nature (Antonucci *et al* 2013). Research suggests that within the network there is a 'pecking order' of those from whom an older person receives support (Qureshi and Walker 1989; Brenning-Ing *et al* 2014). Older people generally receive support first from family members, such as a husband or wife, or if this is not possible, then from a daughter, a daughter-in-law, a son, or other family members. If family is not available, then support is sought from friends, neighbours, volunteers and then from formal sources (Qureshi and Walker 1989).

Formal support means receiving assistance with ADLs or IADLs which is provided on a contractual basis. Formal support can be arranged and paid for privately by an older person, known as a "self-funder" (Miller *et al* 2013). Formal support members include carers, cleaners, PAs and gardeners. If an older person cannot afford to pay someone to help them, then he or she may be eligible to receive formal help from the Adult Services department within their local Council (Department of Health 2013) (see sub-sections 3.2 and 3.3 below). Self-directed support, or personalisation characterise the current social care policy direction and these terms are explained in further detail in sub-section 3.2 below.

2.2.4 Stakeholders

Stakeholders for the purposes of this research are broadly defined as being any organisation or person known to the older person in a formal capacity and who is instrumental in negotiating or providing social care support. In this thesis, stakeholder will include any person who provides support on a contractual basis, such as health and social care professionals, cleaners and gardeners (Alcock 2008).

2.2.5 Social care need and unmet need

Identifying older people's social care needs comprises taking a holistic approach to their personal situation to ascertain what tasks they are and are not capable of accomplishing (Vlachantoni *et al* 2011). At its simplest, unmet need occurs when the level of support available to an older person is insufficient to meet their needs (Vlachantoni 2017). However, there is no universal standard by which to measure unmet need (ibid.), which makes comparisons between national and international data impracticable (ibid.). Two main ways in which scholars have defined unmet need is by taking either an 'absolute' or a 'relative' stance (ibid.:5). The former means an older person has no support with tasks that need to be carried out and the latter means that older people can carry out tasks to some extent, or can only carry out tasks with support from others. For the purposes of this thesis, older people's unmet need is conceptualised as encompassing both absolute or relative needs are unmet in order to understand what an older person might do in circumstances where he or she is unable to carry out a specific ADL or IADL task, or if it can only be fulfilled if they receive support from others (National Statistics 2017).

2.2.6 Concept of negotiation

Negotiation is a fundamental aspect of the thesis research and as such is essential to clarify its meaning at the outset. At its simplest, negotiation is "…a process that certainly leads to decisions about what to do…" (Provis 2004:95), a stance which largely corresponds with Finch and Mason (1993), who define negotiation as being "…the course of action which a person takes emerges out of his or her interaction with other people" (ibid.:60). The concept of negotiation was the subject of much academic debate in the fields of psychology, economics and management in the latter part of the Twentieth Century (Alfredson and Cungu 2008). However, due to its wide remit which covers a myriad of disparate scenarios, ranging from business deals, legal contracts, hostage talks, divorce settlements and so on, negotiation has been considered as incapable of satisfactory evaluation (Sycara 1990) or overall theorising (Strauss 1978).

A literature search was conducted to seek out literature to best inform how to conduct research into negotiation within a social context, which yielded few results. It is important to remind the reader that the aspect of negotiation being investigated within this research is not so much the outcome of the negotiation (within this research context,

this would mean the individuals who ultimately provide support), but the negotiation social "process" which preceded it (Thompson *et al* 1995, p. 31). One source was found which provided a structure for evaluating negotiation, the "social context framework" (ibid.:7). This framework can be utilised within this research to contextualise the negotiation interaction to facilitate providing a deeper insight into the process. Four basic components form part of this framework: "…negotiation parties, social knowledge and goals, social norms…and communication" (Thompson *et al* 1995, p. 7.).

Applying each of these components to the current research, the parties to the negotiation are the older person and others with whom he or she interacts with a view to arranging formal and informal social care support (ibid.). It is necessary to evaluate how much each party knows about the other in order to ascertain the nature of their relationship and the effect it might have on the negotiation process (ibid.). At the same time, exploring the motivations of each party to the negotiation, for example, reciprocity or obligation brings further insight into the process (ibid.). It is also important to identify the manner in which the parties usually conduct themselves as a person, in light of their professional, social or familial status (ibid.). Finally, examining the mechanics of how the negotiation is carried out, by, for example, a one-off conversation, or a series of exchanges of verbal or non-verbal (ibid.).

Strauss (1978) suggested that the venue of the negotiation is also important to consider because it can psychologically influence the behaviour of the parties (ibid.). An older person's home territory can be a source of empowerment for an older person in which to conduct negotiation (Spiers 2002). Therefore, a fifth component is added to the framework chosen for evaluating the negotiation process. Negotiation is also a fluid process, whereby our choices in life are shaped by our dealings with others (Connidis and Kemp 2008). The theory underpinning this research will be discussed in sub-section 2.3 below.

2.2.7 Concept of Biographical Disruption

Biographical disruption refers to an interruption to an individual's life caused by a health condition or accident which results in the need to re-evaluate one's daily routine and life plans and "entails a reorganisation of [an individual's] life on many levels" (Barry and Yuill 2012:194). The concept of biographical disruption also has relevance to this research

because some older participants were living with one or more long-term health conditions which adversely affected their lives, and which resulted in the need to negotiate or renegotiate the support needed with ADLs and IADLs. Biographical disruption was first conceptualised by Bury (1982) and refers to the three-phase process a person goes through when adjusting to the realities of developing a long-term condition affecting their health. In the first instance, an individual starts to become aware that something is wrong with them, known as the "'what is going on here'" phase (Bury 1982:169). The individual then starts to re-evaluate their sense of self and reflect on the potential impact which the illness is likely to have on them and their surroundings in terms of their needs. The final step is for the individual to consider what support is needed to meet their change in needs "the mobilisation of resources" (ibid.:170) and how to negotiate the support needed to meet their needs. It is this third phase which will be the main focus of this thesis.

One criticism of Bury (1982) is the portrayal of biographical disruption as a one-off episode at the outset of a long-term health condition. This assertion was challenged by Larsson and Grassman (2012), who carried out longitudinal qualitative research in Sweden, conducting interviews at different points in time with individuals with long-term health conditions. The main purpose of the research was to investigate the day-to-day experiences of living with a long-term condition and to understand its deeper meaning through the lens of biographical disruption. The authors found that biographical disruption was not a one-off event, but fluctuations in health tended to punctuate an individual's life as a series of biographical disruptions. As 'ageing brings an increased risk of life-threatening conditions…visual and hearing impairment [and] mobility problems from…osteoarthritis' (Lloyd 2012:113), these health problems can represent biographical disruptions to participants' lives, either in the form of a one-off 'trigger event' (see Section 1.1 above) or because of a gradual worsening of a condition. How individuals choose to adapt on the effects that changes in health conditions have on their ability to perform ADLs and IADLs (Yuill *et al.* 2010) has a clear relevance to this research, as the aim of this thesis was to explore how older people (re)negotiate support over time to meet their changing support needs. Having explored the key concepts which were relevant to this research, the theoretical underpinnings of this thesis will now be examined in the section to follow.

2.3 Theoretical considerations

This thesis explores older people's experiences of negotiating support. To gain a holistic view of support negotiations, the author chose to include the voices of different actors involved in support negotiations to make sense of the phenomenon from different angles. One general criticism levelled at social gerontology research has been a lack of application of theory to research (Bengtson *et al* 1997). The purpose of theory in gerontology is "…to provide different lenses through which to view and explain the phenomena of aging." (Bengtson *et al* 1997:S72). This research has been informed by three theoretical perspectives: symbolic interactionism, life course perspective and convoy model. A justification for the approach will be presented. A conceptualisation of the author's theory of the social support negotiation process appears in sub-section 2.4 below.

2.3.1 Symbolic Interactionism

Symbolic interactionist theory is used as a theoretical approach to the thesis enquiry to understand how older people approach support negotiations. The reasons for this are now explained. The three tenets of symbolic interactionism, according to Blumer (1969: 2) are:

> "(1) that people act toward things, including each other, on the basis of the meanings they have for them;
>
> (2) that these meanings are derived through social interaction with others; and
>
> (3) that these meanings are managed and transformed through an interpretive process that people use to make sense of and handle the objects that constitute their social worlds".

Utilising a symbolic interactionism lens facilitates an understanding of the meaning which support negotiations have for older people, which arise from interacting with others. Older people and members of their support network interpret the meaning of support negotiations by drawing on their experiences and interpreting how those experiences affect current support interactions. The meaning derived from negotiation stems from the ways older people and members of their support network members react to and interact with each other. Thirdly, the meaning of the communications is constructed in

the minds of older people and support network members based on their dealings with one another within the context of the support negotiations. To clarify, in the words of Fine (1993:64) "…we know things by their meanings, that meanings are created through social interaction, and that meanings change by social interaction". Thus examining the meaning that older people and their support network attributes to negotiations facilitates a better understanding of the nuances of what happens in practice.

One criticism of symbolic interactionism is that its focus is on "the present, not the past" (Charon 1995:23), in other words, an individual responds to what is happening in the here and now. However, individuals do act on the basis of what has happened in earlier in the life course and so the past is likely to have bearings on negotiations in the present, particularly in support planning by older people with members of their support network with whom they have built a relationship.

Symbolic interactionism is a perspective which has been favoured by many researchers exploring the social negotiation process because it centres on the premise that an individual constantly modifies their behaviour and "…construct[s] realities or social worlds in a process of interaction with others" (Victor 2005:34). Finch and Mason (1990; 1993), Connidis and Kemp (2008) and Coeling *et al* (2003) each framed their social negotiation research within symbolic interactionism because of the emphasis that an individual is affected by liaising and communicating with others and has the ability to make adaptations to their social strategies accordingly (Jones *et al* 2011). Flick (2014) suggests that a researcher must understand each participant as fully as possible because of "…the different ways in which individuals invest objects, events, experiences… form the starting point for research". (ibid:82). Thus, this research aims to understand and contextualise the interactions and feelings about support negotiation and thus understand their life-world.

2.3.2 Life Course Perspective and Convoy of Support Model

The life course perspective is used within social studies to understand how an individual's current circumstances have been moulded by past events and by changes in their social network (Arber and Evandrou 1993; Elder 1994; Kemp *et al.* 2013). Adopting a lifecourse approach to the research is relevant to gain a deeper understanding of individuals' opportunities to negotiate support in later life. Adopting the four ideas underpinning a

lifecourse approach to understanding and investigating social phenomena posited by Elder (1994) to the current research: Firstly, it is important to examine the potential effect of wider historical events taking place from the year when a person is born and their later life as this can offer a broader insight into their life choices and with whom and whether they negotiate support (Alwin 2012). Second, it is important to understand the ways in which an individual's life has become intertwined with others over time (linked lives) (*ibid.*). In other words, it is necessary to examine how an individual's informal support network has been shaped across their life course, in terms of understanding if, or when, for example, an individual formed (or dissolved) partnerships, had children or made friends (or not), and appreciating the changing nature of people's relationships with others. Third, it is important to understand when life events affecting social interactions occur such as marriage, divorce, childbirth, as these all impact on who an individual can negotiate support from in later life (*ibid.*) Fourth, while individuals ostensibly have the ability to choose with whom to negotiate from, it is important to recognise that they do not have the ability to choose the outcome of the negotiation (*ibid.*). The focus of this thesis is to explore how older people negotiate social care support, by way of a case-study approach. Thus older people and members of their social network were studied to investigate their 'circumstances, experiences and/or characteristics earlier in the life course to explain…subsequent outcomes' (Dannefer and Miklowski 2006:30). Adopting a lifecourse approach is of particular importance when examining how older people negotiate social care support from those whom they have known the longest, for example, family members and friends, not least because 'family relationships are multigenerational and diverse, and that one relationship does not operate in isolation from others' (Chambers *et al.* 2009: 28). In other words, connections between older people and their relatives are in a constant state of flux, as each family member moves into different familial roles throughout their lifecourse, for example, child, sibling, parent, grandparent: each role and relationship is continually constructed and reconstructed in light of family events such as births, marriages, divorces and bereavement (Hockey and James 2003). To understand why older people choose to negotiate social care support from specific individuals and not others requires examining their narratives through a life course lens to explore how the past impacts on the present (Davidson 2004).

Considering the potential effect of "cumulative advantage and disadvantage" taking place over an individual's lifetime is important in terms of the impact on their ability to negotiate support (Bengtson *et al.* 2009:16). In essence, cumulative advantage posits a general idea that if an individual gains some kind of benefit or access to resources earlier in their life course, then they are likely to be in a better position later in life (Crystal *et al.* 2017). In a similar way, if an individual experiences some form of disadvantage earlier in their life course, then the impact will accumulate and will negatively affect an individual later in life (O'Rand 2009). Two main circumstances where advantage or disadvantage might accumulate across an older people's lifecourse which affects social care support negotiation will now be discussed: in relation to an older person's state of health and their social network.

Health advantage or disadvantage can accumulate across the course of an individual's life, which results in inequities between individuals in old age (Marmot 2010). Some factors which affect a person's health can be traced to circumstances which occurred prior to birth, but are exacerbated by what happens during a person's lifetime in terms of 'social, economic, psychological and environmental' events and encounters (Marmot 2010:40). Thus, the effect of these events can either have a positive impact 'increasing esteem, life skills, resilience and resistance to ill health and encouraging 'health behaviours', or a negative impact 'destroying self-regard, undermining social skills and the ability to learn and creating the conditions for mental and physical ill health' (ibid.).

Applying a cumulative advantage and disadvantage lens to an individual's social network not only illuminates who has been and is currently a part of an individual's support network, but also who is not, and what effect this might have on who an older person could approach to negotiate support. In particular, the perspective highlights the accumulated impact of a multitude of issues which affect people's lives, including how many individuals a person has within their support network and also the nature of the relationships with their support members (Abramson 2016). Having a smaller support circle in later life can have a negative impact on older people's well-being because there are fewer people that they can draw on for support in times of need (ibid.). Cumulative advantage or disadvantage can accrue across the lifecourse as a result of having or not having children (Umberson *et al.* 2010). However, having children is no guarantee that they will provide social care support to their parents in later life, and similarly older

people without children tend to have a more diverse support network than those with children because their socialising opportunities are generally broader through necessity (Klaus and Schnettler 2016).

To aid the process of mapping the importance of individuals in an older person's life, a convoy model can be used to conceptualise the individuals or organisations within an older person's social network (Antonucci *et al* 2013; Kemp *et al* 2013). A series of three circles are drawn, each surrounding the other, placing the older person in the centre. The individuals closest either in terms of geography or emotional proximity are mapped accordingly: the nearer, the closer to the older person; the further, the more remote (Kemp *et al* 2013). The convoy model has already been used as a conceptual basis within support research to map how support is provided within existing research (Sims-Gould and Martin-Matthews 2010). As changes invariably occur within one's social network over the life course, the convoy model can be used to map how older people negotiate and renegotiate support over time and thus provide a holistic view of changes in the life course (Antonucci *et al* 2013; Kemp *et al* 2013).

2.3.3 Conceptual Framework of the research

Having considered theoretical bases of this research, a conceptual framework showing a theory of what might happen in social support negotiation process has been developed. The main purpose for creating a conceptual framework is to portray a visual representation of key aspects of a research study (Robson 2011). It serves as a useful tool to assist in evaluating "…which are the important features, which relationships are likely to be of importance or meaning, and hence what data are you going to collect and analyse" (Robson 2011, p. 67).

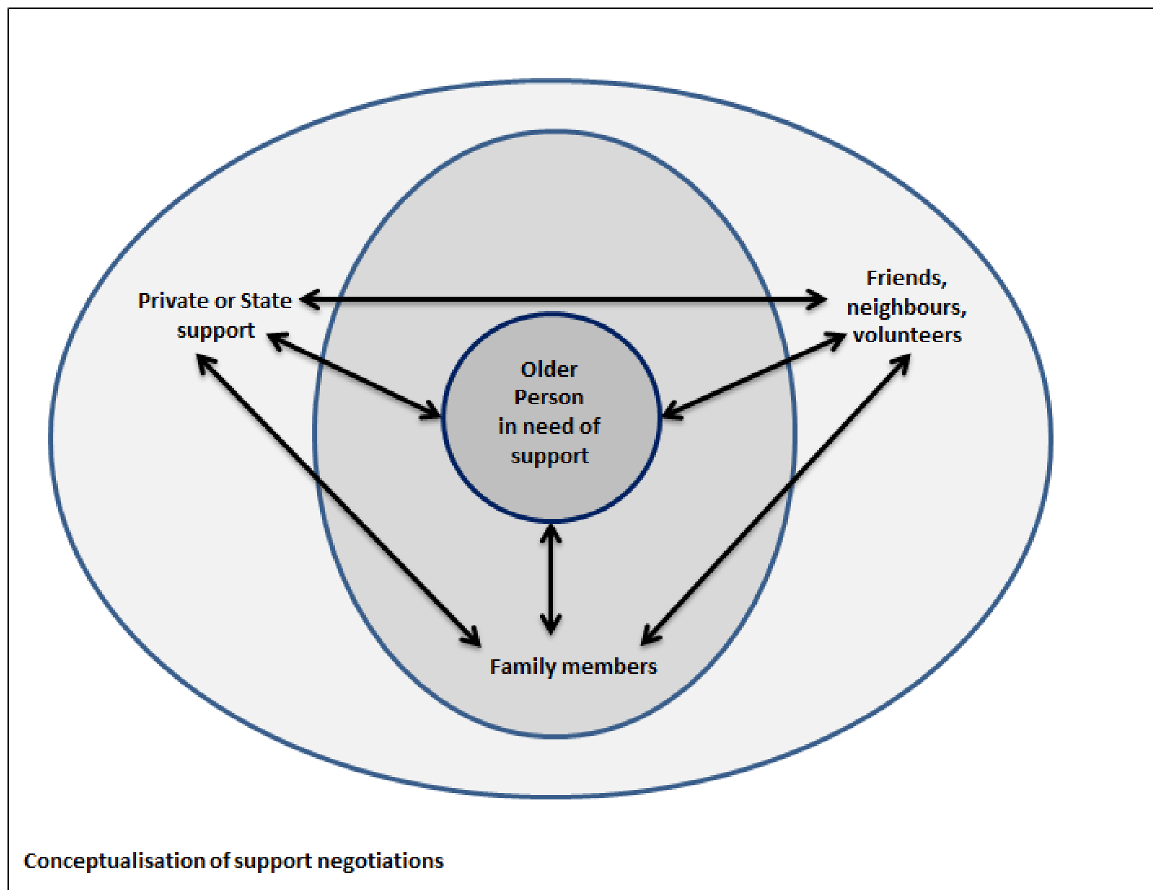


Figure 2: **Author's conceptualisation of the support negotiation process**

Having developed several earlier conceptualisations of the research, Figure 4 above represents the conceptual framework of the research. The conceptual framework will now be explained. A support network (see sub-section 2.3.2 above) has been used as a template to map the relationships existing between an older person as well as the various parties within their network who may be instrumental in the support negotiation process. The three concentrical shapes in Figure 2 above represent a theoretical conceptualisation of the parties involved in support negotiations and the colour gradients represent presumed emotional proximity to the older person on the basis of the research carried out by Qureshi and Walker (1989) and Kemp *et al* (2013). The double-arrowed lines represent the negotiation process to reflect that negotiations are a two-way process which can be instigated by one or more parties and conducted between one or more parties. The older person is positioned centrally, being the support recipient and thus the subject of the negotiation process.

Research suggests that it is more usual for an older person's blood kin to *provide* support than people who are not related, and applying for formal support from the state is usually

as a last resort in cases where informal support is not feasible (Qureshi and Walker 1989). However, what is unclear is which parties are instrumental in *negotiating* support and what form it takes.

The majority of researchers have proceeded with an assumption that there are only two parties to the negotiation process (Qureshi and Walker 1989; Matthews 2002; Horton and Arber 2004; Olaison and Cedersund 2006; Zechner and Valokivi 2012). In practical terms, an older person can negotiate support from a plethora of individuals and sources, both formal and informal (Zechner and Valokivi 2012). It is possible that support could be negotiated for an older person without their involvement if he or she loses his or her mental capacity (Egdell *et al.* 2010). However, an exploration of how older people lacking mental capacity is beyond the remit of this thesis, as this research has not received ethics permission to conduct research with individuals who are unable to provide informed consent to take part (see sub-section 5.8 below). Therefore, only individuals capable of providing their consent can take part in the research participants. It is important to note here that the conceptual framework shown in Figure 2 above altered after Stage Two of the field research was conducted (see sub-section 5.5.2 in the Methodology Chapter below).

2.4 Discussion

No single theory was identified in sub-section 2.3 above which elucidates or explains all aspects of the current research (Bengtson *et al.* 1997). Theory decisions were based in part examining how authors who have conducted research in similar areas have chosen to frame their research. Some authors have adopted a combination of theoretical underpinnings. For example, Kemp *et al* (2013) framed their research within a convoy model, life course perspective, feminist theory, social ecological perspective and symbolic interactionism in order to conduct research examining the relationships between individuals providing formal and informal care for older people in the United States. Similarly, Connidis and Kemp (2008) adopted a life course perspective and a symbolic interactionist approach when exploring relationships between brothers and sisters who were negotiating support between themselves on behalf of older parents.

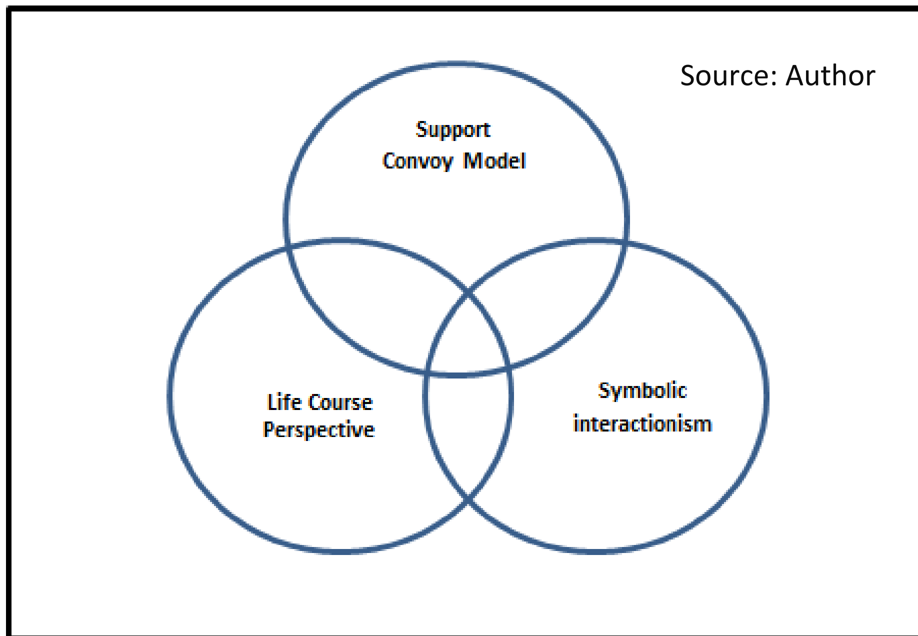


Figure 3: Diagram of the theoretical underpinnings of the research

In this research, it is important to contextualise older people's experiences and relationships with others by adopting more than one theory or perspective because of the research focus which explores negotiation and re-negotiation of support over time (Bengtson *et al* 1997). Following the examples of Kemp (2013) and Connidis and Kemp (2008), three theories will be used to underpin this research: life course perspective and support convoy model, as well as symbolic interactionism. Figure 3 above shows a conceptualisation of these three approaches, which are interlinked because they share the same interpretivist philosophical underpinnings (Robson 2011) (see sub-section 5.3.1). Adopting a life course perspective helped to contextualise older people's choices and experiences throughout their lives which have served to shape their current support network (Kemp *et al* 2013). The life course perspective emphasises that as humans, our lives are interconnected with others within our social network (Connidis and Kemp 2008). It facilitates an understanding of an older person's support network within the context of their lives and the individuals with whom an older person can negotiate support (Dannefer 2003). In addition, as an older person's need for support is liable to fluctuate over time, there is likely to be a corresponding need to interact with others accordingly (Connidis and Kemp 2008). Thus, an older person's current and future support will be mapped and compared using support convoy models to identify support providers and negotiators and to understand how this changes over time. The reason symbolic

interactionism is used to frame the negotiation process is because of its premise that "…human beings interpret or "define" each other's actions instead of merely reacting to each other's actions…based on the meaning which they attach to such actions" (Blumer 1969:79). An individual is in a constant state of re-evaluating his or her place in the world and how to behave in society through the lens of verbal and non-verbal exchanges with others and their observations about surroundings (Victor 2005; Bryman 2008). Understanding the meaning attached to participants' perspectives of the support negotiation process is necessary to construct the process from the perspectives of the research participants.

2.5 Chapter Summary

This Chapter has provided the reader with definitions of key concepts which are pervasive within this research. An evaluation of theoretical perspectives was carried out which have been identified as being relevant to understanding how older people negotiate their support. The research is clearly seated within an interpretivist theoretical perspective (see sub-section 5.3.1 below) because the focus of the research was to understand how older people negotiate support from others. By adopting a symbolic interactionist approach, the verbal perspectives of the participants were used to construct the meaning of their social world. Participants' situations were contextualised by adopting a life course perspective to gain a richer and deeper understanding of their personal circumstances and mapping their support negotiations over time using the convoy model which served to identify if and how support was negotiated and renegotiated over time.

Having provided the reader with a definition of the key concepts of this research and theoretical framework, Chapter Three to follow provides an overview of the policy context relating to formal state-provided support.

Chapter 3 Social Care Policy Context

3.1 Overview of the chapter

The focus of this Chapter is to provide the reader with an overview of the policy context surrounding older people and formal state support in England. As discussed in Chapter Two, older people can negotiate their support from a plethora of sources, including from the Adult Services department within their local authority. The fourth thesis sub-question (see sub-section 1.2 above) sought to investigate and to understand how older people negotiated state support via a personal budget and what factors influenced the choices they made.

An overview of the wider social and political context within which negotiations take place in England will be provided. A definition of care provision will be provided, followed by a brief examination of the social and policy norms regarding caring in UK society. A brief overview of the historical background to self-directed support is provided in this Chapter. The framework for assessing and administering state funded support via personal budgets is explained, together with an overview of some of the challenges experienced by older service users. The Chapter concludes by providing a summary of the key points raised.

3.2 Social and policy context within which support negotiations take place

This section will firstly provide a definition of what is meant by care, and focus on the demographic patterns of care and reflect on how they could affect care provision in the future. There will then be an examination of the broader social and political context within which negotiations for support take place in England, together with a critical discussion of the social and policy norms regarding care provision in UK society.

3.2.1 Care provision

Broadly speaking, there are two main themes within the literature relating to care provision: studies which have focused on the burden associated with care-giving and studies examining the rewards associated with care-giving. Each of these themes will be

examined in turn. Studies exploring the impact on adult children as care-givers for their older parents found that there was a higher likelihood that they would experience care tasks as being burdensome (de Almeida Mello *et al.*, 2017). Female relatives tend to experience higher levels of negative feelings, such as 'burden, stress and depression' which are linked to performing caring tasks, than do males (Raschick and Ingersoll-Dayton 2004:317). One reason put forward in the literature to explain this disparity is that females generally display compassionate characteristics and males exhibit authoritarian characteristics when care-giving for older people (ibid.). However, the most important factor in the literature is shown to be the kind of relationship existing between the carer and the older person, which goes beyond gender norms (Al-Janabi *et al.* 2008). In terms of the nature of care provided, the literature suggests that adult sons generally do not perform care tasks for older parents if they have a sister, and if they do provide care, are more inclined to provide support with tasks other than personal care (Beach and Schulz 2016; Gómez-León *et al.* 2019; Wilkins *et al.* 2019). Thus, younger adult male relatives were more likely to support their older parents with IADLs such as gardening, shopping, giving lifts and help with paperwork (Gómez-León *et al.* 2019).

A separate body of literature focusing on the positive aspects of care-giving observed that adult sons and daughters found that care-giving for their older parents to be a fulfilling activity (Hogstel *et al.* 2005; Raschick and Ingersoll-Dayton 2004), perhaps because they 'may view their parental caregiving as exceeding social expectations – and thus as more rewarding – because their primary role obligations are frequently associated with child and partner care and/or nurturance' (Raschick and Ingersoll-Dayton 2004: 321).

Care itself is a complex concept and its meanings in the literature are often inconsistent or inadequately defined (Bowlby *et al.* 2010) or have been defined very widely (Lloyd 2012). Care for older people who are living at home can be supplied in two broad ways, either informally from family, friends or neighbours (unpaid) or formally from the local Council or through the private sector (paid) (Solé-Auró and Crimmins 2014) (see section 2.2.3).

Many feminist commentators have theorised care through an 'ethics of care' lens (Tronto 1993; Kittay *et al*. 2005), recognising that 'dependence and a need for care must be understood as characteristics inherent within the human condition, not as aberrations' (Lloyd 2012:4). In other words, viewing reliance on others for support as being

undesirable is unrealistic, because in real terms, everyone needs help from others at some point in their lifecourse. Within the ethics of care philosophy, reliance or dependency on others is seen as 'a central feature of human life and human relationships and interdependency' (Kittay *et al*., 2005:453).

Tronto (1993) saw the care journey comprising four steps, from the perspective of the care provider. The first step is where someone sees or acknowledges that an older person needs support. The second step is where the person resolves to take some form of action to fulfil the older person's need. The third step is where the person takes action or ensures action is taken to fulfil the older person's need. The fourth step is where the person evaluates whether the older person's needs are fulfilled by the action taken. One criticism of Tronto's care journey is that it appears to suggest that care decisions are largely taken by the person providing care, presupposing that the older care recipient largely takes a passive role in the care negotiation process. In reality, older people negotiate support from a range of different sources, including from their relatives (Lloyd 2012).

This thesis aimed to explore how older people's negotiated support within their care journey.

3.2.2 Demographic patterns of care provision

The majority of care is provided to older people by their partner-in-life and/or their children (Pickard *et al.* 2007). Whether these trends continue into the future is debatable: a sharp increase in the number of partnership dissolutions in later life may have an impact on who might be available to older people to negotiate support from in the future. In particular, for people aged 65 and above, the latest figures show that the instances of divorce for older men rose by 23% and for older women, rose by 38% (the figures refer to the number of divorces per 1000 people) (ONS 2017d). Consequently, present figures show that the numbers of older people living by themselves has notably escalated over the past twenty years: for the age group 65-74, the number has risen by 15% and by 24% for those over 75 years (ONS 2017c). Within these age ranges, there are more older women living by themselves than older men (ONS 2017c). In addition, according to the latest release of the Births in England and Wales 2017 data, the continuing drop in fertility rates means that fewer children are being born, which means that there are fewer

children available who (potentially) could provide support, and in the longer term, this may result in even greater pressure on an adult child to provide support to their older parents in conjunction with other life commitments (ONS 2018c).

3.2.3 Norms within the social context

This section will first define what are meant by social norms in general and then proceed to consider some of the social norms more commonly associated with the care of older people in the UK, linking their importance to the policy context of caring. According to Ullmann-Margalit (1977:189), a norm can broadly be defined as 'a sophisticated tool of coercion, used by the favoured party in a status quo of inequality to promote its interest in the maintenance of this status quo'. It is important to consider social norms insofar as they relate to the care of older people for two reasons. First, as discussed in Section 2.2 above, older people negotiate care from different sources. Norms in relation to these sources may differ so it is important to examine them to gain a deeper understanding of the wider context within which negotiations for support with older people take place. Secondly, it is important to consider social norms within a policy framework because '[p]olicy both reflects and constructs the social norms and practices of a society' (Himmelweit 2007: 594). At a policy level, social norms related to caring within society are based on an assumption that an older person requiring help with ADLs and IADLs should negotiate support themselves, ideally from within their support network (or less commonly from the Third Sector or (if they can afford to) employ someone to carry out the tasks (Westwood and Daly 2016).

Twigg and Atkin (1995) identify some of the complexities behind the rationale behind care provided by different actors. Help with everyday life tasks which an individual provides to their older partner-in-life is invariably not recognised as care and support in the same formal sense that state-organised carers would perceive it. In other words, the social norms relating to care provided by one's partner-in-life mean that such care is often viewed as 'a natural extension of the love and support' which forms an integral part of a committed relationship (Twigg and Atkin 1995:18). In the current research, all of the participants lived alone (none of the case study participants had a surviving long-term partner), so further discussion of norms surrounding spousal dyads is beyond the scope of this discussion. However, other social norms may be relevant, for example, one of the

most pervasive social norms integral to care provision is the notion that females are innately caring beings who are best suited to provide care to those who need it, particularly those within their social network (Aronson 1992; McKie *et al.* 2001), because by virtue of their very disposition, females 'are or should be natural carers' (McKie *et al*. 2001: 233). Unlike support with healthcare, formal support with social care in England is not free to those who need it: past, present and future care policy direction is based on the assumption that social care tasks form part of the usual household duties, which have historically been performed by women (Walker *et al*. 1995). Over the past forty years or so, the traditional "'male breadwinner'" norm in the household, where the man's role traditionally is to provide for his family through by working and the woman's role was to take care of the house and relatives has been eroded (Fagan 2000: 243). More and more women choose to work, which means that other solutions need to be found to fulfil the care roles towards family members, such as young children and older relatives (Government Office for Science 2016). In addition, the norm of female carers is further challenged as the numbers of men employed within the formal care sector and nursing has continued to rise, which means that formal care roles are gradually being perceived as being less female-oriented (Hussein 2011). Comparing the latest Census data (2011) with the previous dataset (2001), Robards *et al.* (2015) explored what type of individual might typically perform informal care and support tasks for older people living in England and Wales over time. Findings indicated that married women who were aged in their mid-40s to mid-50s were most likely to be the most intensive care-givers for family and friends. However, this finding is reversed in later life, when older men are most likely to be care-givers for their wife or partner-in-life (Evandrou *et al*. 2015). England has experienced a stagnation in life expectancy in recent years, so whether this trend might continue will depend largely on whether life expectancy rises (ONS 2018b).

3.2.4 Norms within the policy context

Three main policy norms relating to older people will be discussed in this section: population ageing and dependency, active ageing and independence, and ageing in place, because they are all directly relevant to the focus of this thesis: how older people negotiate social care support in their own home environment. Each of these norms will now be discussed in turn.

3.2.4.1 Population ageing and dependency

The first policy norm is linked to the Governments' response to the ageing population in the UK. As discussed in Section 3.2.2 above, people in the UK are living for longer, but their additional years are not always spent enjoying good health. Arguably, since 2010, policies aimed at welfare reflect a neo-liberalist approach, in particular, those aimed at older people (Hastings and Rogowski 2015). Underpinning this neo-liberalist philosophy in welfare policies is the premise of individualism, where 'the individual is expected to take greater responsibility for self-care' (Lloyd 2010:195). This represents a policy shift away from the state taking responsibility for the welfare of older people in terms of providing services and resources. The policy introducing personal budgets as a means of facilitating independence for service users in terms of choosing and controlling their formal social care support arrangement under the New Labour Government (1997-2010) was continued by the Con-Dem Coalition Government (2010-2015) (Lewis and West 2014) and subsequent Governments (Conservative Government from 2015-2017 and Conservative-DUP Government from 2017 to date). Self-directed support and personal budgets will be critically discussed in Sections 3.3-3.5 below. To counter the anticipated extra demand by older people placed on the social care state infrastructure for help with ADLs and IADLs, social care eligibility has been re-evaluated in recent years to provide assistance only to those with the highest level of support need (Ipsos 2017). In addition, funding for social care support to local authorities by central Government has been cut significantly since 2009, which means that access to resources has been constrained (Age UK 2018b). One point to note is that conceptualising local authority-provided formal support in terms of 'meeting need' and assessing individuals in terms of their functional abilities positions older people, in particular, as being reliant on others (Milne and Larkin, 2015:10). There is evidence to suggest that older people have internalised this negative perception of themselves as a population group and see themselves as being a burden to their families because they feel that their needs are less of a priority (Cahill *et al*. 2009). Until the idea of interdependency is recognised as a socially acceptable state (Watson *et al.* 2004), arguably, older people will continue to feel less likely to seek help from others, in particular, their family (Walters *et al.* 2001).

This observation by commentators is particularly pertinent to this thesis because it aimed to explore how and when older people negotiate social care support from others. There

is a widespread assumption that older people who are in need help with everyday personal care and household tasks are categorised as dependent (Walker *et al.* 1995; Lloyd 2012). Over at least the past three decades, policy-makers have painted a bleak picture of how a sharp increase in the numbers of frail older people living with multiple health conditions would deplete NHS and social care resources owing to their numerous health and social care needs (Government Office for Science 2016). However, recent evidence shows that although the risk of becoming frail increases as one gets older, frailty does not affect the majority of older people (Age UK 2018a). Despite evidence to the contrary, there is a continuing underlying ageist assumption by policy-makers that vast numbers of older people will experience poor health in later life and thus will become increasingly reliant on the state or others for help with tasks associated with day-to-day living (Department of Health 2001; HM Government 2012; Hastings and Rogowski 2014). This point is illustrated in the White Paper published by the Coalition Government in 2012, where being reliant on others appears synonymous with failing to meet society's expectations of being able to take care of oneself, as "…the daily reality [for older people] can be a life of dependence, of struggling with daily tasks" (HM Government 2012:4).

One reason for this assumption is that in the UK (as is the case with other developed countries), the ability to function as a member of society has become synonymous with being young(er), fit and healthy, whereas being older and in poor health is seen as synonymous with being dependent (Lloyd 2012). Older people are generally stereotyped as a needy population group (Angus and Reeve 2006) and on particular those who become increasingly incapable of performing ADLs and IADLs owing to their deteriorating physical health are perceived by policy-makers as being blameworthy for their shortcomings, evidenced by using terms in policy literature such as 'struggling', 'dependent' and 'burdensome' (HM Government 2014:4; Hastings and Rogowski 2014:23). Arguably, older people, particularly those with physical and mental disabilities are disempowered by an underlying societal view that they become incompetent and inept as they age (Secker *et al*. 2003). Nevertheless, there is an expectation by policy-makers that older people should remain physically capable of functioning within society (NICE 2015). The lack of clarity surrounding the meaning of independence serves to send mixed messages to older people, their families and others within their support network,

and can serve to reinforce to older people that they should not seek support from others with daily living if it can be avoided (Secker *et al.* 2003).

3.2.4.2 Active Ageing and independence

A second policy norm relevant to this thesis is the idea that older individuals should be aiming to "lead an active and independent life" (ibid.:8). However, neither the scope of the meaning of "active ageing" (Boudiny 2013:1078) nor of "independence" are adequately explained within policy literature (Secker *et al*. 2003). Each of these policy ideas will now be explored in turn. Active Ageing was a policy agenda proposed by the World Health Organization in 2002 to help guide governments in making policies for older people aimed at promoting 'continuing participation in social, economic, cultural, spiritual and civic affairs, not just the ability to be physically active or to participate in the labour force' (WHO 2002:12). It is important to point out that since 2015, the WHO policy agenda relating to older people has now been superseded by the Healthy Ageing policy framework (WHO 2015; WHO 2017), but the impact of the Active Ageing agenda remains relevant to this study because the field research was conducted between 2013 and 2015, which was before the change of WHO policy direction.

Although the original Active Ageing WHO agenda incorporated adopting a holistic approach to improving older people's lives, commentators criticised the limited way in which the agenda was interpreted by governments (including the UK): taking steps to retain older people in the workforce for longer (Walker 2008; Lloyd *et al.* 2014). This policy direction is exemplified in two ways: First, by removing the restriction on employers to terminate older people's employment contracts once they reach the age of 65 in 2011, so that there is no upper age limit when someone has to withdraw from the job market (The Employment Equality (Repeal of Retirement Act Provisions) Regulations 2011). Secondly, so that older people can remain in the workforce for longer because the age of entitlement to a State Pension has been extended past the age of 65, and is due to rise to the age of 67 by the year 2028 (Department for Work and Pensions 2017). However, this policy fails to recognise that not all individuals will be capable of working later in life owing to poor health and may contribute towards sending out an unintended message to older people 'where the generalised fear of ageing is replaced by fear of ageing with disability and in which *dependent* older adults suffer from discrimination' (Boudiny 2013:1093). One criticism of active ageing as a policy mantra is linked to how

older people themselves understand what the phrase itself means. Research suggests that rather than the holistic ideal posited by the WHO (2002), older people tend to understand active ageing in binary terms, where either one takes part in activities, usually involving physical exercise or exertion, or where one is sedentary, thus 'increasing passivity/diminishing activity may be associated with losing one's vitality and hence feeling 'old'' (Stenner *et al.* 2011:475). A core feature of active ageing is the notion that an older people should exercise independence, particularly when making decisions surrounding how their health and social care needs might be met (Lloyd *et al.* 2014). One issue with the use of the word 'independence' is that there is no consensus among policy-makers, academics or older people about what being independent means. As summarised neatly by Lloyd (2012:112), older people acting in an independent manner could be '…living in [their] own home and not in an institution, or being functionally well and able to perform activities of daily living…[or]…the care they receive is from family members, rather than from a paid carer…[or]…not paid for by the state'. Indeed, for some older people experiencing difficulties with ADLs and/or IADLs, independence for them is perceived not in terms of their own ability to carry out specific tasks, but in terms of the extent to which they are able to arrange for their needs to be met (Breheny and Stephens 2009; Hillcoat- Nallétamby 2014; Barken 2017).

3.2.4.3 Ageing in place

A third policy norm which is relevant to this thesis is ageing in place, which is based on the premise that older people should be encouraged to continue to live in their home environment for as long as possible (NICE 2015). The main reasons for this are ostensibly based on an assumption that older people would prefer to continue living in an environment which is familiar to them, rather than move into an unfamiliar environment (Sixsmith and Sixsmith 2008; Wiles *et al.* 2011; Centre for Ageing Better 2018). In addition, a more insidious reason could be to discourage older people from moving into costly state-funded care institutions (Sixsmith and Sixsmith 2008). Nevertheless, research indicates that many older people tend to derive a multitude of benefits from living their later years in their family home, such as 'an increase in well-being, independence, social participation and healthy ageing' (Sixsmith and Sixsmith 2008:220). In addition, Wiles *et al.* (2011) suggest that these benefits also extend beyond the property boundary to encompass the wider area outside of the home, such as going to local shops and

socialising with members of one's support network. However, for some older people, navigating their home environment when their physical health is worsening can be problematical, for example, being unable to access rooms upstairs in a house with a staircase (Sixsmith and Sixsmith 2008).

Research has identified two main drawbacks for older people who choose to remain in their home environment, in particular those experiencing a decline in health or a decrease in mobility (Coleman *et al.* 2016). One drawback is linked to the practicalities involved in the upkeep of the interior and exterior of their property to ensure it is in a habitable state, for example, the extent to which one can carry out practical tasks, or can arrange for support to be provided to carry out those tasks (Coleman *et al.* 2016). One impact which arose from these issues was on the mental well-being of older people, as many report feeling deeply concerned and apprehensive about how to arrange the support to meet their needs and also the likely cost it would involve (Coleman *et al.* 2016). A second drawback for older people living alone in their home in later life is linked to the potential consequence of decreasing physical mobility (Sixsmith and Sixsmith 2008), which can lead to a loss of confidence in walking in and around their home, as well as outdoors in their local vicinity because of a fear of falling. This, in turn, may lead to older people who are living by themselves becoming increasingly isolated from their social network (ibid.). However, despite these challenges outlined above, evidence shows that many older people tend to be resistant to the idea of negotiating support from others (ibid.; Secker *et al.* 2003). One possible explanation for this is provided by Secker *et al.* (2003), who suggest that resistance to negotiating support is deeply entrenched within English culture, although no further explanation for this view is proffered. In addition, older people are also resistant to exploring alternative forms of accommodation such as going into a form of community dwelling such as sheltered housing or care home because of a perceived loss of agency over what happens in their everyday lives (Bland 1999; Bowers *et al.* 2009). One unintended consequence of promoting 'ageing in place' as being the optimum residence to live in later life is that it increases the chances of older people of becoming socially isolated or lonely. In England, approximately 1.4 million older people reported frequently feeling lonely and this figure is set to increase to 2 million over the next five years or so (Age UK 2018c). One of the main societal groups identified as being

most at risk of becoming lonely were older widow(er)s, living by themselves, and who lived with disabilities and or co-morbidities (ONS 2018a; Age UK 2018c). Tackling loneliness has been become an increasingly important policy priority, not least because research has shown that people at any age who are lonely or who have restricted access to their social network are at a higher risk of dying at a younger age (Holt-Lunstad *et al.* 2015) and also a greater chance of developing dementia (Sutin *et al.* 2018).

3.2.5 Summary

To summarise, policy norms surrounding older people centre upon promoting 'living independent' and 'leading an active life' and 'staying in one's home environment for as long as possible'. These policy measures reveal an on-going debate which centres on older people's role and agency, where frailty is seen as synonymous with dependency and is thus in conflict with independence, yet active ageing and ageing in place imply continued agency. Independence, particularly when it is applied to the context of older people negotiating their daily lives as discussed above, is an ambiguous concept. Many older people themselves tend to conceptualise independence as meaning the same as self-reliance, in the sense of not needing to be dependent on support from others (or to negotiate from others) to meet their needs. Active ageing could be seen as problematic, as older people may conceptualise it in terms of what the absence of it implies: passivity, which in turn is closely linked to dependency. This view of independence and leading an active life arguably may put pressure on older people to age in (what society and policy-makers see) as being in a successful way. Those who are incapable of conforming to these ideals are in danger of feeling as though they have failed as autonomous individuals and risk being seen by others as being dependent. In other words 'dependency is seen as weakness and something to be avoided, even when this is clearly unviable' (Sixsmith and Sixsmith 2008:229). Remaining in one's own home is seen by policy-makers and many older people as being desirable, but can come at a cost to older people if their ability to perform ADLs and IADLs declines because of 'the reluctance of many older people to accept help' (Sixsmith and Sixsmith 2008:229). Placing older people at the centre of making their formal support arrangements to give them 'choice and control' has been heralded as the optimum approach by policy-makers. Self-directed support, personal budgets and direct payments will now be explored, and a critical evaluation of the extent to which they work for older people is provided in Sections 3.4-3.5 below.

3.3 Mapping self-directed support

Over the past twenty years or thereabouts, responsibility for arranging state support has gradually been shifting from social care professionals to the service user (Alcock 2008). The point of origin for this sea change can largely be traced to the introduction of the National Health Service and Community Care Act 1990 ("the 1990 Act"). The main effect of the 1990 Act was to confer a duty on local Councils to provide support to individuals in need (Lewis and West 2014). Thus to meet the increase in need, local Councils changed the way they delivered services, from a personal approach to commissioning more cost-effective "block contracts" (Lewis and West 2014:5). As a consequence, older people reported being visited by different carers, who were more than often unable to complete all the necessary support activities within the requisite timescale (ibid.).

Further changes occurred as a result of campaigning by disabled groups who wanted to have the ability to exercise greater control over the type of the support they received. Thus, direct payments became a possibility in 1997 as part of the Community Care (Direct Payments) Act 1996. A direct payment means that a service user who is eligible for state funding has the choice to receive his or her entitlement as regular payments into a bank account so that he or she can negotiate with others to buy the requisite support required from outside sources such as from private care organisations or individuals (Gheera 2012). At first, only disabled service users were eligible to receive direct payments, but this right was extended to older people aged 65 and over from 2000 onwards (Glasby and Littlechild 2009). There is evidence to show that some older people prefer direct payments as a method of receiving state support (Clark 2006), yet more recent research suggests otherwise (Glendinning *et al.* 2008; Gheera 2012). Direct payments were certainly a popular choice for disabled service users and in light of positive reports about direct payments increasing choice and independence, three policy reports were published in 2005 which advocated the introduction of individual budgets for all social care users (Department of Health 2005).

The rationale behind individual budgets was to simplify and integrate several sources of benefits and resources (not just funding from adult social care) into one pot, in order to simplify the benefits system and to enable the service user to know the precise amount of their entitlement (Moran *et al.* 2011). An eligible service user would meet with a social

care professional to establish desired support aims and objectives and how best to achieve them (Netten *et al.* 2012). The underlying rationale of individual budgets was summarised as being:

> *"…to promote independent living. This is not just about being able to stay in your own home but is also about providing people with choice, empowerment and freedom"* (Department of Health 2005:34).

Later in 2005, individual budgets were trialled in thirteen local authorities for just over two years and the Department of Health commissioned research by Social Policy departments based in three English Universities to assess the viability of individual budgets (Glendinning *et al* 2008). One crucial barrier to the successful implementation of individual budgets was the practical incompatibility of merging different sources of benefits (ibid.). Another drawback was that individual budgets seemed to work more successfully for some user-groups rather than others: older people experienced greater levels of dissatisfaction than most other service user groups (ibid., Lloyd 2010).

Yet even before the results showing the impact of individual budgets research became known, the New Labour Government implemented a similar system nationally, known as a personal budget (Woolham and Benton 2013). At their simplest, personal budgets are defined as "…a sum of Council money that you can use to arrange and pay for your care and support. The amount you get depends on the needs identified in your support plan and can alter as your needs change." (Age UK 2012:4).

Thus the New Labour Government aspired to increase service user involvement by introducing a "personalisation" approach (Lewis and West 2014:6). This essentially means that there is an increasing shift of emphasis on the individual to articulate their support preferences and, if possible, to carry out the necessary arrangements themselves. This is in contrast to being passive recipients of support organised by social workers with little or no consultation with the service user (ibid.).

There have been several changes in political power since 2010, but each government has continued with the policy direction of "…'personalisation' or 'self-directed support'…" (Gheera 2012:3). The essence of these terms means that users of services must be provided with more "choice and control" over their state funded support arrangements in order to facilitate independent living in one's own home (Her Majesty's Government

2012:26). The current policy direction appears to be discouraging individuals from expecting to turn to the state for help with support needs (Lloyd 2010; Age UK 2014; ibid.).

Although personal budgets have been in existence since 2007, their remit has recently been enshrined in formal legislation in the guise of the Care Act 2014 ("the Care Act"). Data collection was mainly carried out before the Care Act came into force, therefore it is not possible to evaluate how changes made to the social care system introduced by the Care Act might have impacted on older people. The aim of the Care Act was to amalgamate previous social care laws and to put in place some of the recommendations made in the Dilnot Report (Care Act 2014 Explanatory Notes). The Dilnot Report reported extensive shortcomings of the Adult Social Care system (Commission on Funding of Care and Support 2011). One of the main issues examined was in response to increasing concerns over rising costs that an individual pays throughout their life course. Another major concern was a lack of uniformity in the way individuals were assessed for state support and a proposal made was for the introduction of standard criteria to be used to evaluate an individual's entitlement for state services in order to increase fairness (ibid.).

However, these proposals set out within the Dilnot Report were not applied fully within the Care Act. The recommendation for a maximum amount a person would pay for social care services has been shelved and social care for older people is currently under review by the present Government. The results of a consultation with experts on social care and older people will be disseminated in a Green Paper by July 2018.

The recommendation to introduce national standard criteria in order to assess an individual's entitlement to state services was adopted and introduced from April 2015, together with a legal obligation for local authorities to offer personal budgets to all service users (Care Act 2014).

One aspect of this thesis enquiry seeks to understand how older people in receipt of direct payments as part of a personal budget negotiate and renegotiate their support over time. In addition, the research seeks to understand the opportunities and challenges that older people face when receiving a personal budget and what influenced their decision to receive a personal budget as a direct payment. The following section provides

a critical examination of existing research involving older people as service users and personal budgets.

3.4 Older people and personal budgets

As outlined in sub-section 3.2 above, this thesis identified how older people negotiated and renegotiated their support through formal sources. Older people are the largest group of state funded social care users (Department of Health 2010; Age UK 2014). In the recent Census, one-third of older people reported needing help with at least one ADL (National Audit Office 2014). Older people with multiple support needs have increased over the past ten years from 551,000 to 631,000 and this trend is likely to continue (Gridley *et al* 2014). However, since 2013, central Government has decreased the budget it provides to local authorities by 19.6% (Age UK 2014, p. 1). The effect of this finding decrease was that local authorities have reduced their overall expenditure, which meant that the local authority support services budget has been reduced accordingly (National Audit Office 2014).

As older people have been identified as being the largest users of state support, these budget cuts have had the biggest impact on older people (Age UK 2014). Many older people enter the formal state system at a stage in their life course when they are vulnerable or unwell (Lloyd 2010). At that time, older people are more likely to be disinclined to participate in personal budget support negotiations (Newbronner *et al* 2011; Orellana 2010; Routledge and Carr 2013), or perceived by social care staff as being disinclined to negotiate their own arrangements (ibid.). Older people are therefore more likely to receive a personal budget which is arranged and managed for them by the local authority, rather than having the opportunity to manage it themselves (Newbronner *et al* 2011; Orellana 2010; Routledge and Carr 2013). Older people's conditions may deteriorate or improve, making their ability to take part in initial and on-going negotiations for social support care difficult or impossible (Newbronner *et al* 2011). According to Hatton and Waters (2011:26):

> "*older adults are less likely to use direct payments, less likely to know how their personal budget was managed, and more likely to have a personal budget managed by the council*"

Thus, findings from the literature suggest that older people were less likely to be able to negotiate support and to voice their preferences about how their social care needs might be met. This finding contradicts one of the underlying principles of the National Service Framework for Older People, which was to "…enable older people to make informed choices, involving them in all decisions about their needs and care" (Department of Health 2001:23). In addition, older people's personal budgets are reported as being generally lower than other service user-groups, which provide more limited scope for older people to negotiate innovative support arrangements to meet their assessed needs (Lloyd 2010; Routledge and Carr 2013).

Before April 2015, an individual was assessed by a care manager using national eligibility criteria called "Fair Access to Care Services (FACS)", which was issued by the Department of Health (Department of Health 2013). The purpose of the FACS was to "…identify the needs which call for the provision of services (eligible needs), according to the risks to independence and wellbeing both in the immediate and longer term" (Department of Health 2010, paragraph 52). Under the FACS framework, a care manager evaluated an individual as either having critical, substantial, moderate or low needs (Department of Health 2013). Only those with substantial or critical needs had their support arranged by the local Council (ADASS 2014; Hampshire County Council 2014). Eighty-five percent of local Councils in England reported arranging support for those assessed with the greatest support needs who met the critical or substantial categories (Thornton 2011; Age UK 2014; NAO 2014; Lewis and West 2014). This resulted in a decreased number of older people being eligible in financial terms to receive state support to receive practical help they need (ADASS 2014).

Arguably, if help was provided to older people at the lower end of the eligibility spectrum, many admissions to hospitals and walk-in centres in emergency situations would be obviated (National Audit Office 2014; Age UK 2014). If an older person is eligible for state support, he or she can receive a bespoke support package to meet his or her specific support needs in order to enable him or her to continue to live at home (Department of Health 2007). Anyone can ask for a community care assessment regardless of their level of need and a local Council is under a duty to provide an assessment if it is requested (Department of Health 2013). There are four main parts to the assessment process: discussing support needs, evaluating support needs and financial eligibility, negotiating

tailored support and ongoing re-evaluation of support needs (Hampshire City Council 2014).

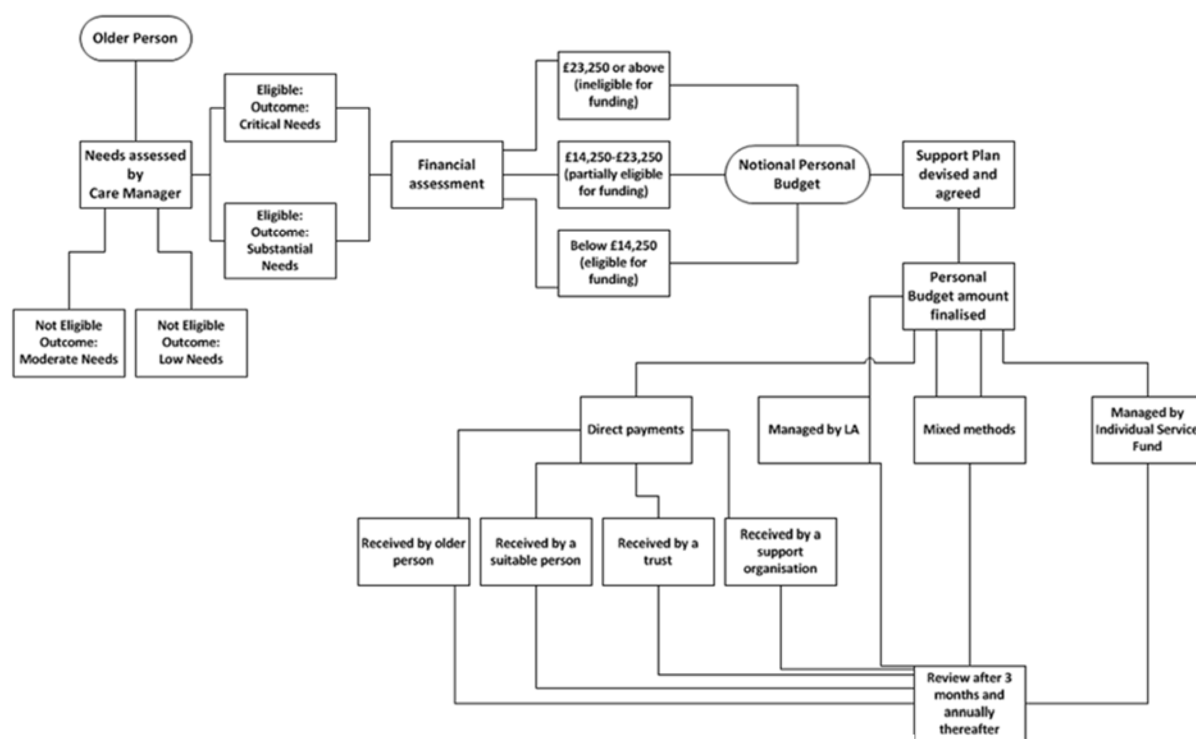


Figure 4: Flowchart depicting PB process (adapted by author from Hampshire City Council (2014))

Figure 4 above sets out the process for applying for formal support in the shape of a personal budget system in a conceptual form. In order to assess whether an older person is eligible to receive state-funded support or must make a financial contribution, a financial assessment is undertaken by a care manager to determine the level of an individual's assets and income (Department of Health 2013). Older people with assets worth less than £23,250 can qualify for state support (ibid.). Those with assets worth more than £14,250 but less than £23,250 must make a financial contribution towards their support costs and individuals with more than £23,250 will need to pay for their own support. Once the amount of the budget is known, the older person is encouraged to consider what services to put in place to best meet his or her needs. Once this has been agreed, the care manager sets out a 'Personal Budget Support Plan' containing an assessment of the older person's support requirements (Hampshire County Council 2014). The older person is given the choice about how to manage the budget. The amount can be paid via direct payments to the older person, or to a proxy, a trust or a charitable organisation (ibid.).

Alternatively, the local Council can manage the personal budget or it can be transferred to an external organisation as an Individual Service Fund (Hampshire County Council 2014). The funds can be applied to pay for any services which fulfil the requirements set out in the Personal Budget Support Plan, not just to pay for carers to provide traditional personal care (Baxter *et al* 2013). For example, a personal assistant might be employed to provide bespoke support, rather than relying on supplied carers working either for the local authority or in the private sector to visit twice a day. Physiotherapy sessions might be substituted for gym membership, and socialising at a Day Care Centre might be substituted for an Art Class (Glendinning *et al* 2008).

The main criticism of current support provision sourced by local Councils is that care providers devise unrealistic amounts of time in which carers must visit older people in their homes and carry out the tasks an older person has been assessed as requiring (NAO 2014). There is little flexibility to the arrangement, so if an older person needs help with a task they have not yet been assessed as needing, the carer is unable to help (Seddon and Harper 2009). This effectively provides a superficial solution to older people's needs without addressing deeper issues, such as encouraging older people to "…rehabilitate or improve user independence" (NAO 2014:8).

The Coalition Government set a target for all adult recipients of social care to receive a personal budget by April 2013, preferably received through the medium of direct payments (NAO 2014). In 2012-13, 56% of service users or their carers were in receipt of a personal budget, which represented an increase from the figures in 2009-10 but below the target of 70% by April 2013 (Gridley *et al* 2014). The "one size fits all" approach is not necessarily suitable for everyone, as older people are characterised by the diversity of their individual characteristics and their family and living arrangements (Seddon and Harper 2009).

The field research ended in July 2015, and Part 1 of the Care Act 2014 became law in April 2015 (Care Act 2014). Therefore, eligibility and the personal budget process are discussed under the previous regime. This thesis seeks to understand how older people negotiate and renegotiate their support within the remit of a personal budget and to explore their reasons for renegotiation. Two older people in receipt of a personal budget were included as research participants.

3.5 Critical Reflections on Personal Budgets and Direct Payments

Policymakers have advocated a policy shift away from Councils being the main providers of social care support for eligible service users, and moving towards enabling service users themselves to play a key role in arranging their own support from a range of different sources (HM Government 2012). It is widely documented that older people are the greatest users of formal social care provided via the adult social services department of their local Council (Department of Health 2010). This section critically reflects on the extent to which personal budgets and direct payments work for older people.

One of the main advantages put forward by policy-makers advocating a personalisation agenda for older people is that personal budgets can foster “choice and control over their support” (Department of Health 2010:36). As outlined above, service users are able to receive their personal budget via direct payments, which are transferred into their bank account to pay for bespoke arrangements which meet their own specific care and support needs.

In theory, the main advantage for older people opting to receive direct payments through a personal budget is having the ability to recruit a personal assistant to meet their personal care tasks (Clark 2006; Bartlett 2009). The main benefit for older people is in taking control of their care arrangements by being actively involved in deciding who they want to provide them with support to meet their personal care needs. In practice, this means older people have the ability to recruit, interview and select who they would prefer to help them to carry out intimate personal tasks (such as using the toilet, bathing or showering and dressing) in their home. In addition, the duration of each care visit can be negotiated and renegotiated with their personal assistant to suit the older person as part of a contract of employment. Certainty in knowing who will be arriving each day and being instrumental in selecting their own carer(s) is of particular importance in ensuring continuity of care (Clark 2006). However, continuity of care cannot always be guaranteed with care agencies, as different agency carers are usually allocated to visit the older person at home to perform care tasks (NAO 2011). Generally speaking, care agencies offer less lucrative employment packages to care staff, who are often paid little more than the minimum wage, who work on zero hour contracts and who work different shifts during unsociable hours (Hussein 2017). These combined factors often result in a high

turnover of care staff and in a reduced likelihood of continuity of care for service users (*ibid*.). In addition, the time in which agency care staff need to carry out personal care tasks is pre-allocated into short periods, usually in 15-minute increments, which often means that personal care tasks are rushed in order to be completed within the limited time-frame (Age UK 2018b).

Recent academic studies exploring the impact of personal budgets and direct payments on older people have largely reported negative findings in practice Glendinning *et al.* 2008; Woolham *et al.* 2017). The main reasons will now be examined below.

First, older people are generally assessed as needing a higher level of support with personal care tasks than other groups of service users and lower levels of emotional and social support than younger service users in their Care and Support Plan (Glendinning *et al*. 2008). Younger service users, particularly those with learning difficulties, are allocated a larger budget which is aimed at fulfilling their social needs through paying for creative activities and joining social groups (*ibid.*). In other words, older people's personal budgets are predominantly assessed on the basis of requiring help with personal care tasks, which means they are the amount of budget allocated is generally lower than other (younger) population groups (Woolham *et al.*, 2017). Older people's options are generally limited to using their personal budget either to make arrangements to pay for a carer from a care agency, or to assume the position as employer in order to recruit their own personal assistant(s) to meet their personal care needs (NAO 2011). One interesting reason put forward by Woolham *et al.* (2017:980) is that 'most older people may want different things from personal budgets and direct payments to younger people…[which]…continue to be unrecognised and unacknowledged in current policies'. This suggests an ambivalence by policy-makers to seek an evidence-base to investigate what older people might want, instead of applying a blanket approach to social care support provision.

Second, since their introduction in 2007, and since the passing of the Care Act 2014, a lower number of older people have opted to manage their personal budget themselves (Routledge and Carr 2013; Woolham *et al.* 2017). One reason for this could be because prior to the Care Act 2014, social care staff were not legally bound to offer direct payments via personal budgets to service users needing social care support (Glasby and Littlechild 2009; Baxter *et al.* 2013; Ellis-Paine *et al.* 2014). Some commentators suggest

that in some instances, social workers may have decided not to promote direct payments through a personal budget as an option for frail older service users, based on a preconceived impression that the older person would not be capable of coping with the complex administrative process involved, unless it was evident that they had a good support network in place (Bartlett 2009; Neville 2010; NAO 2011; Routledge and Carr 2013). Indeed, older people have been more likely to report feelings of apprehension about the idea of managing direct payments and in making their own arrangements to meet their social care needs (Glendinning *et al.* 2008). Older people were particularly fearful of becoming employers of their own care staff because of the necessity to understand and comply with complex legal, contractual and administrative requirements such as calculating income tax, holiday and sickness entitlement and remedies in the event of a breach of contract (NAO 2011). Another important criticism identified in the literature is a lack of clear on-going information or support relating to personal budgets and direct payments available through the local Council to help service users with queries once their personal budget and direct payments were in place (*ibid*.). Older service users expressed apprehension about inadvertently making an honest mistake by spending their budget on unapproved services or items because they were unsure about the remit of the terms of their personal budget (*ibid.*).

Third, a further criticism of personal budgets is the extent to which choice is a reality for older personal budget holders in terms of services, activities or resources that are available to them. Bartlett (2009) identified a lack of diversity of social venues and outlets which were available for older people living in the community and which were located within an accessible distance from their home.

To summarise, the main advantages for older people in opting to receive their personal budget as a direct payment are twofold: the ability to employ care staff of their own choosing to provide care and support to them; and to have the ability to negotiate and renegotiate with care staff concerning what type of support they want to meet their needs and when they want it. However, in reality, the complex administrative and legal requirements associated with managing a personal budget pose a barrier for many older people, who either do not have the requisite expertise to manage their personal budget themselves, or who are unable to draw on the expertise of others in their social network who could offer help or reassurance. In addition, the amount allocated under the

personal budget for older people is generally lower than other service user groups, so there is generally less scope to provide creative solutions to meet their needs. For example, evidence has shown that younger people with learning disabilities are allotted a larger proportion of their personal budget to spend on recreational pursuits and hobbies (Zamfir 2013).

With the passing of the Care Act in 2014, personal budgets are now embedded within the law (Care Act 2014). Thus personal budgets as the main vehicle of personalisation are likely to remain for the foreseeable future. Successive governments since 2014 continue to advocate the merits of the personalisation agenda. For example, the current policy emphasis continues to advocate 'choice and control' for the service user, emphasising the need for health and social care to be integrated by trialling the merging of health and social care personal budgets in different areas of England and Wales (Commons Briefing Library 2019), in other words, promoting 'choice' and promoting 'control' through taking a 'holistic and person-centred' approach (ibid.). The implication remains that personal budgets represent the means by which older people can be supported to 'stay in their homes and remain independent for as long as possible…[and for] more care…[to] be delivered in the home' (ibid:13). Thus as the policy emphasis continues for older people to arrange for social care support to be delivered in their own home environment, the current research is both relevant and timely in order to gain a deeper understanding of how older people negotiate care and support from their support network.

3.6 Chapter Summary

Older people are the largest users of state funded care and support (Department of Health 2010; Age UK 2014). However, as many local Councils have restricted state eligibility to target only those with the greatest support needs, many older people with lower levels of need have been left largely unsupported and at risk (Age UK 2014). Providing support to older people at an earlier stage is more likely to result in better outcomes in terms of health and well-being (NAO 2014, p. 35). Research suggests that older people only access state support when other options have been exhausted, that is, they are unable to negotiate the support they need informally from within their social support network or who cannot afford to engage private help (Qureshi and Walker 1989).

So, in light of the challenges identified in state support provision for older people, how do older people negotiate the support they need? The following Chapter will include an examination of existing research which has addressed that question, at least in part.

Chapter 4 Literature Review

4.1 Overview of the chapter

Having identified the main research question and thesis sub-questions (see sub-section 1.2 above), defined the key terms and concepts used within this thesis (see sub-section 2.2 above), discussed the theoretical underpinnings of the research (see sub-section 2.3 above) and provided an overview of the current social care policy context (Chapter 3 above), this Chapter provides a critical synopsis of research relating to how support is negotiated by or for older people in England and other developed countries. It is necessary to conduct a search to ascertain the scope of existing research and to identify gaps in knowledge. The focus of this thesis is not on who *provides* support to older people, but how the support is *negotiated*. Therefore, the following questions were posed in relation to the literature, in order to inform the direction of the research and to begin the process of formulating answers to the main research question and peripheral research questions (see sub-section 1.2 above): What negotiation strategies are adopted by the parties? How is informal support negotiated and who is involved? What does existing research say about how older people negotiate formal support in the shape of personal budgets? An overview of the extent to which the literature identified addresses the questions will be presented and gaps in knowledge are highlighted.

4.2 Overview of the literature review

A review of the literature was conducted to identify existing research which relates to how older people negotiate their support at home. The search was carried out to map the parameters of existing research to ascertain the scope of current knowledge, to highlight gaps in knowledge and to address the research questions of the thesis (see section 1.2 above). The results of the literature search are presented below in the form of a critical literature review (Jesson *et al* 2011). The parameters of the literature review and search strategies are explained further in sub-section 5.3.2 of the Methodology Chapter below. The literature has been examined within three broad sections in order to ascertain what research has been carried out and issues explored, to identify gaps and to inform and address the peripheral research questions (see sub-section 1.2 above).

First, a critical examination of how different negotiation strategies have been conceptualised within key studies investigating older people and informal support is provided in sub-section 4.3 below. The reason for this is to explore how negotiation tactics adopted by parties have been explicated within existing research.

Secondly, a focus is made on who has been the subject of research within the informal support negotiation process in sub-section 4.4 below.

Thirdly, an examination of how older people have negotiated state support via personalisation, in particular, personal budgets is provided in sub-section 4.5 below.

The Chapter will conclude by drawing together the gaps identified within literature and how this research aims to address knowledge gaps.

4.3 Negotiation tactics

Negotiation as a term has been used within the literature to mean finding one's way through the support system (Price 2011). However, few studies provide a clear definition of negotiation (Zechner and Valokivi 2012). Only four qualitative studies reflected in any depth on different tactics adopted by the parties to negotiating support arrangements: two English studies (Finch and Mason, 1990; Finch and Mason, 1993; Horton and Arber, 2004) and one New Zealand study (Allen and Wiles 2013). Overt/direct tactics are those where the origins of the support can be clearly mapped and which involve some form of identifiable communication between the parties and implicit/indirect negotiations tend to arise spontaneously after little or no planned debate (Strauss 1978). These two approaches will now be examined in turn.

4.3.1 Negotiating directly

Three English studies focusing on informal support negotiations specifically discuss overt negotiation strategies (Finch and Mason, 1990; Finch and Mason 1993 and Horton and Arber 2004). Finch and Mason (1993) conceptualise this strategy as containing specific dialogues between family members in response to the need, or probable need, for support, described as "explicit" (Strauss 1978:224; Finch and Mason 1993:64), characterised by clearly identifiable incidences of individuals coming together to discuss and plan support-related issues (Strauss 1978). Finch and Mason (1993) reported many

examples in their data where participants had described circumstances leading to support that had arisen in this way. The authors investigated how families negotiate support in general, rather than focusing on older family members in particular. In instances where the authors focused on support provided to older family members, there was no clear indication of whether the older person was present during the explicit support negotiations (ibid.). In later research carried out by Horton and Arber (2004), the authors clearly conceptualised overt planning as being “negotiating actions” (ibid.:86), where an older person takes an active role in negotiating their own informal support arrangements (ibid.). The thesis seeks to uncover whether direct tactics are evident in support negotiations.

4.3.2 Negotiating indirectly

“Implicit” negotiations are conceptualised as situations where someone demonstrates willingness to provide support by their actions, rather than by clearly stating their intentions (Strauss 1978:224; Finch and Mason 1993). Examples of this kind of negotiation are cases where family members offer support before being asked to do so or where a family member assumes a support role because it is expected of them by their relatives (Finch and Mason 1993). The authors cite by way of an example of a childless spinster who provided support to a series of older relatives because she was viewed by her relatives as a natural choice owing to her circumstances (ibid.). Another example of implicit negotiations was conceptualised by Horton and Arber (2004) under the remit of “engaging actions” (ibid.:87). The authors noticed this strategy was more prevalent between spouses and in father-daughter dynamics and observed it to be a (female) gendered support strategy aimed at surreptitiously encouraging a male to make the decision she wants him to make, but to appear as if it was his idea, in order to protect his sense of self (ibid.). This thesis seeks to uncover whether this strategy is also evident in support negotiations.

4.3.3 Negotiation tactics

Few studies have focused on the negotiation tactics which older people use in the course of communicating their support needs to others. Only two studies were identified which examined methods of communication between families: Finch and Mason (1993) and

Grootengoed and Van Dijk (2012). However, no studies were located which investigated older people's negotiation tactics. Finch and Mason (1993) examined how family members chose to communicate with each other about their needs, and found that individuals adopted different tactics at different times, depending on the nature of the need. Tactics were linked strongly to whether a person "expected" help and if so, whether the request shifted the "dependence-independence balance" existing between the parties (ibid.: 138). Tactics such as "asking" and "hinting" were identified as key tools in framing requests for support. Similarly, in Grootengoed and Van Dijk (2012:688), hinting was also identified as a tool for framing requests for help "so as not to offend their relatives and to uphold their self-reliant image".

4.3.4 Avoiding negotiating responsibilities

In two studies adopting a case-study approach examining family dynamics, the authors observed a negotiation tactic which emerged amongst siblings when each were discussing who could, and could not, provide support to their older parent (Finch and Mason 1990, Finch and Mason 1993; Connidis and Kemp 2008). This tactic has been conceptualised as "a legitimate excuse" (Finch and Mason 1993:97), which broadly means a party to the negotiation presents his or her case to others taking part in the negotiation, explaining why he or she is unable to provide support, using their personal circumstances as supporting evidence. The others then judge how justifiable it is. A person who is simply reluctant to provide support, yet whose circumstances indicate they are capable of providing support is in a weaker position. The authors each identified a sibling who lives alone, or has never married, or who is not working is perceived by the others as the prime candidate to provide support, if the others can cite living further away, employment, immediate family commitments, poor health or lack of affection for the older person as bargaining tools (Finch and Mason 1993; Connidis and Kemp 2008; Price 2011).

4.3.5 Absence of negotiation

An absence of negotiation has been conceptualised in several different ways. Coercion as a tactic has been cited in the literature as one type of absence of negotiation (Finch and Mason 1993; Horton and Arber, 2004; Allen and Wiles, 2009). However, Strauss (1978) warns that coercion and negotiation are two separate concepts and should be treated

differently, but the author offers no guidance on how to differentiate these concepts in practice. It is arguable that coercion is simply another process of achieving support outcomes, as an absence of an older person's voice does not equate with an absence of support provision. Finch and Mason conceptualise coercion as a form of "moral blackmail" (ibid:171). However, the authors paid little attention to coercion in their research, seemingly to overlook a scenario where they described an incident of a son bullying his mother into providing care to his father as a form of coercion (ibid.). Coercion is also examined by Horton and Arber (2004) in relation to exploring negotiations between sons and their mothers within two themes: "protective actions" (ibid:82) and "coercive actions" (ibid:83). In the former case, the authors speculate that sons want to ensure that their mothers stay safe (ibid.). It is arguable that as a male, the son took the most expedient action as opposed to taking the time to discuss other solutions with his mother (Barbee *et al.* 1993).

Another example of non-negotiation is best described as unsolicited assistance, or "smothering support" (Allen and Wiles 2013:8). This is described as assistance effectively foisted onto older people by other people without any discussion, usually with the best of intentions. Older people reported that this type of support undermined their self-sufficiency and ability to cope (ibid.). A similar finding by Baur *et al.* (2010) suggests that older people are often excluded from, or exclude themselves from, negotiation, particularly in formal settings. The study, conducted in the Netherlands, concluded that those in a position of power should make allowances for older people to express their needs.

4.4 How is informal support negotiated and who is involved?

A critique of research which has been conducted exploring the different ways in which informal support has been negotiated by older people, or on their behalf will now follow, including an examination of who is involved. Factors identified within the literature as reasons why individuals take part in support negotiations will also be examined.

4.4.1 Gender of family members and negotiation

Rather than examining the gender of those providing support, Horton and Arber (2004) examine how gender affects the negotiation dynamic within family support. The authors

conducted qualitative interviews with thirty-five older people who recently had a fall (comprising 23 females and 12 males) and their main family carer who did not live with them. The authors largely determined that male carers adopt a dictatorial approach to their mothers, whereas female carers of older females tended to enter into diplomatic discussions about support preferences and issues (ibid.). The authors concluded that sons who did not discuss matters with their mother fostered dependency and daughters who discussed support matters facilitated their mother's independence (ibid.). This finding is in stark contrast to Matthews (2002), whose similar research conducted in the United States concluded that supportive daughters undermined parental autonomy and thus cultivated reliance, whereas sons adopting a more distant role promoted parental self-sufficiency. Further research examining whether support changed over time would have provided a deeper understanding of the dynamics evolving within the support negotiation process. There are two main reasons given to explain why researchers consistently find that female family members generally provide more support than their male counterparts: there is an assumption that women are the primary carers within the family setting as a part of their socially constructed role (Fox and Murry 2000; Silverstein *et al.* 2012;) and females are generally considered to be more compassionate and understanding than males (Baez *et al.* 2017) and therefore most research has historically tended to focus more on women's experiences of care, rather than men (Arber and Ginn 1995).

In relation to providing support, Finch and Mason (1990) observed that "…people do not appear to have a clear sense of precisely what constitutes the proper thing to do in respect of their parents. This is something which needs to be negotiated" (ibid., p. 169).

Apart from Finch and Mason's seminal study which included a focus on sibling negotiation (Finch and Mason 1993), no English studies could be located which focused solely on how brothers and sisters discuss and plan support with each other for their parents, or in conjunction with their parents. However, a study conducted in Canada explored sibling relationships and how support for parents was negotiated between them, adopting a case-study approach (Connidis and Kemp 2008). The research was based on the outcomes of two case-studies: one consisted of four daughters who provided support to their mother; the other consisted of three daughters and two sons where support for their parents was not yet required. Participants were asked about their lives and how

their family circumstances had been shaped over the years, in order to contextualise the research. One sister, living alone nearby, who had no work commitments was seen by her siblings as being the "logical choice" (ibid:235) to take care of their parent, which mirrors the findings in Finch and Mason (1993) of her not having a "legitimate excuse" (ibid.:97). This research would have been greatly strengthened by a series of follow-up interviews with participants to map how negotiations changed over time. Additionally, not all of the siblings could take part, which arguably would have provided additional credence to the research findings because the evidence provided about the missing members was hearsay. However, the research highlights four valuable insights into how best to understand the negotiation process. First, a longitudinal approach can track changes to levels of assistance and how it transpires. Second, by interviewing multiple parties, researchers can glean a deeper insight into the support dynamics. Third, adopting a life course approach provides a richer insight into how the parties' lives are intertwined. Fourth, adopting a symbolic interactionist approach to negotiation can map how discussions are shaped.

Qualitative research exploring how brothers and sisters negotiated between themselves to provide support to older parents was also conducted in the United States (Matthews 2002). Siblings who negotiated support between themselves and without their parents' involvement reported a tendency for their parents to oppose the arrangements (ibid). In many cases, parents negotiated sources of support from other avenues rather than relying completely on their children to meet their needs (ibid.). Finch and Mason's "legitimate excuse" (Finch and Mason 1993, p. 97) was not explored within this research. One barrier reported by siblings to providing effective support to their parents was a lack of complete information about their parents' circumstances, as parents were not always forthcoming about reporting difficulties they encountered (ibid.). One important finding was that "…brothers and sisters often had different ideas about the best way to meet their parents [sic] needs…" (ibid., p. 206), a similar finding to Horton and Arber (2004) (see sub-section 4.4.1 above). However, in cases where parents were able to communicate their support preferences, there were fewer instances of disagreements developing between the siblings (ibid.). One disadvantage of this research was that the voices of their older parents themselves were missing from the research, which arguably would have provided a better insight into why parents displayed particular behaviours as

reported within the research. Another drawback was that as participants were only interviewed once, there was little insight into how negotiation dynamics between siblings altered over time. Sims-Gould and Martin-Matthews (2010) also conducted qualitative research with family and friends who provided informal support to older people living in Canada. The main purpose of the research was to identify what was working well with the formal support which the older person also received (ibid.). Negotiating support was partially addressed by the research, where participants would report pre-empting the needs of formal carers to complete support tasks more efficiently. Examples cited were filling up the bath tub in readiness for the formal carer to wash the older person and leaving a home prepared dinner in the refrigerator for the formal carer to place in the oven (ibid). However, little information was provided within the research on whether these pre-emptive arrangements were negotiated explicitly or whether some form of implicit negotiation took place where informal support providers were ultimately trying to make life easier for the older person (ibid.). Neither formal carers nor older people's perspectives were included within the research, which arguably would have provided a richer understanding of how support in the home is arranged. Participants were only interviewed once, so again, there was no appreciation of how support arrangements or negotiations might alter over time.

Families reported little advance support planning or negotiation takes place before it is needed (Willyard *et al* 2008; Price *et al* 2014). Support provision cannot always be planned in advance because it is largely determined by family circumstances existing at the time, dynamics between family members and of feelings of personal responsibility towards providing support (Leinonen 2011). Motives for support provision were explored in a quantitative, longitudinal study conducted in the United States (Pillemer and Suitor 2013) which examined how brothers and sisters decided to support older mothers, using secondary analysis of a national dataset. The research focused on finding indicators for possible motives for adult children's decision to provide support taken from previous three qualitative studies which had been conducted to ascertain such motives. The main finding was that the closer an adult child lives to his or her mother, the more likely he or she will be to become a support provider. It was also found that a daughter was more likely to provide support than a son. In England, similar research conducted using secondary analysis of data from the English Longitudinal Study of Ageing dataset indicates

that the more children an older person has does not necessarily mean that those children will provide more support (Grundy and Read 2012).

4.4.2 Negotiations between older mothers and adult daughters

Interestingly, most qualitative studies focusing on negotiations between mothers and daughters about support negotiations took place in the latter half of the Twentieth Century and in the United States. No such studies could be located which took place in England. The studies which were located are considered relevant because they considered strong references to support negotiation, even though negotiation itself was not discussed in any detail. In all studies, daughters were either in the process of providing or considering providing support to their older mothers (Pohl *et al* 1997; McGrew 1998; Pecchioni 2001; Hartmann *et al* 2016).

McGrew (1998) conducted qualitative research with ten daughters providing support to their frail mothers to elicit what led them to start supporting their mothers. However, mothers were not included as research participants. Common themes which emerged from the data were that the daughters wanted to help but had to balance the support they wanted to give with the support they could provide without adversely affecting their lives and their immediate families. This finding supports the ‘pecking order’ of support provision (Qureshi and Walker 1989). Daughters reported emotional closeness or bonding with their mothers and described their motive to provide support as something they had always assumed would happen. A similar finding emerged from research conducted by Pohl *et al* (1997), as daughters reported that they had always assumed that they would eventually take care of their mother. One possible reason suggested by the authors was internalised behaviour: daughters reported observing that their mother had provided support to their grandmother and thought that it was the right thing to do (Pohl *et al* 1997). This finding is in line with Finch and Mason (1993). A similar result emerged from research carried out by Pecchioni (2001), who used vignettes to investigate mothers’ and daughters’ views on how support in the future might be provided to the mother. One finding which emerged was that older people and their families do not negotiate support in advance, largely because older people are reluctant to voice future support needs and their relatives usually consider it inappropriate to raise the subject

(ibid.). Mothers and daughters felt that they had spent sufficient time together and mothers trusted their daughters to know what needed to be done.

4.4.3 Negotiations led by older people

A search of the literature revealed a dearth of research in England which focuses on support negotiations led by older people. Tetley (2013) utilised a qualitative narrative approach to elicit how older people decided what support to receive in England and what choices older people felt they had. Twenty-four participants were interviewed who were recruited from outreach services aimed at older age groups. The author noted that decisions to receive state formal support at home were "…affected by the tensions between what services are able to offer and what the older person themselves wants" (ibid.:7) and that in some cases "…people felt they had no choice at all" (ibid:15). This research portrayed a snapshot of older people's support experiences received at that time and the challenges and benefits it represented.

Other literature which included older people as main research participants has been conducted in other countries. One study in Sweden was discovered which is broadly similar in its approach to the current research within this thesis. Dunér and Nordström conducted qualitative research with older formal support recipients in Sweden to explore and map who provided them with informal care (Dunér and Nordström 2006). The results suggest that older people tend to build their support network strategically wherever possible, so that their different needs were met by individuals with the requisite skills to undertake different tasks, as needed: "Some family members and/or friends were more used to making contact with the authorities, for instance, while others were better able to handle practical matters and give practical support" (ibid.:76). Although this research is similar in essence to the current research, it did not include interviews with the members of the support networks who were identified as helping the older person and there were no follow-up interviews to map how support was renegotiated over time. Another study investigating how older people living in Finland and Italy arrange their support noted that older people also tend to arrange support from a myriad of sources (Zechner and Valokivi 2012). Yet the authors only conducted interviews with an older person, plus one other support member (ibid.). Surprisingly little emphasis was included within the research of how older people negotiated their support,

as the authors focused predominantly on making support policy comparisons between Finland and Italy. One observation made by the authors was that "…need, money and social ties" (ibid:137) were at the heart of most support negotiations.

In addition, the authors identified that it was imperative for older people to have the requisite skills to enable them to be effective negotiators if they do not have some form of support network to draw upon. This is also highlighted by research conducted in Sweden (Breitholz *et al* 2013(a)). Twelve older people living in their own home were interviewed to determine the extent to which they perceived they were involved in decision-making about their support. Three themes emerged from the data. First, some older people felt more positive when visited by skilled carers with whom they could build a rapport, who actively listened to their needs and took appropriate action to help them to make decisions. Second, some participants felt precluded from making their own decisions and had no say over what happened to them. This generally occurred when carers were working against the clock and had no time to consult with the older person about their preferences. Third, some older people felt as if they had a daily battle with carers in order for tasks to be carried out in the way they preferred. The research highlights how current support practices undermine older people's self-worth and highlights the importance of older people being in a position to be involved in their support negotiations (Zechner and Valokivi 2012). It was evident from the data that some of the carers were under time pressure to do their jobs, yet torn between wanting to spend quality time with the older person. Carers were not interviewed within the research and arguably, presenting both the perspectives of the older person and the carer would be valuable to policy-makers and care providers because it would demonstrate the impact of time-restricted care provision on the individuals involved in the support process.

Self-sufficiency was a key finding in two studies which specifically examined how older people negotiated support in New Zealand. Breheny and Stephens (2009) interviewed 16 men and 20 women to investigate their perceptions of being supported in later life. All participants framed themselves as currently being self-sufficient and talked about the importance of having support networks and the importance of mutual exchange. One male participant believed his children would look after him in later life to repay him for looking after them when they were growing up. Another participant did not position

herself as being dependent on her friends for help because she made soft furnishings for them as recompense. The research highlights the importance to those interviewed of not becoming in someone's debt and has strong parallels with the findings of Finch and Mason (1993). The themes of exchange and self-sufficiency also emerged from research carried out by Allen and Wiles (2009) and Allen and Wiles (2013) examining older individuals who had never had children. An older man living by himself mentioned he swapped a newspaper each day with his neighbour as a signal that he was safe and sound, and was confident that she would investigate if this arrangement suddenly stopped (ibid). Negotiations for support were considered as part of research aimed at eliciting the circumstances under which participants felt able to accept assistance with activities of daily living. Findings indicated that participants felt able to accept help from others who were "…special in some way" (ibid:6) or where there was some form of mutual benefit between the parties. Again, there was no longitudinal element to this research and the individuals who were providing the support were not included as participants, which arguably would have provided a deeper perspective of the support narratives.

4.4.4 Negotiations between a support dyad

Research focusing on the relationship between carer and cared-for has typically simply focused on the two individuals as two separate and distinct entities (Horton and Arber 2004). However, another way that the negotiation has been examined within research is by treating the pairing as a distinct unit which is capable of being studied in its own right (Spiers 2002; Coeling *et al* 2003). Spiers (2002) conducted comprehensive qualitative research which explored how nurses negotiated support with older people in their homes. Negotiation was framed as "…a mutual experience…[where]…both nurses and patients are empowered and at the same time made vulnerable by the skills drawn from their everyday social encounters." (Spiers 2002:1052). Spiers noted that negotiation takes many guises within the professional interaction between nurse and patient. This research provides an excellent analysis of nurse and patient interactions, which are presented in mainly a positive light. However, the author does not provide a reflective account of her research and does not consider that perhaps the participants might have been influenced by an awareness of being video and audio recorded. Similarly, Coeling *et al* (2003) conducted qualitative research in the US which examined how the dynamic

between the cared-for and main informal care-provider coupling is negotiated. Sixty units (120 individuals) were interviewed together and independently to elicit their perceptions of the support provided or received, as the case may be. The emphasis of the analysis was more to explore how the parties navigated their relationship together and established protocols about what constitutes acceptable or unacceptable behaviour. The authors argue that if protocols are not adequately negotiated between the parties or if each party does not feel valued, it can lead to tension or disruption to the support provided. The research attempts to apply formal negotiation steps to the implicit process which occurs throughout the course of the care dynamic. The authors consider that valid research can be carried out in relation to how support is negotiated even if only one party to it is studied. One of the weaknesses of this research is it only provided a snapshot of negotiations currently occurring within the entity: there was no focus on how the entity was originally negotiated or renegotiated over time, even though the authors assert that negotiations alter over time (ibid.).

4.4.5 Negotiations between older people and non-kin informal carers

Only two qualitative studies were identified which focused, to some extent, on support negotiations between older people and their friends and neighbours: one in England (Nocon and Pearson 2000), the other in the United States (Barker 2002). Both studies involved interviewing older people and non-relatives who provided some form of support. The research by Barker (2002) was longitudinal, involving 156 case studies. Four types of dynamics were identified through thematic analysis, each representing a gradient of closeness and trust existing between the individuals: "…Casual, Bounded, Committed, and Incorporative" (ibid:S162). Nocon and Pearson (2000) recruited a lower number of participants, but focused more on the negotiation process, which was reported as sometimes beginning with a party either offering, or asking, for help with a household task or similar. Barker (2002) provided a more descriptive account of how support arrangements evolved. Both studies reported similar motives for support provision were couched in terms such as mutual exchange, money, pity, Christian duty, altruism and self-satisfaction. Where this was not present, some carers reported feeling harassed and exploited. This was combated by establishing boundaries. Carers felt resentful of adult relatives who did not provide assistance. The authors reported that although state care was arranged (sometimes by the support provider who no longer felt

able to continue providing assistance), the older person cancelled it for a variety of reasons, such as: not wanting to be reliant on the state, preferring the familiarity of the neighbour, having to wait in for carers, or not offering the service required. Older people who retained state-provided carers reported dissatisfaction with a lack of permanent staff and frustration at Health and Safety restrictions which prevented carers from carrying out particular tasks. This research highlights the gradual transition that can take place between helping out a friend and then over time becoming his or her main carer, thus extending the boundaries of that friendship. Although participants were interviewed once, the nature of how the support is negotiated and renegotiated was captured neatly. One criticism of the research is that the older person's perspective was largely ignored in favour of recounting the experiences of the main carer. Adding both sides of the negotiation process would be contributed an even greater understanding of the dynamic between the non-kin negotiation processes.

4.4.6 Motives for taking part in negotiations

Negotiation of support is central to this research. However, it is prudent to explore some possible motives to explain why individuals might enter into support negotiations. A literature search revealed three key motives which may explain why individuals become involved in support negotiations in Western societies: feeling obligated, reciprocation and altruism. These motives will each be examined in turn.

4.4.6.1 Feeling obligated

Literature examining obligation within family relationships is important because it represents a reason why an adult child might be involved in negotiating support with older relatives. Finch and Mason (1990) explored the concept of obligation in the first stage of their research using survey data based on frequencies. Their aim was to investigate what is considered to be the "proper thing to do" (ibid:160). Having posed a question asking respondents whether adult children ought to support their older parents, only 57% of the 978 respondents believed that they should. This represents a majority, but not an overwhelming one. The authors suggest that much depends on the length of time that it is anticipated that support will be required for, that is, whether it is a temporary or permanent situation (ibid.). Finch and Mason (1993) also explored the appropriateness of making a request for support and presuming that someone would

automatically provide support within the bounds of an informal relationship. The authors suggested that the person making the request for support may be viewed as being demanding, as they assume their request will be granted (ibid.).

A more recent English study exploring the impact of parental separation on adult children indicated they may feel less responsibility towards supporting their older parents in later life (Sage *et al* 2014) and adult children may feel more responsibility towards a step-parent who has provided material or emotional support than their blood parent (Ganong and Coleman 2006). The same authors carried out a survey using a broadly similar method to the first stage of Finch and Mason's (1990) research. Respondents were given a hypothetical scenario about a family member who had been diagnosed with diabetes and asked questions about who should provide support. Respondents were then informed that the diabetes was preventable and were asked the same set of questions. The results indicated that the changed emphasis of the family member being liable for their condition was not a prohibiting factor in the decision to provide support, but that respondents felt more responsible for looking after parents than step-parents. This study could have been strengthened by introducing a qualitative element by interviewing respondents to ascertain their reasons for their responses, similarly to the study conducted by Finch and Mason 1990. Oudijk *et al* (2011) examined motives behind informal carers' decisions to provide support to older relatives in The Netherlands using the SHARE dataset and compared participants throughout Europe. One of the main motives for informal carers to provide support was the extent to which he or she feels obligated to provide support to an older relative, which may indicate "…a straight exchange or a 'repayment' for what the caregivers have themselves received in the past…" (ibid:234). However, participants were not asked directly and the data used in the analyses were over seven years old, which was not discussed as a possible shortcoming of the research.

4.4.6.2 Reciprocal arrangements

Finch and Mason (1993) conceptualised reciprocity between families in terms of the negotiation for support provision as maintaining "…a proper balance between dependence and independence…" (ibid., p. 58). The authors determined from survey scenarios that reciprocation was a prevalent motive for support provision between younger and older relatives. The latter were more likely to provide this in monetary

terms to the former, whereas the former provided assistance with daily tasks to the latter. The authors determined that past support history can influence future support provision: thus, if each party provides some form of benefit to the other, there is more chance of ensuring that demand and supply of support are equitably matched. However, these results are mainly based on hypothetical scenarios, where participants might have responded by voicing what they thought was the correct course of action (ibid.). Reciprocity between parents and children was examined from the perspective of an exchange of resources (Grundy 2005). The author undertook secondary data analysis and found that where parents help a child, there was a corresponding level of assistance supplied in turn, although there was no indication of how that support was negotiated or explanation of the reasons underpinning the support.

4.4.6.3 Altruism

A third motive which may explain why individuals might provide support to older people is altruism. It is important to discuss altruism in relation to this thesis because it represents another potential motive behind support members' willingness to enter support negotiations with older people. Altruism has been defined as 'giving to others with the most need and the least ability to repay' (Silverstein et al. (2012): 1250). In other words, altruism can represent an explanation of why some individuals provide help to others with no obvious outward reason, such as a reward or as some form of identifiable exchange for past help or reciprocal motivation. The type of relationship existing between each party is not necessarily an indicator of whether or not a person will act in an altruistic manner (Rachlin and Jones 2008). Logan and Spitze (1995) identified that altruistic tendencies can also manifest themselves in non-kin relationships between older and younger individuals. Thus, being related to someone does not always presuppose a willingness by kin to provide support (ibid.; Bernheim and Stark 1988). Adopting a life course approach can help in understanding why particular family members provide support to older relatives, as 'two of the most important predictors of intergenerational behavior and exchange: [are] love and guilt' (Bengtson and Murray 1993: 113).

4.4.6.4 Maintaining independence

Research framed within the concept of reciprocity examined how an individual copes with the transition from being independent to becoming dependent on others for support

(Breitholz *et al* 2013(b)). Older people often pretend they are coping with life and present an independent 'front' to the world because they may perceive themselves as a failure to ask others for help (Breheny and Stephens 2009). Research has indicated that it is important for older people not to be perceived as a burden or as needing help (Horton and Arber 2004; Allen and Wiles 2009; Allen and Wiles 2013; Ipsos MORI 2017). In Western societies, being dependent in later life is largely perceived as a weakness and something to be avoided if possible (Portacolone 2011). Independent living is heralded by policy-makers as being the optimum strategy for achieving a fulfilled life and a signal to others of "successful ageing" (Breheny and Stephens 2009:1311; Her Majesty's Government 2012). Being independent is a highly subjective and divergent concept, summarised neatly by Portacolone (2011:806): "It is possible to feel independent while relying on others for help, or to feel dependent while not relying on anyone". Many older people want to ensure their interactions with others are equitable, otherwise they consider there might be a risk of dependency (Finch and Mason 1993; Breheny and Stephens 2009). Similar observations were made by researchers in New Zealand, where older people vigorously defended their ability to cope with everyday life without the need for outside intervention (Allen and Wiles 2009). However, many did not equate the help they received with everyday tasks from their adult children, friends and neighbours as constituting "support" in any formal sense (ibid.:156). More recent research has also highlighted the importance for older people of drawing on their existing support network to help with home repairs (Coleman *et al* 2016) and also for support with IADLs (Ipsos Mori 2017). Therefore, it would appear that 'independence is in the eye of the beholder' and that many older people will accept support if they can justify it within the context of reciprocity or some form of exchange (Breheny and Stephens 2009).

4.5 Negotiation within personal budgets (PBs)

An examination of literature relating to negotiation with PBs is necessary because the rationale of PBs is to give service users the flexibility to find innovative ways to meet their formal support needs. The aim of this section of the literature review is not to provide a synthesis of literature relating to older people and personal budgets per se, but to examine literature which has included a focus on how older people, or others on their

behalf, have undertaken negotiating older people's support within the framework of their personal budget.

4.5.1 Negotiation and older people with individual budgets

Most literature relating to older people and self-directed support has used data from the pilot study for individual budgets (see section 3.1 above) (Glendinning *et al* 2008; Netten *et al* 2011; Moran *et al* 2011). Arguably, as time passes this research is becoming increasingly irrelevant, as individual budgets were based on a different premise from personal budgets (see sub-section 3.2 above). Older people felt valued when asked about their preferences (Moran *et al* 2011). One aspect highlighted by the study which could impact on the extent to which older people are able to actively negotiate their support within the remit of an individual budget was that social workers might assume older people are incapable of managing a direct payment (ibid.) and that some older people expressed reluctance managing their own budget (Glendinning *et al* 2008; Moran *et al* 2011).

Few studies have focused on negotiation within personal budgets. Research discourse focusing on older people and personal budgets has tended to explore the effectiveness of the personalisation policy agenda (West and Needham 2017).

Slasberg (2010) argued that in order for personalisation to be achieved for older people, their voices need to be heard during the planning and review processes. The author identified older people as having different priorities from other service users such as "…want[ing] things like services that are responsive to them, [carers to] come at times that are right for them, do the tasks that are important to them at that particular time and do them in ways which are right for them, and to have carers that they know and are comfortable with, who do not constantly change." (ibid:18).

There are two main points during the personal budget process when it becomes necessary to enter into negotiations to arrange a personal budget: first, at the support planning stage and second, at the review stage (see Figure 5 in sub-section 3.3 above). Research carried out by Baxter *et al* (2013) suggests that older people are not always given the option to receive their PB via direct payment. Conducting research at three different local authorities, the authors were interested in ascertaining how Council staff

incorporated choice for older people who received support with ADLs at home when the personal budget was managed either by an outside agency or by care workers. The authors concluded that "…constraints on opportunities for choice and control by older…[clients]… are likely to continue, not least because of the relatively small size of their budgets and their high levels of need for essential personal care…" (ibid., p. 406). This would appear to suggest that older people use their PB to purchase conventional care and support services and are not fully informed about their options within the personal budget at the outset. The research would have been greatly strengthened if older people had been included as research participants to include their perspectives on PBs. A similar focus was made by Xie *et al* (2012), who distributed questionnaires to social care professionals based at all local authorities in England. One finding of the survey data was that older people receiving their entitlement via direct payments were more likely to choose to pay to arrange for help buying the weekly groceries, gardening, social activities and household chores than those whose budget was administered by the local Council (ibid). However, as highlighted by the authors, only survey data was collected and there was no qualitative data from older service users to provide a deeper insight.

Three qualitative studies were located which included older people's perspectives about negotiating support within the context of a personal budget. One Welsh study carried out focus group research with older Welsh service users (Seddon and Harper 2009). Important findings which emerged from the research were concerns raised about not being listened to and a lack of funding for additional services that older people need, such as assistance in the garden, home maintenance and being accompanied on shopping trips. Similar findings emerged from research carried out by Newbronner *et al* (2011), where older people reported they felt valued when they voiced their requirements to social care professionals and most older people prefer to have an opportunity to discuss their plan, though some people did not want to have to negotiate support (ibid.). Again, older people chose to use their personal budget to pay for similar services as reported in Seddon and Harper (2009). Barriers identified by researchers to negotiating support for older people was a lack of information about what items a personal budget could legitimately be used to pay for (Newbronner *et al* 2011.). Social care professionals who presented restricted choices or ideas to older people were also seen as preventing

effective negotiation for tailored support (ibid.). Two criticisms of the research are that the authors conducted the research soon after personal budgets were introduced, therefore not allowing time for them to become established. A second criticism is that the research is cross-sectional and arguably it could have been improved if older service users had been approached for interview some months on to capture negotiations over time. In longitudinal research conducted between 2007 and 2011 to map how personal budgets have been implemented in Essex, older people were more likely to engage relatives and other people known to them to provide support for them, rather than paying qualified carers (Sheikh *et al* 2012). In line with Seddon and Harper (2009) and Newbronner *et al* (2011), older personal budget holders generally used their entitlement to pay for support with ADLs or to enable relatives to go on vacation.

One important finding of this research was that personal budget holders consider it imperative to be "…**confident, determined and able to articulate and negotiate** [in order to ensure that] Personal Budgets work well for them" [emphasis as in the original] (ibid., p. 5). This presupposes that these abilities are a prerequisite for obtaining tailored support through a personal budget and recognition that not all service users would be capable of negotiating their own support, which is a similar finding to Zechner and Valokivi (2012). One major criticism arising from the research was a lack of clear information provided by the local Council about the extent or remit of allowable personal budget expenditure. This finding also emerged from research carried out by Bright *et al* (2013), whose research focused on how service users access information about available services in response to an emergency support situation.

No studies could be located which were based in England that included either older person's perspectives or their family's perspectives of either the assessment or support planning process or review stages of the personal budget process (see sub-section 4.5.2 above). Studies of the assessment stage have been carried out in Sweden seeking to explore how formal support has been negotiated. Janlöv *et al* (2006) carried out qualitative research interviewing twenty-seven relatives of older people who required formal help in order to understand how family members were involved in the formative stages of setting up formal support services. The main finding of the research was that family members' wishes were not highly regarded within the planning process (ibid.). Although older people's views were not included within this research, other research in

Sweden has been conducted which has. Olaison (2009) provided an in-depth analysis of how older people negotiate their formal support at home. Three broad themes relating to negotiation behaviour emerged from the data: first, older people might offer resistance to support as they were in denial about their lack of ability to cope with carrying out daily tasks; second, older people were willing to receive as much support as possible; third, social workers and older people worked together to plan support (ibid.). Olaison reports that "…both older persons and care managers employ implicit and explicit ways of using dependence as an argument in the assessments" (ibid:62). Thus overt and implicit types of negotiation strategies were found to be adopted within the formal assessment process in Sweden (see sub-section 4.3 above).

4.6 Identifying research gaps in the literature

There are four gaps in knowledge which have been revealed as a result of conducting the critical literature review to date which are summarised below.

First, there appears to be a lack of knowledge about how older people negotiate informal support that they receive in their home. Few recent studies in England have focused on this area of research. Finch and Mason (1990) and Finch and Mason (1993) conducted the most comprehensive English study of how support is negotiated within the family setting in north-west England. However, the remit of that research was to identify the circumstances under which family members of any age would be prepared to support their kin and to identify motivating factors, exploring the concepts of obligation, balancing dependency and independence and responsibilities (ibid.). The study examined families as a unit and not older people *per se*, did not focus on non-family support networks, semi-formal or formal support provision and data were collected almost thirty years ago.

Although more recent research was carried out in the north of England which investigated older people's motives for arranging support at home (Tetley 2013), the research focus was finding out about older people's decision-making and not understanding the negotiation process itself.

Second, there is a lack of knowledge surrounding how older people negotiate formal support, in particular at the assessment and review processes within the personal budget

process (see sub-section 3.3 above). Research in Sweden has concentrated on how older people and their support network negotiate formal support provision and their involvement within the decision-making process (Janlöv *et al* 2006; Olaison 2009), yet little focus has been made on how older people negotiate their formal support, apart from incidentally as part of the remit of wider research focusing on formal social care (Newbronner *et al* 2011; Sheikh *et al* 2012). In my study, although it was not possible to accompany participants to the assessment or review meetings, it was possible to obtain an account of the personal budget negotiation experiences encountered by older people and others.

Third, little is known about how older people negotiate all sources of support. It is well documented that older people receive support from a variety of sources, both formal and informal (Dunér and Nordström 2010; Nocon and Pearson 2000), yet most studies identified have focused on one specific source of support (for example, adult child, formal), rather than mapping and understanding how older people negotiate all sources of support they receive (Horton and Arber 2004). Several studies explored informal support within a carer and cared-for dynamic (Finch and Mason 1990; 1993; Nocon and Pearson 2000; Horton and Arber, 2004; Allen and Wiles 2009; 2013). However, only one study (Dunér and Nordström 2006) which was conducted in Sweden explored older people negotiating support from a variety of avenues and their motives for doing so.

Fourth, gender differences in support negotiations have also been under-investigated. Horton and Arber (2004) examined gender differences in support negotiations with older people who had recently had a fall, but their study assumed there were only two parties to the support negotiations: the older people and a main carer who did not live with them. Whilst research has focused on support provided by more than one person, for example, adult children to their parents (Gans and Silverstein 2006; Grundy and Henretta 2006) and adult daughters to their mothers (Pohl *et al* 1997; McGrew 1998), little research has been conducted which focuses on negotiations between mothers and sons, fathers and daughters or fathers and sons (Horton and Arber 2004).

Fifth, researchers have tended to adopt a top-down approach to recruiting research participants in the negotiation process. In other words, assumptions are made at the outset that the actors who provide support are also involved in the negotiation process. Therefore the type of participants to be recruited is predetermined, for example, an older

person and a carer (Qureshi and Walker 1989; Horton and Arber 2004; an older person and their daughters or children (Gans and Silverstein 2006; Grundy and Henretta 2006), or siblings negotiating support for their older parents (Matthews 2002; Connidis and Kemp 2008). Only one study was located which adopted a bottom-up approach: Finch and Mason (1993) recruited their initial participants and obtained permission to approach other members of the participant's family to take part in the next stage of their research to gain a holistic and richer understanding of the negotiation and support process from multiple perspectives (ibid.).

Sixth, few studies include older people as main research participants (Dunér and Nordström 2006; Breheny and Stephens 2009; Allen and Wiles 2009; Tetley *et al* 2009; Zechner and Valokivi 2012; Tetley 2013; Allen and Wiles 2013; Breitholz *et al* 2013 (a)). Most research has been conducted from the perspective of one carer or the perspectives of family members, rather than the older person (Pohl *et al* 1997). Yet it was noted that even in research where older people were included as participants, their perspectives did not appear to be explored in as much depth as carers or other participants (Finch and Mason 1993; Nocon and Pearson 2000; Horton and Arber 2004). Most research exploring support for older people has been framed within the dependence versus independence/interdependence debate, reciprocity of support or asking for their perspectives on existing services (Finch and Mason 1993; Allen and Wiles 2013). Little attention has been paid to asking older people what support they might want (Slasberg 2010) or exploring reasons for seeking support from a variety of sources to meet their needs.

Seventh, few studies have incorporated any element of longitudinal research (Finch and Mason 1993; Barker 2002; Sheikh *et al* 2012; Pillemer and Suitor 2013). No recent English qualitative studies have been located which examine how the support negotiation process alters over time. It is well documented that support needs fluctuate (Nocon and Pearson 2000). Yet only research carried out by Barker (2002), exploring how non-relatives provide support to older people introduced some element of investigation of how support changes over time, although there was little focus on how that support was negotiated or re-negotiated.

Eighth, there is a lack of knowledge about how older people as 'self-funders' negotiate receiving private formal care. One study was located which focused on how older people

negotiate receiving formal care from the private sector (Tanner *et al* 2017), which found that negotiating different sources of support was problematic and recommended further research examining the interplay of relationships between older people and members of their support network. This area is significantly under-investigated, mainly because this group is difficult to identify, mainly because of a lack of records documenting those who arrange their own support.

Finally, little research has been conducted which focuses on how childless older people negotiate support. Four qualitative studies were identified: one conducted in New Zealand (Allen and Wiles 2013), one conducted in England eighteen years ago (Wenger *et al* 2000) and two studies focusing on support arranged by neighbours and friends for older people (Nocon and Pearson 2000; Barker 2002).

4.7 Chapter Summary

The above literature review mapped existing research relating to support negotiation and negotiation strategies adopted by the parties (Finch and Mason 1993; Horton and Arber 2004).

The literature search revealed preliminary answers to the three questions posed in sub-section 4.1 above. The broad negotiation strategies adopted by the parties can be either overt/direct or implicit/indirect in nature (Strauss 1978; Finch and Mason 1993; Horton and Arber 2004). Negotiation strategies themselves are complex and their shape largely depends on the parties involved. Gender, needs, resources and relationship status of the parties themselves can all affect the negotiation dynamic (Connidis and Kemp 2008). Individuals within the support network may present some form of socially acceptable justification for not being in a position to provide support to older people (Finch and Mason 1993). However, reluctance or refusing to act per se was not perceived as a valid defence (ibid.). Some bullying or coercion tactics were reported as being adopted, as well as more moderate methods (Finch and Mason 1993; Horton and Arber 2004).

Research indicates that older people are actively involved in negotiating or arranging their informal support and that it is usual for an older person to negotiate with individuals within their support network to fulfil their needs (Dunér and Nordström 2006). Older people have also been identified as passive recipients of informal support which can be

arranged for them by their children (Matthews 2002; Connidis and Kemp 2008). However, little research has taken place in England aimed at understanding how older people negotiate their formal support in the shape of personal budgets (Newbronner *et al* 2011; Sheikh *et al* 2012).

The search has revealed a clear gap in knowledge surrounding how older people negotiate and renegotiate receiving support at their home in England. In reviewing existing research, it became clear that no study in England has been conducted which aimed to understand how older people negotiate and renegotiate their support in their home. The aim of this thesis was to remedy the position by undertaking research to ascertain how older people negotiate support for themselves at home, what form the negotiation takes and who takes part, as well as what factors were present which influenced older people to negotiate support from the sources they chose, and not from others. In addition, in cases where older people received state support, participants were asked how they negotiated receiving a personal budget and what influenced their choices and decisions. The perspectives of older people were elicited and in addition, were asked to identify all those individuals or organisations which were instrumental in negotiating support. Those individuals or representatives were approached for interview in order to construct an overview of the meaning of the negotiation process, with the older person as a central figure. Older participants were also approached six months further on in time to understand whether their support levels had changed and if so, how that support was negotiated or renegotiated.

This Chapter provided a critical analysis of pertinent literature relating to negotiation of support by and for older people (Finch and Mason 1993; Horton and Arber 2004) and personal budgets (Newbronner *et al* 2011; Sheikh *et al* 2012), from which gaps in research knowledge have been identified (see sub-section 4.6 above). Chapter Five to follow provides a critical explanation of the research structure and design, as well as the rationale behind the methodology decision-making.

Chapter 5 Methodology

5.1 Overview of Chapter

Having conducted a review of literature reporting similar or related studies in Chapter Four above, it was noted that many researchers adopted qualitative investigative methods. This Chapter provides a critical evaluation of the rationale of the research methods used in this thesis and provide a more in-depth exploration of the methodological aspects of closely aligned studies, which helped to inform the research methodology, strategy, design, sample, recruitment and setting of the present study.

5.2 Rationale of the research

Following on from my discussion of the literature at the conclusion of Chapter Four, few studies have attempted to investigate the support negotiation process itself. Investigating negotiation processes first-hand has historically been viewed as challenging by researchers (Thompson *et al* 1995). Arguably, witnessing negotiations of support as they occur is particularly challenging because they are usually unplanned and take place in a private setting (Finch and Mason 1993). This is because offers of, or requests for, informal support emerge unexpectedly during conversations between individuals, rather than as an outcome of a formal family meeting (ibid.) or occur in response to unplanned or unforeseen events, such as (non)medical emergencies (Horton and Arber 2004).

Within this context, the possibility of obtaining "'naturally occurring data'" (Ritchie 2003, p. 34) is extremely challenging. In an ideal world, capturing the negotiation process would involve witnessing it in real time, by becoming 'a fly on the wall', or in other words, a participant observer, in the homes of older people over a period of time to witness how such negotiations take shape. However, this method would involve spending long periods of time in the presence of an older person in their home, or installing cameras to record day to day activities, which would be impractical, undesirable and unethical. In addition, even if this were possible, in light of the practical barriers outlined above, I considered that the very presence of me as a researcher would likely influence the nature of the

negotiation process. Thus the data obtained consist of verbal accounts by older people and other parties about the support negotiation process (ibid.).

5.3 Initial methodological considerations

Flick (2007) emphasises the importance of research having "…*a clear focus*…[which] is built around a clear research question. Both design and questions allow the research to *reduce* the study *to the essential issue* for answering the question" (ibid:50). The focus of my research was to understand how older people negotiate support from others. I considered that a qualitative approach would be best suited because I am interested in the understanding the support negotiation process through the perspectives of older people and others parties to it. When designing a research study, a diligent researcher should consider the philosophical underpinnings of their research, devise research questions and to set out the reasons for conducting their research (Mason 2002). In the following sub-sections, I will address these considerations in relation to my research in order to defend my decision to conduct the research in the way I have chosen to. I am adopting an inductive approach as I aim to explore and capture the social worlds of my participants in order to address the research questions and use the results to build upon existing theory relating to the negotiation of support in England (Gomm *et al* 2000; Bryman 2008; Hennink *et al* 2011).

5.3.1 Ontological and Epistemological considerations

Guba and Lincoln (1994) highlight the importance of a researcher having a clear understanding of how they frame reality before commencing any research pursuit. The authors advocate considering the ontology, epistemology and methodology of the thesis in order to clarify the conceptual underpinnings of the research enquiry (ibid.).

Examining the ontological position, the rationale behind my research was to gain a deeper understanding of how older people *negotiate* their support, in conjunction with others, such as family members, friends, neighbours, carers, employed helpers and so on. Negotiation is not a concept which exists as a separate being in its own right and it therefore cannot be measured objectively as an external phenomenon (Blaikie 2007). So ontologically speaking, the essence of what I wanted to investigate could only be obtained by communicating with participants to gain access to their views, perspectives,

opinions, experiences, memories and attitudes about negotiation experiences (Mason 2002). In other words, I approached the research from an "*idealist* position" (Blaikie 2007:17 [emphasis in the original]) because I believed for the purposes of this thesis "Social reality consists of the shared interpretations that social actors produce and reproduce as they go about their daily lives" (ibid.).

An epistemological perspective is defined as '…what is…appropriate knowledge about the social world…' (Bryman 2008:4). My research approach was best described within the philosophical ambit of interpretivism (Blaikie 2007; Ormston *et al* 2014) or constructionism (Ormston *et al* 2014). This is because I believe that the knowledge I was interested in accessing could only be imparted from the minds of the participants as they made sense of their negotiation experiences, fashioned by their individual narratives (Bryman 2008; Ormston *et al* 2014).

5.3.2 Research methodologies used in existing studies

At the outset of my research, I considered one of my first priorities was to ascertain what, if any, research had been carried out in England about how older people negotiate support. The reasons were two-fold. First, I wanted to establish whether, to date, the topic of research had already been investigated in England, and if so, how such research had been carried out and what the results were. Second, I wanted to gain a deeper understanding of the methodological considerations applied by established researchers who had faced analogous limitations when conducting similar research. I therefore conducted a preliminary on-line literature search via Web of Knowledge, AgeInfo, Delphis and Social Care Online databases. Only three relevant studies were located. Extending the initial search to include all other countries revealed that studies with a focus on negotiation had been conducted in the United States, Scandinavia or Canada. Table 1 below shows the studies most closely positioned to my study. The aim of this section is not to provide a critique, per se, of the literature identified, but rather to provide a synopsis of the methodologies chosen to give credence to my research design choices.

Table 1: Qualitative studies examining older people and social care support negotiation or decision-making				
Authors, Year and Country	**Methodology**	**Number and type of Participants**	**Sample Frame**	**Location of Research**
Qureshi and Walker (1989) (England)	Non-random sample Two stages: (1) Structured interviews (2) Semi-structured (dyad)	(1) 306 older people aged 75+ (2) 57 non-resident main carers (dyad)	(1) Older people in stage one (2) Carers identified by older people in stage two	Sheffield, UK in 1982 and 1983
Finch and Mason (1993) (England)	Two stages: (1) Two-stage stratified cluster sampling (2) Two interviews with family members within a clan (case studies)	(1) 978 adults aged 18+ (2) Theoretical sampling. 88 adults (49 women, 39 men)	(1) Electoral Register (2) Chosen from participants in stage one	Greater Manchester, UK between 1986 and 1988
Matthews (2002)	Two stages: (1) Questionnaire to (2) Semi-structured (dyads)	(1) 149 siblings dyads (298 adult children)	Community groups, University Campus, snowballing	Cleveland USA in 2000/2001
Horton and Arber (2004) (England)	(1) Older person (2) Main family carer (dyad)	(1) 35 older people (2) 23 female and 12 male carer	(1) 311 day-centre users and 127 sheltered housing tenants (2) Main carer	Southeast England in 2000
Olaison and Cedersund (2006) (Sweden)	(1) Recording formal assessments (2) Interviews with older people and care manager (dyad)	20 older people and care manager	Forms part of a larger study – no details	Sweden in three municipalities
Dunér and Nordström (2010) (Sweden)	(1) Participant/observation of formal care meeting between older people and care manager (2) Interviews with older people (3) Follow-up interviews with older people, carers, relatives and friends	8 care managers 22 older people aged 67+ recruited through gate-keepers	Municipalities	Sweden in two municipalities
Connidis and Kemp (2008) (Canada)	Two stages: (1) Questionnaire to (2) Semi-structured interviews	86 participants – sampling strategy not discussed	Multi-Generational Families Study: 678 aged 55+	Urban Canadian city
Breitholz *et al* (2013(b)) (Sweden)	Part of a larger study Semi-structured interviews	7 older people aged 70+	Not stated	Sweden in two municipalities

Source: Author's research of existing literature

The commonality between the studies shown in Table 1 above is that the researchers all adopted a qualitative methodology. One criticism of qualitative research is that the results produced are highly subjective and non-generalisable to the population as a whole (Mason 2002). However, exploring a person's experiences contributes a depth of knowledge and understanding that cannot be captured by quantitative methods, in particular when investigating human interactions (Flick 2014). Therefore, I considered it prudent to adopt a qualitative approach within my research because it best facilitates exploring the negotiation process surrounding support (Ritchie 2003).

Some of the studies identified in Table 1 above did not clearly explain their research design. Three studies appearing in Table 1 adopted some form of two-stage approach (Qureshi and Walker 1989; Finch and Mason 1993; Connidis and Kemp 2008). The first stage is a form of screening process, aimed at eliciting background information in order to select participants for in-depth investigation in the following stage. Qureshi and Walker (1989) produced a questionnaire which was in three parts. One part focused on mapping the older person's surviving relations in terms of proximity and how often they were in communication. The next part posed questions to determine health level and self-esteem. The final part investigated who currently provides support to them. The older person and their main carer were then interviewed in greater depth to determine the nature of the dynamic between them. Finch and Mason (1993) used scenario-based questions from the Family Obligations Survey. These elicited whether respondents felt that support should or should not be provided to a family member in a set of prescribed circumstances. Participants for the next stage were chosen on the basis of the results of that stage. Connidis and Kemp (2008) recruited participants from the Multi-Generational Families Studies who had given their consent to be contacted in relation to future research. A structured questionnaire was sent to participants which asked about "…individual characteristics, family structure and relationships, living arrangements, paid and unpaid work, marital history, health and socioeconomic status" (Connidis and Kemp 2008, p. 231). In-depth, follow-up interviews followed which asked how family members would react in hypothetical circumstances in relation to providing and receiving support.

Another shared characteristic was all studies adopted semi-structured interviewing to elicit relevant information about negotiation from participants. In addition, researchers decided to interview more than one party to the negotiation process to explore the

negotiation process in more depth. Three studies chose to explore negotiation between two parties. Qureshi and Walker (1989) asked older participants to name one family member who provided the most support but who lived elsewhere. The family member was then interviewed in-depth using a semi-structured schedule. The data were collated to create a case-study of the dyad.

Horton and Arber (2004) adopted a similar approach by interviewing an older person and asking them to identify one main family carer, who was interviewed at a different time, again with a focus on the care dyad. Olaison and Cedersund (2006) and Dunér and Nordström (2010) examined a different support dyad: the negotiation between older people and care managers in the Swedish equivalent of adult social services, both observing assessments carried out for formal care and interviewing older people. Interviewing also formed part of the case-study approach adopted by Finch and Mason (1993). The researchers aimed to capture as many members of a family unit as possible to gain a deeper insight into the essence of support negotiations which had taken place in the past. Connidis and Kemp (2008) utilised a slightly different approach to their case studies. Their focus was on adult brothers and sisters who were either currently providing support to older parents or speculating about how the sibling unit might arrange support. Breitholz *et al.* (2013(b)) conducted semi-structured interviews with participants on three separate occasions, thus adopting a longitudinal approach to understanding decision-making in relation to their care. The sample frame and recruitment in the studies will be considered in the section to follow.

5.3.3 Sample frame and recruitment of existing studies

The underlying purpose of participant recruitment is to gain access to individuals who might be relevant to the research (Porter and Lanes 2000). Not all studies encountered were transparent in describing their sampling frame and recruitment (Breitholz *et al* 2013(b)). Three studies used some form of register or existing research as a sample frame. Qureshi and Walker (1989) used the Family Practitioner Committee register to conduct initial recruitment. Finch and Mason (1993) accessed the Electoral Register and adopted random sampling in the first instance and theoretical sampling in the qualitative aspect of the research. Connidis and Kemp (2008) contacted former participants of the Multi-Generational Families Study who had expressed a willingness to take part in future

research. Horton and Arber (2004) accessed facilities aimed predominantly at older people, such as day-care centres and sheltered accommodation and adopted a purposive sampling approach. The Swedish studies used formal state care as a research setting (Olaison and Cedersund 2006; Dunér and Nordström 2010; Breitholz *et al* (2013(b)), yet only Dunér and Nordström (2010) mentioned challenges with recruiting participants through gatekeepers. Horton and Arber (2004) recruited their participants from facilities aimed predominantly at older people and the low number recruited indicates how challenging it can be to recruit willing individuals to take part in research. The numbers of participants recruited in each study varied considerably, but sample size will differ according to the research questions posed and the setting accessed (Mason 2002).

5.4 Research questions

I highlighted and discussed gaps in existing knowledge in sub-section 4.6 of the Literature Review Chapter above. When considering what research questions to ask and having reflected upon my research topic in light of the existing research, I examined the research questions other authors posed. The studies in Table 1 (published in journals (Horton and Arber 2004; Olaison and Cedersund 2006; Dunér and Nordström 2010; Breitholz *et al.* 2013(b)) did not provide the research questions. Qureshi and Walker (1989), Finch and Mason (1993) and Matthews (2002) published books about their research, which provided greater insight into how the researchers carried out their research.

I wanted to find out how older people negotiated or planned their support received at home with others and how, or whether, this alters over time. In particular, I was interested in knowing about older people's lived experiences regarding negotiation support, the tactics they used to ascertain commonality and diversity, challenges and positive outcomes, and to gain a deeper appreciation and understanding of the negotiation process itself. One way to help to crystallise one's thought-processes is to formulate research questions (Mason 2002). With that in mind, I devised four peripheral questions (see sub-section 1.2 above). Having considered what research questions I wanted to ask, I considered what research methods would be appropriate to address each question (Mason 2002). Mason (2002: 28-29) suggests devising a chart to show how each research question can be addressed within the research. I created Table 2 below which I consider is a clear way of depicting how each question was addressed:

Table 2: Research Questions and How to Address Them		
Research Questions	Data Sources and Methods	Justification
1. How do older people negotiate social care support from different sources?	Older people via structured interviews Older people, family members, friends, stakeholders via semi-structured interviews	Structured interviews to ascertain support network and level of need (screening process) Semi-structured interviews to gain access to participants' experiences of negotiation for social care support
2. To what extent do social care support arrangements change over time?	Older people via structured interviews Older people, family members, friends, stakeholders via semi-structured interviews encased within a longitudinal case-study approach Literature-based review	Structured interviews to ascertain support network and level of need (screening process) Semi-structured interviews to gain access to participants' negotiation of different types of social care support Critical analysis of relevant literature
3. What barriers or enablers are present which influence older people to negotiate support from different sources?	Older people via structured interviews Older people, family members, friends, stakeholders via semi-structured interviews encased within a longitudinal case-study approach Literature-based review	Structured interviews to ascertain support network and level of need (screening process) Semi-structured interviews to discern different types of negotiation and factors influencing negotiation of different types of social care support Critical analysis of relevant literature
4. How do older people negotiate arrangements within a personal budget and what factors influence that choice?	Older people via structured interviews Older people, family members, friends, stakeholders via semi-structured interviews encased within a longitudinal case-study approach Literature-based review of policy documents and personal budget research	Structured interviews to ascertain support network and level of need (screening process) Semi-structured interviews to find out about personal budget negotiations Critical analysis of relevant literature

Source: Adapted from Mason (2002:28-29)

5.5 Designing the research

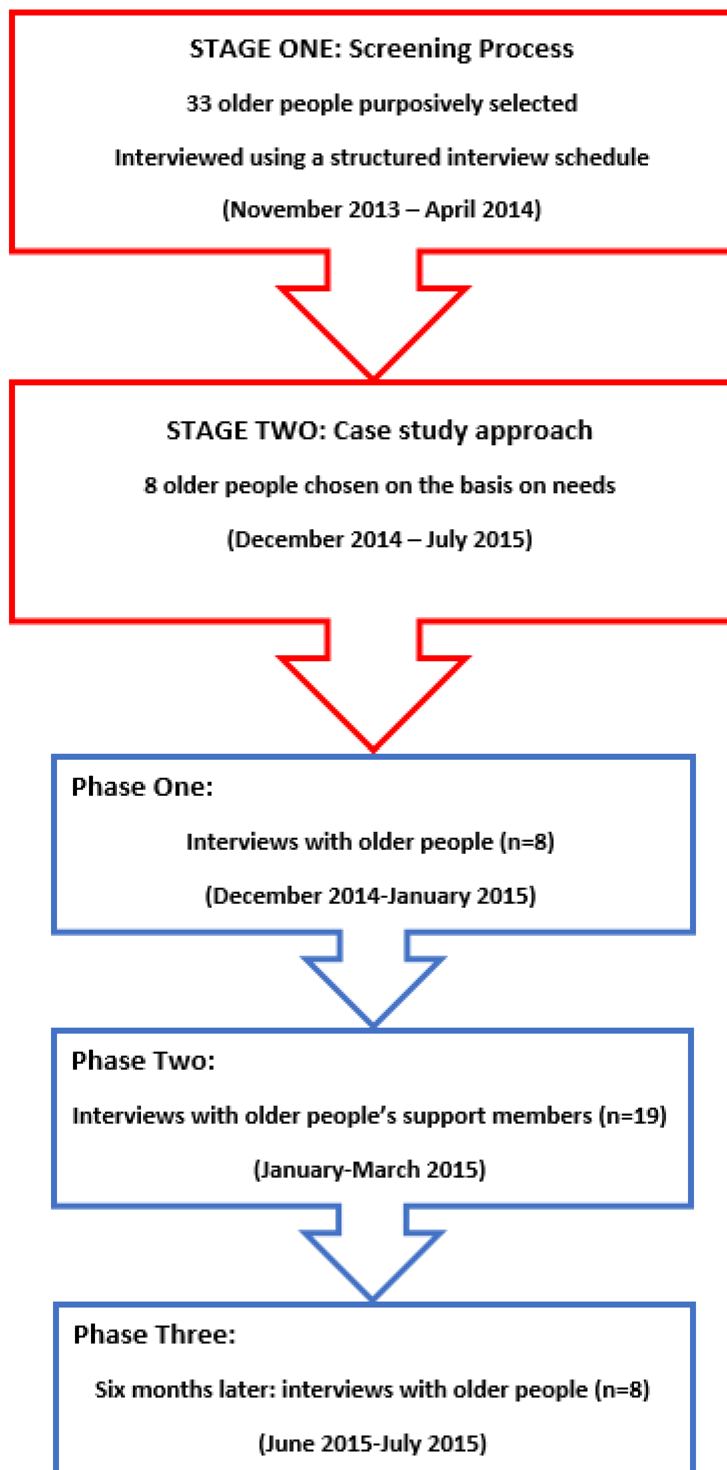
Having formulated my research questions and considered the rationale of my research in light of existing studies, I then considered how I wanted to structure my research, thinking about a suitable sampling frame and number of participants. Qureshi and Walker (1989), Finch and Mason (1993) and Matthews (2002) all conducted large-scale qualitative studies within families. Qureshi and Walker (1989) and Finch and Mason (1993) both include well-documented accounts of methodological considerations. Finch and Mason (1993) examined negotiation within families, capturing as many views within the family unit as possible; Qureshi and Walker (1989) focused on family care of older people, mapping out relatives, but choosing to focus on the care dyad (that is, the older person and one main carer living elsewhere) and Matthews (2002) focus was on family support exploring how adult children approached providing support to older people. All three studies made the assumption that family members are involved in the support negotiation process and thus recruited their participants from families accordingly.

The research approach is original because it did not include the assumption that only family members would be involved in negotiations for support, or form part of the support network. My research included older people as the primary research focus. I interviewed the older person to find out about their support circumstances and during the interview, asked the older person to map out all those individuals that he or she considered were instrumental in providing support to them, not limited to family members, but also friends, neighbours, carers, PAs and cleaners.

I interviewed as many individuals as possible in order to obtain multiple perspectives of the negotiation process. The older person was interviewed again six months later to investigate any changes in their level of support and how it had been negotiated. During the initial interviews with the older person, I created a convoy model (see sub-section 2.3.2 above), using the older person as the focal point, to identify the extent of their support network and any other individuals who were involved in the negotiating process. I then compared the original social network with the social network six months later in time. Thus, my research incorporated a longitudinal element, which is absent in most of the studies shown in Table 1 above. Few qualitative studies have adopted a longitudinal approach (Flick 2014). An advantage of taking a longitudinal approach to this research

was to map changes in older people's health (which can worsen or improve over time), and map changes in the members of older people's support networks. Figure 5 below shows the structure of my research in a diagram form.

Figure 5: Structure of the research



Source: Author

In Stage Two of my research, I adopted a case study approach, where more than one person within the support network of the participant was approached for interview to ask their views about negotiation experiences. Arguably, the interview data from the other participants can be viewed as an additional source of information (Bryman 2008) and thus gives more weight to all those interviewed. All interviews were transcribed verbatim in Stage Two. I made clear notes about the decisions taken throughout the research and took contemporaneous notes throughout the fieldwork process.

5.5.1 Stage One design

Stage One of the research took place between November 2013 and April 2014. Following the examples of Qureshi and Walker (1989) and Finch and Mason (1993), I devised a structured interview schedule, designed to obtain basic knowledge about the participant, his or her family circumstances and social network, health considerations and support needs. The interview schedule appears in Appendix A. I mainly used questions forming part of the English Longitudinal Study of Ageing (Wave 5) as a baseline because I wanted to capture 'tried and tested' basic details about my participants. Mason (2002) reminds researchers to be aware that if different methods are adopted in research, then there is a danger of ontological incompatibility. Although these questions were derived from a national survey questionnaire, the aim of the structured interview schedule within my research was to simply act as a filter to determine which older persons, their families and stakeholders would be chosen for further study. I considered including vignettes within the research to emulate the approach taken by Finch and Mason (1993). However, I rejected this idea because I did not want vignette scenarios to influence the conceptualisations of the support negotiation process which I was seeking to uncover with my research (Barter and Renold 1999). Stage One participants were interviewed face-to-face because I considered it vital to establish contact with the research participants from an early stage in the research, not only to foster trust but also because I was interested in hearing about their negotiation experiences (Flick 2014).

I considered where would be best to interview participants. I decided to conduct the interviews at participants' homes to minimise inconvenience to them in light of potential health constraints or for them to incur travel costs. I was aware that my decision has

advantages and disadvantages. Participants can be easily distracted or interrupted by visitors or telephone calls (Bryman 2008). I considered the possibility of posting or emailing the structured questions to my chosen participants, but I did not want to risk the likelihood of a lower response rate as it is far easier for people to ignore postal surveys (ibid.).

Contemporaneous notes were taken and written up as soon as possible after the interview was completed. Data from the first stage were thematically analysed (Mason 2002). The reason for adopting this form of analysis was because my Stage One notes were in script form and I considered it was prudent to analyse my Stage One results to ensure that my line of questioning in Stage Two could address any themes identified.

5.5.2 Stage Two design

This stage aimed to explore the themes which emerged from Stage One to elicit a deeper understanding of the negotiation process surrounding support for older people and who else was involved. Eight older people were chosen to take part in Stage Two of the research from the screening process outlined in Stage One above. In Phase One of Stage Two, semi-structured interviews were carried with the eight older people selected to explore the negotiation process in further depth and to identify members of their support networks. With the older person's permission, the support members whom they identified as providing them with support were also approached for interview regarding the support provided to identify how support is negotiated within an older person's life, forming part of a case-study approach.

The case study approach has been under-utilised as a research tool within the field of social sciences (Yin 2014). I considered the approach to be an ideal vehicle for my research as it enabled me to explore negotiation within an older person's social network as a holistic entity. After careful consideration, I chose to adopt an "explanatory" case study approach (Yin 2014, p. 89) rather than a "descriptive" approach (Yin 2014, p.49) to best capture the life-worlds of the participants and to analyse the reasons behind and the ways in which the negotiation processes took shape. Older people from different backgrounds were chosen to explore a range of different support arrangements. The support network was identified by using a convoy model (see sub-section 2.3.2 above). All interviews were transcribed and data analysed using thematic analysis, with an emphasis

on interpreting the data through the theoretical lenses of symbolic interactionism and the life course perspective (see Section 2.3 above) in order to provide a grounded context within which to understand the underlying meanings of the interactions between the negotiating parties. Themes were elicited via coding and categorising the data to identify themes (Bryman 2008), which will be explained further in Section 5.7 below. The phases within Stage Two are explained in the sub-sections below:

5.5.3 Stage Two

Phase One took place between December 2014 and January 2015 and comprised in-depth, semi-structured interviews with the eight older people to establish their level of support, to map those individuals who were involved in providing support to the older person (for example, family members, cohabiting partners, friends, employed cleaners, care workers or any other individual involved within their care, as the case may be) and to establish how the negotiation process was established. This method has been adopted within other studies as outlined in sub-section 5.3.2 above (Qureshi and Walker 1989; Finch and Mason 1993; Matthews 2002).

Phase Two took place between January and March 2015 and comprised in-depth, semi-structured interviews with individuals who were identified in Phase One above as being involved in negotiating support with the older person (and whom the older person had given permission for the researcher to approach to take part in the research). This was to ensure that, as far as possible, an in-depth and holistic view of the support negotiation and associated issues could be ascertained. Again, a similar method was adopted within other studies as outlined in sub-section 5.2.3 above (Qureshi and Walker 1989; Finch and Mason 1993; Matthews 2002).

Phase Three took place six months later, between June and July 2015. All eight Phase One participants were interviewed again using a semi-structured interview schedule. Similar open-ended questions were asked to ascertain whether any changes had place in the type or level of support provided to the older person and how the support was negotiated or renegotiated if so. The longitudinal approach is missing from the three major studies identified (Qureshi and Walker 1989; Finch and Mason 1993; Matthews 2002). Breitholz *et al* (2013(b)) conducted a study in Sweden examining decision-making by older people over a time-scale and that by examining the negotiation process over

time provided an in-depth insight of how support needs alter over time, which I believed was an essential missing element from English studies.

5.6 Research methods

I chose to interview participants and adopt a case-study approach as my research method had the best ‘fit’ with what I wanted to achieve. Case studies enabled me to "…understand a real-world case and…involve important contextual conditions pertinent to [a] case" (Yin 2014:16). The Stage One structured interviews (see Appendix A below) as explained in Section 5.5.1 above could have been produced in a questionnaire format and posted to participants. However, I chose not to adopt this method because I wanted to establish an early rapport with my participants and to take the opportunity to write preliminary notes of their comments (Hennink *et al* 2011).

The subjective material I wished to access (opinions, experiences, views, attitudes) was best obtained from a flexible interview format, enabling interactive communication, rather than any other data collection method I considered (Mason 2002). I wanted to have an opportunity to develop a line of questioning which organically stemmed from interviewees' responses (Bryman 2008). The interviews were conducted at the participants' home so there was no need to offer reimbursement for travel fees (ibid.). Any misunderstandings during the interview were easy to remedy as the question was repeated or rephrased if the interviewee misheard or did not initially understand it (ibid.).

I was able to read the participant's body language and facial expressions and react to non-verbal responses to questions (ibid.). There was a greater scope to ask complicated questions, which were qualified or explained in more depth as or when needed (ibid.). There was also greater opportunity to build up a rapport with each participant, which increased my chances of eliciting delicate information. As I was the only interviewer, there was consistency in the way the interviews were conducted and the questions asked (Mason 2002). There were few disadvantages to conducting face-to-face semi-structured interviewing in this research. Some Phase One participants were unwilling for me to approach potential Phase Two participants owing to the nature of their relationship. Some Phase Two participants did not want to take part because they could not spare the time to attend the interview. I considered utilising a focus group approach to Stage Two,

whereby Phase Two participants might have an opportunity to discuss negotiation together. Focus groups can manifest rich data, particularly when mapping the thread of discursive conversations, disagreements and lines of enquiry (Bryman 2008). However, none of the studies listed in Section 5.3.2 above utilised this method and I felt that focus groups would be unsuitable for two reasons. First, there was a possibility that owing to the nature of circumstances surrounding the support negotiation, it might be unsuitable for discussion within this setting, as the topic might be too sensitive (Bryman 2008). Second, it is difficult to arrange focus groups (Finch and Lewis 2003) as the participants are likely to have different commitments, some of working age, others living some distance away. I therefore felt that it would be easier to organise a mutually convenient time to meet with an individual to conduct an interview, rather than co-ordinating one meeting with several individuals (ibid.). Also, focus groups can prove challenging if one or two participants dominate the conversation flow with their views which can alter the group dynamic, especially so if there are vulnerable or less confident members present (Bryman 2008).

5.7 Thematic Analysis

The data obtained via the semi-structured interviews were analysed using thematic analysis, which constitutes "…a method for identifying, analysing, and reporting patterns (themes) within data" (Braun and Clarke 2006:79). I chose to adopt thematic analysis as a tool to analyse my Stage Two interview data because it provided a comprehensive guide to systematically evaluate data and elicit themes (Flick 2014).

Figure 6 below provides a depiction of the steps taken during the analysis process. One criticism levelled at thematic analysis is that it is only suitable for eliciting data patterns rather than developing a theory (Flick 2014). However, it is arguable that theory can only be developed after immersion within the data itself and after obtaining a deep knowledge and understanding of the issues arising, which can only occur after the data were comprehensively studied and evaluated.

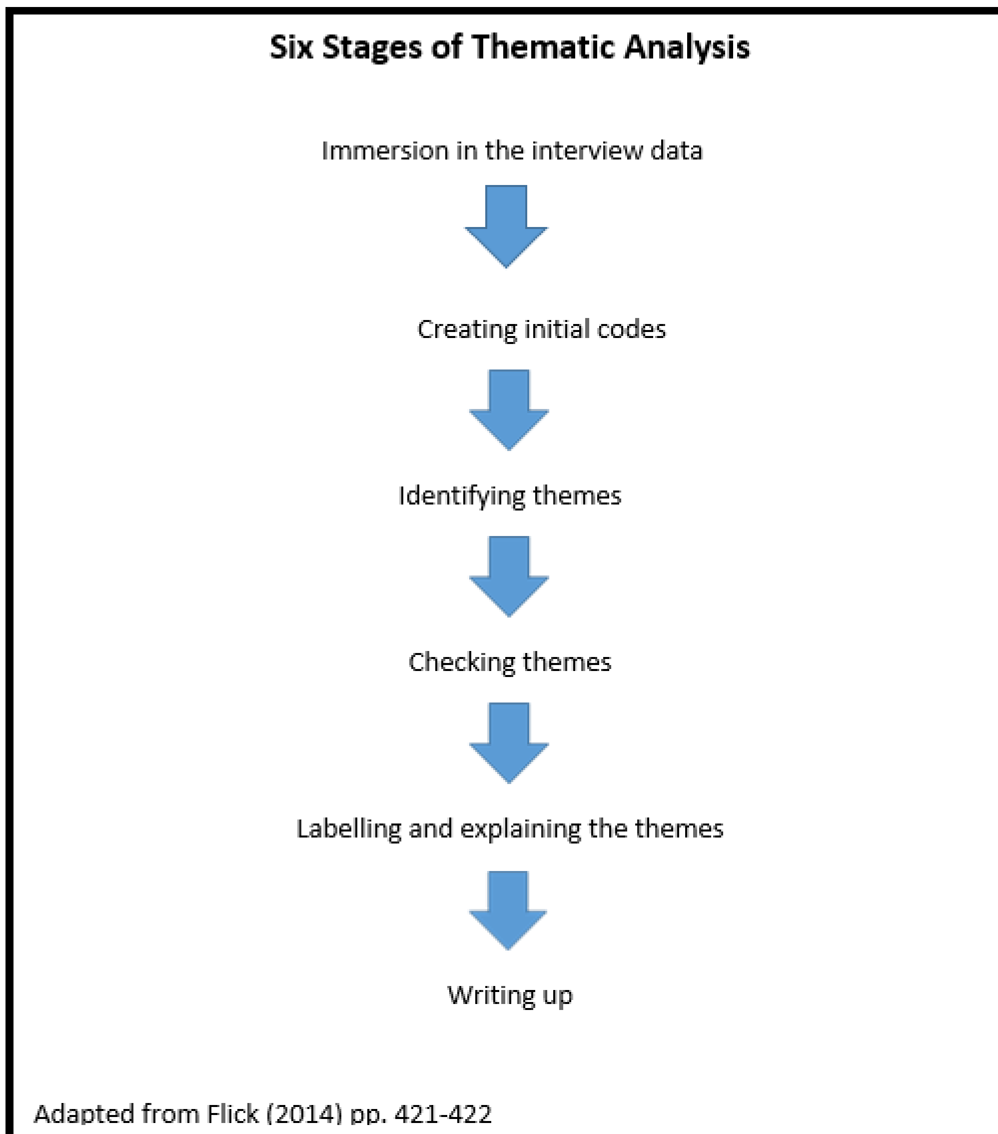


Figure 6: Stages of Thematic Analysis (Adapted from Flick (2014), pp. 421-422)

The six stages were followed rigorously, as described in Chapter Six below. In the first instance, I transcribed all of the interview recordings word-for-word. I considered using a specialist transcription company to transcribe some of the interviews, but I decided against this because I wanted to ensure that I was as familiar with the content of each interview as possible. This is because analysis of data is an on-going process which takes place from the time of the interview and throughout the transcription process (Braun and Clarke 2013). While I was transcribing the interviews, I became very familiar with the content of them and made handwritten notes about my observations and my preliminary ideas about themes and patterns.

5.8 Ethical Considerations

Before I commenced my fieldwork, I considered the ethical implications of my research and submitted an application for ethical approval to the University of Southampton Ethics and Research Governance Online (see Appendix A). Writing my ethics application compelled me to think deeply about what I wanted to investigate, how best to hone my research and to consider moral and practical implications of my proposed research. I needed to anticipate what risks my research might pose both to my participants and to me, as the researcher. I took the decision only to interview participants who were able to give their informed consent to take part in the research (Flick 2014). The reason for this was because I was interested in finding out how older people negotiated support, rather than how others might negotiate support for older people. I chose to adopt a research strategy which would cause a minimum of disruption or distress to participants (ibid.). Having thought carefully about what I wanted to ask participants, I was aware that the imperative need to minimise distress as far as was reasonably foreseeable, if, for example, a participant had experienced a traumatic incident involving their support (Mason 2002). I was aware and mindful of the University of Southampton's safeguarding policy in relation to potentially interviewing vulnerable older adults (as this definition included 'frail older people or the infirm') at the time the research was carried out (University of Southampton 2012). I was also familiar with the provisions of the Mental Capacity Act 2005, which governs vulnerable older people (Mental Capacity Act 2005) and the corresponding Code of Practice (Mental Capacity Act 2005 Code of Practice). However, only older people who were capable of giving informed consent were recruited into the research, to minimise the risk of including vulnerable older people as participants (Dempsey *et al.* 2016). In addition, the Volunteer Co-ordinators who were gatekeepers were made aware that only older people with mental capacity should be approached to take part at the outset (ibid.). Reflecting on my personal skills, I felt that I have a good level of experience in determining whether a person is capable of providing informed consent due to my previous role as a (currently non-practising) solicitor. I was, and am, mindful that an individual's mental capacity to give consent can fluctuate over time, so I checked with participants that they were still willing to participant in the study several times during the research process (Sammut Scerri *et al.* 2012). As the research area was potentially a sensitive one because older people would be discussing personal issues

relating to their social care support, there was a higher risk that a participant might become distressed (Dempsey *et al.* 2016). Thus, at the outset, a risk assessment was carried out to consider what harm the research might possibly cause to participants and concluded that there was a chance that participants may become distressed when recalling and recounting their experiences (ibid.) In such cases, depending on the circumstances, I would pause the interview, offer to postpone it or rearrange the interview if the participant preferred and reminded the participant that he or she could withdraw from the study altogether (ibid.). I also considered referring the participant to relevant counselling facilities recommended by Age UK Southampton (ibid.).

It was important to ensure that interview data were kept confidential on a password protected system. Hard copies of any documents were stored in a locked drawer (Berg and Lune 2012). The participants' details were anonymised to protect their identity, for example, pseudonyms were used instead of their given names, and other identifying details such as towns or shop names were altered (Webster *et al.* 2014). As I intended to visit participants in their homes, I also devised a safety system of notifying someone of my whereabouts while I was conducting the interviews (Davies 2007). The Ethics Committee granted approval of my research under reference number 6134 in May 2013, which appears in Appendix A. The charity I chose as a research setting did not require any additional ethics clearance prior to embarking upon my research. All participants in Stage Two of the research were asked before the start of each interview whether they would be willing for me to audio-record the interviews. All participants agreed and gave their consent in writing for their interviews to be audio-recorded.

5.9 Sampling frame and recruitment

Having mapped out my research structure, the main challenge I then faced was how best to gain access to my target audience, being older people (Luborsky and Rubinstein 1995). Having conducted an initial review of the literature, I identified many academic studies relating to support have mainly focused simply on formal care provision and thus have used Adult Social Services as a sampling frame (Glendinning *et al* 2008; Baxter *et al* 2013). No studies in England were identified that have attempted to map how older people negotiate support in England from the different sources to which they have access, although Dunér and Nordström (2007) have carried out similar research in Sweden.

Research which informed the Care Life Cycle project (see Section 1.1.2) was mainly being conducted in the South of England. Only one academic study identified in the literature search which focused on support negotiation was conducted in the South of England and used a charity as a research setting (Horton and Arber 2004). I initially considered approaching the local Adult Social Services to obtain permission to access their social care user client base as a sampling frame. However, I was reticent to do so for two reasons. First, my research focus is examining how older people negotiate support from all sources which are available to them, and not just simply from one avenue. Second, in light of budgetary constraints, many older users of Adult Social Services were eligible to receive support when their needs were greater (NAO 2014). Thus, I thought that by approaching older service users may prove counter-productive to my research potentially because of a higher risk of attrition as individuals may decline to participate on health grounds. These factors made me consider other local organisations offering services aimed assisting a range of older people with a range of support needs.

Coincidentally, I attended a presentation given by a Volunteer Co-ordinator from a local charitable organisation which provides services to people aged 50 and over. I decided to take steps to approach the charity to assess the feasibility of recruiting users of services to participate in my research. I applied to become a volunteer at the charity in order to gain the trust of the charity organisers and of the clients of the charity, and also to gain a better understanding of what services were provided for older people (Reeves 2010). I was transparent about my background as a researcher at the University when I met with the Chief Officer of the charity to present my research proposal. The Chief Officer granted me limited permission to use the charity as a research setting, pending approval from the University of Southampton Ethics Committee. I started as a volunteer in February 2013 and began recruiting older people into my research in or about November 2013.I was assigned a client and took the decision at the outset not to ask my client to take part in my research. To clarify, none of the contacts in my role as a volunteer were recruited as participants in my research, as I was concerned that this might constitute a 'conflict of interest' or that potential participants might feel obligated to take part in my research (Hurst and Mauron 2008:119). Although my roles as a volunteer and as a researcher overlapped, my volunteering role within the Charity was kept completely separate from my involvement with the charity in my role as a researcher. The Volunteer

Co-ordinator who was responsible for deciding which clients I was allocated to as a volunteer also decided the clients whom I was allocated to as a researcher. I made it very clear to each of the Volunteer Co-ordinators at the start of the recruitment process that any older person which I was allocated to as a volunteer should not be approached by them to take part in my research. This system worked well because each of the Volunteer Co-ordinators had a list of the volunteer/older person pairings, so it was easy for them to recruit clients that I was not involved with as a volunteer. The main reasons for not recruiting older people whom I visited in my role as a volunteer was to avoid them feeling obligated to take part because they knew me, or feeling that they could not refuse to take part in case the services provided to them by the Charity would be reduced or withdrawn (Wilson *et al.*, 2008). My role as a volunteer involved making and maintaining conversations with older people which helped me when I was carrying out interviews with participants as I was usually able to establish a good rapport with the participant early on in the interview process by finding common ground (Robertson and Hale 2011). Reflecting on my twin roles being positioned as an ‘insider’ by virtue of being a volunteer and an ‘outsider’ by virtue of being a researcher (Arber 2006:147), I was able to compartmentalise each role because I drew on my training and experience gained in my previous profession working as a solicitor (Section 5.11).

Having gained provisional approval to use clients of the charity as my sampling frame, I then considered who I wanted to take part and how I was going to recruit participants (Porter and Lanes 2000). I decided to select older people aged 65 and over who were clients of the charity and who were in receipt of some form of support and who were able to give their consent to take part in my research. As I was interested in the ways in which older people negotiate their support, I wanted to interview people who were able to voice their own experiences, so individuals who were unable to make their own decisions, for example, people with dementia, were excluded. Initially, I adopted a purposive sampling strategy to recruit in the region of thirty older people to take part and I initially considered recruiting an equal number of males and females using a similar approach to Horton and Arber (2004). I initially chose thirty individuals because I had no prior knowledge of the ethnicity, gender or upper age-range of clients of the charity or their support needs and I wanted to have a bigger frame of participants from which to select for participation in Stage Two. I was able to recruit 33 older people, 11 of whom were

males and 22 were females. All but three participants were White British, one participant was Irish, one participant was Mixed Ethnicity and one was Asian, which means that the generalisability of the results across different cultural and countries contexts should be exercised with caution.

To clarify, the methodological decision to choose clients from a local charity held both advantages and limitations. Similar to Horton and Arber (2004), the main advantages of the decision to recruit participants from a local charity were having the ability to gain access to a broad range of community-dwelling older people with a variety of different support needs and support networks, and who were capable of recounting their experiences of how they approached negotiating support with ADLs and IADLs from others. There is a risk that selection bias could be present because it is likely that a disproportionate number of confident older people took part, evidenced by their actively seeking support from the charity in the first place (Smith and Noble 2014). By choosing to recruit older people who were users of the charity services meant that self-selection bias (Ellard-Gray *et al.* 2015) was present because the voices of older people living in the community who had not sought assistance from the charity were absent (such as individuals who are socially isolated or homeless, those with complex social care support needs which are associated with multiple long term health conditions and individuals with conditions affecting mental capacity), as were the perceptions of older people staying in institutions such as care homes, hospitals or prisons. It is challenging if not impracticable to remove self-selection bias in qualitative research, therefore it is up to the researcher to identify the self-selection shortcomings so that the reader can reflect upon and judge the extent to which the findings are generalisable to other similar settings (Robinson 2014). However, the research is generalisable in the sense that 'the research resonates with the reader's personal engagement in life's…experiences' (Smith 2018:140).

One of the main challenges I faced was not having access to the client databases because of the charity's Data Protection policy. The Volunteer Co-ordinators responsible for managing each of the services acted as a gatekeeper (Reeves 2010; Scourfield 2012; Bailey *et al* 2012) and thus passed on the details of potential participants for me to approach. Two of the services were aimed at visiting older people in the community, one was aimed at helping older people to apply for benefits and one organised lunch clubs in the community. Therefore, I had to rely on the Volunteer Co-ordinators to choose

suitable clients from their database to take part in my research. Having worked previously in an environment where client confidentiality is paramount, I was hardly surprised by the implementation of a gatekeeper role. However, I am aware that this probably influenced which clients were referred to me for recruitment and which were excluded (Scourfield 2012).

Three of the programmes were co-ordinated by desk-based employees. I sent an email to each of the Volunteer Co-ordinators containing a short synopsis of my research, the participant eligibility criteria as described above in this Section and with an outline script of how to describe my research to clients during the recruitment process. The fourth programme consisted of co-ordinating Lunch Clubs in a variety of community settings. After a further meeting with the Chief Officer, I was allowed to accompany the Lunch-Club Volunteer Co-ordinator to five Lunch Clubs. Lunch Clubs are day-time events aimed at older people and take place once a month in different community centres throughout the city. Older people receive a two-course meal at a subsided rate, followed by some form of entertainment, such as a singer.

I asked Volunteer Co-ordinators to refer any client aged sixty-five or over with mental capacity to make decisions. One Volunteer Co-ordinator referred no clients to me (even though I had been informed that in excess of fifty clients were regular users of the service), one Volunteer Co-ordinator referred fifteen clients to me and the third Volunteer Co-ordinator passed on the details of two clients. I made contact with each of the referred clients by telephone to explain about the research and to schedule a time and date for the interview to take place. Only two declined to take part.

I had greater success in recruiting client users of the Lunch Clubs, when I recruited fourteen participants: four less than the total referrals from the three Volunteer Co-ordinators. This is probably because I felt I had greater control over the recruitment process. On reflection, at the first Lunch Club I attended, I delivered my presentation to those present after they had eaten lunch. There was little interest in my research and I felt a little demoralised. I sensed that in being introduced by the Volunteer Co-ordinator as a Researcher from the University of Southampton delivering my presentation to a group had created a barrier for some clients. At the next Lunch Club, I decided to change my recruitment strategy. I spoke to clients individually and had a much higher success rate when I approached clients directly, established a rapport and had the opportunity to

explain about my research face-to-face in a less formal way. I was also under the impression that many clients did not label themselves as support recipients and thought that my research did not apply to them.

5.10 Pilot Study for Stage One

Once ethics approval was granted, I decided to test my Stage One structured questionnaire by interviewing three older people. It is important to conduct a pilot study because it can enhance the quality of the research by checking that the questions posed are relevant and also to identify poorly worded questions so that they can be eliminated or amended accordingly (Davies 2007). One of the Volunteer Co-ordinators at the charity provided me with the telephone contact details of three clients. Two out of the three clients agreed to take part. I made arrangements to visit each of them in their homes. Both participants were provided with a Pilot Participant Information Sheet in advance of the meeting. Before I commenced the interviews, I checked that each participant was happy and willing to take part. Each agreed to take part and signed a Consent Form before the interview took place. Each pilot interview took approximately one and one-quarter hours and was not recorded. I took contemporaneous notes during the interviews. On reflection, I decided to change the order of three of my questions. I decided to ask about ethnic origins at the beginning of the interview when I was asking for basic details, such as name and date of birth. I also removed two superfluous questions about providing care to others.

5.11 Limitations of the research

Having thought critically about my research, I have identified five main actual or potential limitations of my research. These limitations will each be discussed in turn.

First, apart from one occasion, I was unable to witness real-time actual negotiation processes between older people and others. I was relying on the memories and experiences of my participants, similarly to other researchers such as Finch and Mason (1993) and Horton and Arber (2004). To assist with eliciting data about the negotiation process, I considered posing vignettes of negotiation scenarios to participants to investigate how they might react hypothetically in a given set of circumstances (Robson

2011). However, although there are merits to this line of enquiry, I discounted adopting this approach because I felt it would not capture the negotiation process, but would be more suited to capturing decision-making, which is not the focus of my research.

A second limitation of my research is that it does not include individuals who do not have mental capacity. This is because the main focus of my research was to ascertain how older people negotiate support in conjunction with other individuals. Many studies have already been conducted which include the views of proxies such as carers, deputies or attorneys (Bamford and Bruce 2000; Livingston *et al* 2010; Egdell *et al* 2010). In addition, as this research informed the Care Life Cycle (CLC) project (Section 1.1.2), there was potential for overlap as other researchers within the CLC project were conducting research involving participants who lacked mental capacity.

A third limitation is that recruitment for Stage One of my research at the charity was not within my control. Four Volunteer Co-ordinators were responsible for passing the details of potential participants to me from the services database (see Section 5.9 above). Therefore, I have no means of knowing why particular individuals were selected to take part in the research and others were not. Gatekeepers may have chosen not to invite a particular older client to take part in the research for any number of reasons, including: a client being perceived as vulnerable and thus would not want to increase the risk of distress; physical impairment such as deafness, physical disability or speech problems; language barriers or cultural differences; dislike of a particular client; or simply apathy, reluctance or forgetfulness on the part of the gatekeeper to inform clients of the research opportunity (Robson 2011). Thus, it is important to be mindful of gatekeeper bias because the choice of participant was selected by the gatekeeper which may have an effect on the validity of the research results (Bailey *et al* 2012).

A fourth limitation of the research is that the vast majority of participants are White British and there are more females than males (Sections 6.2.1 and 6.2.3 below). Again, this outcome may be attributable to gatekeeper bias, as discussed above. Another explanation could be that a higher number of White British females access services provided by the charity rather than other user groups (Marhánková 2014). The reason I chose the charity as a research setting was because I believed it would offer me the opportunity to gain access to a client base with a wide range of support needs and not just those who received formal state support.

A fifth limitation is that I was unable to interview all people identified by Phase One participants, because of a number of different reasons. In some cases Phase One participants did not want me to approach individuals because they did not think that they would be interested in taking part. This reason could have been masking the fact that some Phase One interviewees might have felt apprehensive about what might be disclosed. I chose eight participants for Phase One of Stage Two mainly as a contingency in case any of my research participants was no longer able, or no longer wished, to take part in Phase Three of Stage Two of the research, as it is possible to conduct valid research using one case study (Yin 2014).

A sixth potential limitation is researcher bias (Flick 2014). I am aware that my experiences may have affected the way I chose to conduct this research. I tried, as far as possible, to retain an impartial outlook. I believe that my prior professional training and experience working as a solicitor have helped me to achieve this. The reason I wanted to conduct this research is because I became aware of issues affecting older people when I was practising as a Private Client solicitor in England, specialising in legal matters affecting older people. A number of my older clients expressed personal concerns about feeling marginalised and their voices unheard by society. These reports prompted me to observe more carefully how older people were treated by others in daily life. I came to realise that these experiences were neither unfounded nor unjustified. This prompted a desire to learn more about social issues affecting older people. I therefore decided to undertake the MSc programme in Gerontology, choosing the Research Pathway for two reasons. I considered the programme would provide me with a solid knowledge-base of social gerontology issues. I wanted to develop my research skills, so I considered it would equip me with the tools I would need to become a rigorous and effective Social Sciences researcher.

My decision to conduct qualitative research was largely based on how other researchers conducting studies with a similar focus had decided to approach their research (see Section 5.3 above). Qualitative research seemed an ideal way to investigate the research because I was seeking to identify how older people construct meaning from their recollections of social care negotiation experiences and to grasp a deeper understanding of older people's inner worlds (Mason 2002) and the complex factors present during their support negotiation process (ibid.). First of all, I reflected on what I did not want to

achieve by conducting this research. It would be meaningless to achieve results based on numbers or amounts for statistical analysis because that would clearly fail to capture the knowledge required to explore and address the research questions. Conducting qualitative research enables me to access older people's "…'hidden world', give a voice to those who are invisible and raise the profile of this issue among policy-makers…" (Becker 2012). The findings of this research are not only important in their own right to understand how policies affecting older people have an impact in practice, but also provided richer meaning to the results of modelling of the supply and demand of support within the Care Life Cycle project (see Section 1.1.2).

5.12 Chapter Summary

This Chapter has provided a critical account of the rationale behind my methodology decision-making. In particular, the Chapter has outlined the steps I have taken when considering the structure of my research and has led the reader through the steps I took in designing my research. The following four Chapters will provide the results and analysis of the data of Stages One and Two of the research.

Chapter 6 Results of Stage One

6.1 Overview of Chapter

The purpose of this research was to identify how older people negotiate support from others. This Chapter provides an overview of the results of Stage One of the field research and a short overview of the themes identified from the handwritten notes taken during the structured interviews. The themes helped to inform the semi-structured interviews in Stage Two of the research. The aim of Stage One was interviewing at least thirty older service users of a local charity to ascertain their support networks and the types of support received. A Structured Questionnaire (see Appendix A) was created which acted as a filter to facilitate choosing participants for case study research in Stage Two on the basis of their support network and support need (see Section 5.5.1).

6.2 Profile of Participants

Older people aged 65 and over using services provided by a local charity were selected using a combination of purposive and snowballing sampling methods. Table 3 below shows the demographic characteristics of the thirty-three participants. Fourteen of the thirty-three participants were purposively recruited by the author by conversing with older people attending Lunch Clubs organised by the charity. A further three people were identified through snowballing from existing participants. The remaining sixteen participants were chosen by gatekeepers (Volunteer Co-ordinators of services provided by the charity) and the implications of each of these recruitment strategies have been critically examined in Section 5.9. The following sub-sections report on the demographic characteristics of participants.

Table 3 Demographic characteristics of Stage One participants (n=33)

(Source: Author)		
Gender	Males	11
	Females	22
Ethnicity	White (British)	30
	White (Other)	1
	Mixed Ethnic	1
	Asian	1
Marital Status	Single/Never Married	2
	Widowed	23
	Divorced	5
	Married	3
Living Arrangements	Living alone	24
	Living with spouse	3
	Living with adult child/ren	3
	Living with lodger	3
Type of Accommodation	Detached (owned)	1
	Semi-detached (owned)	9
	Terraced (owned)	2
	Flat/Maisonette (owned)	1
	Life interest Trust	2
	Sheltered housing (rented)	17
	Rented (other)	1
Support source (main)	From spouse	2
	From daughter	14
	From son	3
	From neighbour	1
	From friend/lodger	3
	From grand-daughter	1
	No support	9
Sources of recruitment	From Lunch Clubs	14
	Gatekeeper referrals	16
	Snowballing	3

6.2.1 Gender

Table 3 shows the number of males and females who took part in Stage One and it is evident that more females than males participated, which may be attributable to a higher number of women accessing the services provided by the charity than men (Marhánková 2014) or because there are more older women than men (ONS 2015) Three other males initially expressed a willingness to participate but two changed their mind without an explanation and a third male did not answer the door on the day of the interview and failed to return a follow-up telephone call. In addition, two females declined to take part owing to health reasons.

6.2.2 Marital Status/Living Status

Three of the participants were married and lived with their spouse and one participant lived with her adult son, suggesting that informal support was more likely to be available to these participants if needed. However, most participants lived by themselves (30 out of 33): a high number of participants reported being widowed (23 out of 33), five were divorced and two were single (never married) suggesting that these participants would need to negotiate support from external sources.

6.2.3 Ethnicity

Table 3 shows the majority of participants (30 out of 33) were White British. All but three were White British: one male described himself as being from a mixed ethnic background and another male reported he was Asian. One female was White (Other) as she was born in Ireland. Ethnicity of participants was less important in this study, as the main focus was identifying how older people negotiate support needed in general.

6.2.4 Age range

Table 4: Age Range (Source: Author)			
Age Range	Total	Male	Female
65-69	5	2	3
70-74	2	1	1
75-79	3	2	1
80-84	12	1	11
85-89	6	2	4
90-94	4	2	2
95-100	1	1	0
Total	33	11	22

Table 4 shows a breakdown of the age ranges of the thirty-three participants. The youngest participant had just reached 65 when he was interviewed; the oldest participant was aged 95. The highest number of participants overall were aged between 80 and 84. All participants were born between 1918 and 1948 and most required some form of support.

6.2.5 Accommodation and living arrangements

Table 3 above shows the type and tenure of participants' accommodation. As can be seen, most participants lived in sheltered accommodation. A total of 17 participants out of 33 chose to live in a community setting with an alarm system in place. A high number of participants lived alone (24 out of 33). Six of the nine males living alone because of widowhood, two were divorced and one had never married and had never had a partner. Of the females, twelve of the fifteen living alone were widowed, two were divorced and one had never been married. Interestingly, none of the participants described themselves as cohabiting. Of the three cases where older females were living with an adult child, two had medium care needs. In one case, a son aged in his early 60s, who had never been married and had always lived in the family home, was providing practical support to his mother. The other case involved a situation where a daughter who had

never been married and aged in her early sixties had sold her house to return to live with her mother after emotional pressure had been applied by her siblings. The third instance was quite different. A son aged 39 had returned to live with his mother (who has low support needs, see Section 6.2.7 below) because his relationship had irretrievably broken down and he could not afford to rent or buy a property of his own. No males reported living with a lodger. Of the three females, two reported they formed a reciprocal arrangement for support and the other reported that their lodger lived a completely separate life.

6.2.6 Informal support

Table 3 shows the main source of informal support reported by the 33 participants. Aligned to the literature, the male who received care from his spouse reported that she provided support to him with personal care and household tasks. Daughters tended to provide informal support to their fathers, such as shopping, cleaning and socialising, but none reported that their daughter provided assistance with bathing. Most males described their relationship with their daughters as close, but one male felt his relationship with his daughter was stilted and suspected she provided support to him out of a sense of duty. Of the four males reporting they received no informal support, only one felt he did not require any assistance. The remaining three felt they needed support but as they had no family to rely on (one male explained that his only son lived abroad and the other two males were childless), two relied on formal support and one was in the process of arranging formal support.

Four females reported requiring no informal support: one female considered she did not need any assistance because she felt her care needs were minimal, but the other three females explained there was no-one they felt they could ask for help. One female mentioned she had a daughter who lived some distance away but she felt she could not approach her daughter for help. Three females described receiving informal support from sons: one female mentioned her son lives with her, another confided she was closer emotionally to her son rather than her daughter and the third did not have a daughter.

One female who received support from a friend or lodger reported that they did not want to bother their relatives. The other two described having a reciprocal arrangement with

their lodger, indicating receiving support with household tasks as and when needed, but no support with personal care tasks.

6.2.7 Level of Support needs

As discussed in Section 5.5.2, an "explanatory" case study approach was used in Stage Two of the research (Yin 2014:89) to understand the reasons behind and the ways in which negotiation processes took shape in a variety of different cases. When choosing cases for qualitative case study research, the selection criteria is based on making 'decisions about people, settings, events, phenomena, social processes' and using 'specified criteria' (Harrison *et al.* 2017: 9). As the research question explored how older people negotiate social care support, I decided to choose diverse cases, based partly on the support needs of older people, in order to ensure that a range of different support circumstances were included in the eight case studies. The reasons for choosing cases on this basis were partly methodological and partly practical. The qualitative case studies in Stage Two were chosen on a purposive basis, based on their level of need (Meyer 2001). In Stage One of the research, I decided to collect demographic information about older people, such as their age, ethnicity, living arrangements, health conditions, support network and participants' support needs because at the outset, I had no prior or well-defined knowledge about client-base of the Charity from which to make an informed selection for in-depth case study research in Stage Two. Older people who approach the Charity for support are not a homogeneous group and their motivation to approach the Charity for support may arise from a plethora of reasons, as the Charity offers a range of different support services which are designed to meet a diversity of needs in the latter part of the lifecourse (Age UK n.d.). In addition, I had to mainly rely on gatekeepers' decisions on who would be invited to take part in Stage One and thus had little direct control over the recruitment process.

The recommendations of Ritchie *et al.* (2014:126) were followed, who advocate the use of a 'conducting a short structured interview…to collect further information relevant sample selection' in cases where little is known in advance about the 'target population'. As I had no prior knowledge about client-base of the charity and am not qualified as a social worker or medical professional, I decided to gather pertinent information about the Stage One participants to help me to make an informed choice when purposively

selecting older people to participate in Stage Two. Information was gathered from two sources: via a structured interview, where participants answered a range of questions designed to help me to build up a picture of their lives, together with gaining some indication of how participants perceived their ability to perform a range of ADL and IADL tasks (see Appendix A: Structured Questionnaire, question 43 (rating how difficult they found doing specific everyday tasks) and question 46 (rating whether the extent to which the help they received met their needs)) and by directly observing how older people performed incidental tasks during the interview (for example, noting if a participant experienced difficulties in sitting to standing, if they were capable of making a hot drink, if they were able to walk unaided from and to the front door). To clarify, the purpose of the structured questionnaire was for use simply as a screening tool in order to collect demographic information and was not designed as a measurement instrument to carry out quantitative data analysis (Rahim and Arthur 2012; Connidis and Kemp 2008).

I devised a scale of between 1 and 10 to represent participants' abilities and level of need, where each participant was ascribed as having either a low (1-3), medium (4-6) or high level (7-10) of support needs, as shown in Table 5 below. In addition, participants were asked whether they felt that their support needs were met (always, usually, sometimes, hardly ever, never). The purpose of Table 5 was to depict information about the level of support needs and the extent to which needs were felt to be met for all Stage One participants (n=33). The rationale of this selection approach was in order to provide the author with a more robust evidence-base from which to choose Stage Two case study participants. This was because I wanted to explore how older people with diverse levels of need negotiated support from members of their support network and to thus understand different perspectives on help-seeking.

One advantage of this selection approach was that more than one source was used to triangulate information on participants' level of need and their perceptions of the extent to which they felt that their needs were met (Noble and Smith 2015), as the participants' self-reported views of their support needs, together with my own observations of participants' levels of mobility, were combined. Two disadvantages of this approach were identified, which will now be discussed. First, decisions about the participants' level of need were based in part on the author's observations of the participants' abilities, which were made as a layperson, rather than in the role of an expert who was qualified as a

health or social care professional. Second, reports by participants and observations by me were made on one occasion only, thus at one point in time, so there is a likelihood that support needs, as well as perceptions of unmet need may have fluctuated during the intervening time between the Stage One and Stage Two interviews. Nevertheless, the reason for creating an evidence-base was to facilitate purposive sampling in order to facilitate selecting cases to explore a diverse range of support negotiation experiences.

Table 5: Level of Needs Scale	**Number of participants**	**Reported met need**
1 Low level (participants find all tasks easy)	4	Needs always met (4)
2 Low level (participants find more tasks easy than fairly easy)	8	Needs always met (2) Needs usually met (6)
3 Low level (participants find more tasks fairly easy than easy and fewer than four tasks fairly difficult or difficult)	5	Needs always met (2) Needs usually met (1) Needs sometimes met (1) Needs hardly ever met (1)
4 Medium level (participants find more tasks fairly easy than easy and fewer than four tasks fairly difficult or difficult)	5	Needs always met (1) Needs usually met (2) Needs sometimes met (2)
5 Medium level (participants find more than five tasks fairly difficult than easy or fairly easy and fewer than five tasks fairly difficult or difficult)	2	Needs sometimes met (2)
6 Medium level (participants find most tasks fairly difficult)	2	Needs always met (2)
7 High level (participants find some tasks fairly difficult and some tasks difficult)	3	Needs always met (1) Needs usually met (2)
8 High level (participants find more tasks difficult than fairly difficult)	2	Needs always met (1) Needs usually met (1)
9 High level (participants find more tasks difficult or cannot perform than fairly difficult)	2	Sometimes (2)
10 High level (participants cannot perform most tasks)	0	
Total **Source: Author**	**33**	**33**

6.3 Stage One themes from notes taken during the structured interviews

The author decided not to include direct questions relating to how participants negotiate their support within the Stage One structured questionnaires. The reason for this was because the purpose of the Stage One enquiry was to gain an insight into the lives of the individuals selected, in terms of learning more about their family circumstances, social network and current support needs. In other words, Stage One interviews were simply designed to act as a screening tool from which to select Stage Two case-study participants.

Interestingly, some Stage One participants offered unsolicited, yet insightful comments to justify their underlying reasons for answering questions. The author made a note of any such comments in the margin of the questionnaire script.

Thematic analysis (see Section 5.7 above) of the participant synopses was conducted to identify preliminary themes emerging from the data in relation to negotiating social support needs. A symbolic interactionist approach (see sub-section 2.3.1 above) was not adopted at this juncture because participants did not discuss negotiation tactics during Stage One of the research. Three initial themes emerged from the data: first, reticence about negotiating support from family, but older people will accept help if it is offered; second, conveying independence, whether real or not, is a primary concern for many participants; and third, ‘Not wanting to bother’ or be a burden is a recurring anxiety among respondents. These preliminary themes will be discussed in light of data from three of the participants: Ron, Luke and Wendy, who are all aged in their 90s, mainly because a literature search revealed that very little research has been conducted which includes this particular age group.

6.3.1 Ron

Ron is aged 95, White British, widowed and lives alone in a detached house he owns. He was married for 60 years and misses his wife, Kathleen, enormously. He cried when he spoke about her. He has two adult daughters: Georgina (aged 68) and Nicky (aged 66). Georgina is very busy and lives about eighty miles away. Nicky and her husband, James,

live about forty miles away. He has four grandchildren, but he does not see them regularly, generally over the Christmas period. Ron has no siblings. Nicky and James visit him approximately three times per week. He described Nicky as 'lovely'. James is very practical and suggested Ron had a stair lift to be installed when Ron confided in him that he was having difficulty going upstairs to use the bathroom. James made the necessary arrangements to install it. James seems to anticipate Ron's needs and Ron appreciates that James takes the time to think about him. When asked who Ron would contact in case of emergency, Ron said he would contact Nicky and James. Ron has a personal alarm, again, after James suggested having this, Ron decided it was a good idea. Ron has arthritis and finds it difficult to walk. In addition, Ron had two blockages in his arteries in his leg, which means that his leg is weakened. He can walk round the room slowly and uses a walker or a stick. Ron explained that he finds this frustrating, as he used to have so much energy and would organise walks and cycle rides and he misses doing that terribly. Ron took the decision last year to move into a care home to be near to Nicky and James. Ron said that he was so unhappy there that he decided to move back into his home. Ron said that he feels slightly guilty about this, as this means that Nicky and James have further to travel to come to see him. He feels vindicated by Nicky and James telling him that if Ron had not decided to move back of his own volition, they would have discharged him.

Ron finds it difficult to prepare meals, shopping for groceries and doing housework. Ron has a care package which he pays for privately. A carer will visit three times a day to prepare Ron's breakfast, to get dressed and put the washing out. Another carer will come at lunchtime and put his meal into the microwave. In the evening, the carer will prepare his meal and turn down his bed. This arrangement fulfils Ron's needs, but Ron would prefer the same carer or carers to visit him. He finds it frustrating because each time, he has to show a new carer how to operate kitchen appliances and which cupboards contain food items. Nicky and James go shopping for Ron each week and make sure everything is operating as it should in the house. Nicky will do the housework. Ron is immensely grateful to his daughter for doing this. Ron feels grateful for living a long life and having a good life and a happy marriage. Ron feels that he is nearing the end of his life and believes the secret to coping with life is being able to live with your own company.

6.3.2 Luke

Luke is aged 92 years, White British, is widowed and lives alone in a semi-detached bungalow that he owns. His wife, Lucy, died four years ago. Luke misses Lucy and said that he had wished he had died with her. Luke has two adult children, his son, Bill (aged 61), and his daughter, Lacey (aged 50). Bill lives about twenty-five miles away and Luke does not see him very often. Lacey lives three miles away and visits her father once a fortnight. Luke has four grandchildren, all aged in their thirties and forties. Luke sees his granddaughter, Vera, two or three times a week. Luke has a sister, Pam, who is nine years younger than him. He speaks to her on the telephone, but does not see her very often. Luke made it clear that he is very independent and does not like to be a bother to anyone. He said that he sometimes feels annoyed because although he likes to present himself as coping with life, inside he feels that he is not. Luke would like it if his children would sometimes offer to do household tasks and shopping. Luke said that he 'would never ask in a million years'.

When asked who he would contact in an emergency, Luke said that he would keep his children informed and Vera. Luke makes all decisions about his life himself and does not confide in anyone.

Luke has arthritis which makes it difficult for him to walk and to stand for long periods of time. He also has osteoporosis and angina. Luke fell outside in the garden about a year ago onto a concrete path when he was cutting a branch from a tree. He said that he was lucky he did not break a bone. Luke does not currently have a care package. He does not engage a cleaner or gardener because he sees that as a sign he is not able to cope. Luke sometimes finds it hard to bathe as he is worried about slipping. He can cope with most household and personal tasks. Luke does not provide care to anyone else.

Luke said that he desperately needs to make new friends, because his existing friends have either died or moved. He often feels lonely and lacking in companionship. Luke is happy with the way his life has turned out and feels that shortage of money often prevents him from doing things he would like to do and his health and age are sometimes a barrier.

6.3.3 Wendy

Wendy is White British, widowed, aged 93, living alone in an adapted, rented, sheltered flat. Her late husband died thirty-five years ago. Wendy has one daughter, Coral, aged 67. Coral has a daughter, Kayleigh, aged 38. Coral lives abroad with her husband and Kayleigh lives about five miles away.

When asked who Wendy would call upon in the event of an emergency, Wendy said that she would activate her personal alarm. There is no-one she would call, as Coral is abroad and she does not like to bother Kayleigh. Wendy said that she had also emigrated with Coral, but had chosen to return to live in England two years ago, as the healthcare in the country she was living in did not meet her increasing health needs. Coral did not want her mother to leave. Coral told her daughter Kayleigh to support her grandmother, which Wendy feels that Kayleigh does this out of duty and does the bare minimum for her. She and Kayleigh do not get on very well. Kayleigh suggested she manages Wendy's finances, which Wendy says she now needs help with because of her failing eyesight. Wendy does not completely trust Kayleigh but feels that she has little choice because there is no-one else nearby. Wendy says she hates losing her independence. Wendy broke her back in the past and although she has made a recovery, she cannot walk far. She is registered blind. Wendy said that she asked the Warden to make arrangements for her to be visited by a chiropodist and a hairdresser. Wendy receives a local authority managed personal budget from Adult Social Services. A carer will visit once a day for three-quarters of an hour, seven days a week to wash up and on three days, the carer will shower her and empty the commode. Wendy finds it difficult to dress, bathe, eat, get in and out of bed, shop and do housework. The carers help her with shopping, but are unable to carry particular items. Wendy recounted a distressing incident where she had asked for bottled water as she had a bad case of cystitis. The carer had shouted at her for asking for this and told her that a family member should get it for her, as it would be too heavy. Wendy said that she did not like to bother Kayleigh and felt quite helpless, frustrated and that no-one cared about her and her needs. Wendy feels that the carers are not always as well trained as they should be and there is little time for carers to carry out all the necessary tasks. Wendy does not provide support to anyone else.

Despite living alone, Wendy reports she does not feel lonely. She has adapted to her situation and to her health constraints over the years. She feels her health and her age

prevent her from doing things she would like. She sometimes feels left out of things, mainly because of her sight loss. She regrets that Coral lives so far away as mother and daughter get on so well and that she does not get on as well with Kayleigh, but accepts that this is part of life.

6.4 Theme 1: Reticence about negotiating support from family, but older people will accept help if it is offered

One underlying theme emerging from the Stage One data was a reluctance on the part of older people to actively seek help or negotiate help from family members with activities of daily living. The author was surprised that many older people chose to admit to her that they were reluctant to seek help, but upon reflection, felt pleased that she had been able to establish a good rapport and level of trust. Finch and Mason (1990) who summarised findings from previous literature examining support arrangements within families which suggested that older people "…overstep the mark by demanding *too much* and also by making demands in the *wrong way"* (ibid:152, emphasis in the original), which appears to contradict the views held by the Stage One participants, who rather than make demands on their relatives, perceive themselves as not overtly asking them for help.

The three cases chosen manifest this theme in similar yet different ways. Ron made it very clear that he enjoys a close relationship with his daughter and son-in-law, James, but he tries not to ask them for help if he can. He admitted that he sometimes feels frustrated and bitter about his physical deterioration, as he used to enjoy hiking and has always been very energetic. His reticence about seeking support could stem from his male identity perception as being the father, breadwinner and head of the family who provides solutions to his own and other people's problems (Smith *et al* 2007). Ron reported that he had been finding it increasingly difficult to walk upstairs to use the toilet (which is located on the first floor of his house) and that there had been one or two times when he had not quite made it in time. He was mortified about this and he admitted that it was this extreme incident which had prompted him to confide in James when his daughter had left the room. Ron felt more comfortable talking 'man-to-man' about what had happened to James rather than to his daughter. Interestingly, Ron told me that he had secretly hoped that James might be able to provide a solution but there were no

overt negotiations about what form that solution might take. James investigated the possibility of installing a stair lift on the internet and consulted with Ron about whether he wanted this. Ron agreed to this and James arranged and paid for the stair lift to be installed. Ron seemed pleased and proud that his son-in-law always seems to anticipate his support needs before he has to ask, or before he had had to worry about it (for example, the stair lift). Conversely, Luke expressed the wish that his adult children would recognise that he struggles with everyday activities, rather than listening to his words, when he tells them he is coping. Luke lives alone and reported that he worries that his physical health is deteriorating but that he does not want to admit that to his family. He said he would rather struggle on than negotiate help from his family, but that he would willingly accept assistance from them if it was offered. Luke admitted he does not want his children to have to worry about him, yet another part wishes that his children might look below the surface and recognise that he is finding it increasingly difficult to cope with everyday life. Luke mentioned that some months before, he had fallen over in the garden when he was cutting a branch off a tree. He sprained his ankle and told me that he was lucky not to have broken a bone. He said that he lay on the ground for about two hours before he felt confident enough to crawl into the house. Luke said that he did not telephone his children at the time to tell them what had happened and only mentioned the incident when his son visited a week later. Luke admitted that he had struggled to perform household tasks, such as cooking, but down-played his injuries to his family. He sees himself in the role of being the responsible head of the family and not as weak or dependent.

Wendy reported a similar situation, as she was reluctant to call her daughter, who lives abroad. Wendy's granddaughter lives locally and was asked by her mother (Wendy's daughter) to 'keep an eye' on Wendy to make sure Wendy had everything that she needed. Wendy said that she felt that her granddaughter felt duty-bound to provide support and was sometimes dismissive or rude. Wendy mentioned that several weeks would elapse in between visits from her granddaughter, but that she was reluctant to telephone her granddaughter to negotiate support. She was also reluctant to telephone her daughter to report that her granddaughter was not visiting, because she did not want to make a fuss or cause trouble. Wendy said that she sometimes felt powerless because she had no control over when her granddaughter might choose to visit, if at all

(Portacolone 2011). Wendy admitted that she struggled to cope at times, but she did not want to intrude into her granddaughter's life or be perceived to be 'telling tales' about her granddaughter to her mother. Wendy said that she did not feel as close to her granddaughter as she did to her own daughter and that she did not have the impression that her granddaughter liked her very much and felt obligated to look after her grandmother.

These three different but similar scenarios have highlighted the importance of examining in further depth the level of support an older person receives and to be aware that older people might have complex reasons for not negotiating support, which are not immediately evident.

6.5 Theme 2: Conveying independence, whether real or not, is a primary concern for many participants

Many participants conveyed the impression of wanting to be seen to be coping with everyday life, rather than actively entering into negotiations of support with others. Independence has already been highlighted as a complex and subjective concept (see Section 4.4.6 above). There are many reasons for wanting to be seen as independent and factors such as balancing obligations and mutual exchanges help to justify an individual's perception of independence (Breheny and Stephens 2009). Participants have conveyed different, yet similar meanings of independence.

Luke wants to convey an image of being independent and in control of his life to his adult children, but he wishes one of them would anticipate his needs and see beyond what he presents to them. He was clear that he would never ask them for help. Luke said he is now struggling with daily tasks and wishes that one of his children would ask him how he is really feeling. He said he would tell them the truth: how lonely and difficult he finds life. But he said he would never instigate that conversation or ask them for help because he would not want to appear weak or diminished in their eyes. Luke said that it takes almost twice as long to tidy up the house and he always does this in readiness for when his children arrive. He said that his children always telephone him to arrange to visit him, so he has time to make sure his house is in a state of order. When Luke fell over in his garden, he chose not to call his children for help. Instead, he said that he lay still outside

until the pain in his ankle had subsided and he felt physically able to return to his house on his hands and knees. Luke also chose not to report what had happened to his children until he had had a chance to recover. Yet he struggled with daily life while he was recovering, rather than asking for anyone for support, even though any support he received would have been in the short term only. One possible reason for Luke demonstrating this extreme behaviour could be a fear of losing his male identity and status within his family unit (Smith *et al* 2007). Yet, Luke admitted that he would willingly tell his children his true feelings if he were asked outright: but he would never volunteer this to his children.

Ron paid privately for carers to visit him at his home. For Ron, independence means that he can pay for his support needs and having the ability to stay at home. He does not have to rely on the state or his daughter and son-in-law to visit him to provide support. Ron mentioned that a few months ago, he decided to move to a care home to be closer to his daughter and son-in-law (who live about 40 miles away). He said that he had talked openly with his daughter and son-in-law and the three of them considered this to be a sensible idea, as Ron's physical condition had worsened and he was becoming increasingly isolated. Ron admitted that he had not been looking forward to leaving his home of many years, but that he was a rational man and he felt that he was making the right decision because he wanted to make new friends. Ron did not feel pressured by his family to make the move. However, Ron described life in the care home as being like 'a slow death'. He said there were no like-minded individuals there to have a conversation with, just lots of older women sitting around on chairs doing nothing. Ron said that he was so bored and disappointed that he discharged himself from the facility and returned to his home. Ron said that he sometimes feels guilty about his decision to return home, as it means that his daughter and son-in-law have to travel a long way to see him. Ron still feels lonely, as most of his friends have died and he knows his daughter worries that he spends the majority of his time by himself. Ron said that he presents a positive image to his daughter and does not voice how lonely he feels because he does not want to appear dependent in her eyes.

Wendy would rather convey a front of independence than contact her granddaughter to ask for assistance with her activities of daily living. As highlighted in Section 6.5 above, Wendy does not feel as close to her granddaughter as she does to her daughter. Wendy

said that she felt as if her granddaughter was visiting her under sufferance, which made Wendy determined not to rely on her for support and to negotiate support through other means. As a result, when Wendy was unwell and wanted some bottled water, she asked her carer to go shopping for her to buy this rather than her granddaughter. When the carer's supervisor discovered that Wendy had asked her carer to do this, she rebuked Wendy and told her that the items were too heavy to be purchased by a carer and that Wendy should ask a family member. Wendy went without her bottled water rather than contacting her granddaughter to ask her to purchase it on her behalf. In addition, Wendy wanted to look in a box which was on a top shelf in her wardrobe, which she could not retrieve herself because of her physical condition. She said that she would rather wait until next month when her daughter was due to visit her than contact her granddaughter to ask her to do this for her. Wendy managed to convey a front of independence by acting to her detriment by minimising her requests for support from her granddaughter and going without items she would rather have.

6.6 Theme 3: 'Not wanting to bother' or be a burden is a recurring anxiety among respondents

Fear of being a perceived negatively was a common refrain amongst most participants, particularly by those living alone (Portacolone 2011). Older people reported deploying different tactics to negotiate maintaining their relationship with their support network, such as not disclosing their inner-most feelings, not discussing their problems, understating their health needs and going without essential items.

Ron is widowed and lives alone. Last year, he discussed his future with his daughter and son-in-law and decided to move into a care home to be near to his daughter and son-in-law. As discussed in Section 6.5 above, Ron reported that he was so unhappy there that he decided to move back into his home. Ron said that he feels guilty about the burden this places on his daughter and son-in-law, as they have further to travel to come to see him. He had not voiced his feelings, but Ron said that his fears were allayed when his daughter and son-in-law mentioned that if Ron had not taken the decision to move back home, they would have discharged him because it was evident the care home was wholly unsuitable for his needs. Ron does not express how lonely he feels to his daughter and son-in-law because he knows that they would want to try to remedy this by visiting him

more often. Ron said that he already feels very guilty that he is visited by them three times a week and is acutely aware that this constitutes an eighty mile round trip.

Luke is also widowed and lives alone. He was adamant that he is highly independent and would not want to be a burden to anyone, particularly his family. Nevertheless, Luke said that he would be pleased if his children offered to help out, but he did not think it would occur to them to do so. Luke seemed to think they took it for granted that he could cope because he always had in the past and he 'would never ask them in a million years' for help. Luke makes all decisions about his life himself and chooses not to confide in anyone because he does not want to be a bother.

Wendy is widowed and lives alone. She does not like to bother her daughter because she lives abroad and she does not want to make her feel guilty about being so far away. Wendy does not like to burden her granddaughter, who lives locally. Wendy is made to feel that she is an imposition if she asks her granddaughter for assistance. She will wait for her granddaughter to offer to help her. Wendy knows that if she told her daughter that her granddaughter made her feel this way, then it would be highly likely that her daughter would be furious and would return to England. Although Wendy misses her daughter terribly, she could not bring herself to tell her daughter because of the guilt that she would feel in burdening her daughter with her problems.

6.7 Discussion

Adopting a life course perspective (see Section 2.3.2 above), at this stage in each of the participants' lives, each finds himself or herself living alone because in each case, their spouse predeceased them. Each had reported having a long and happy marriage and missed the companionship and support that their spouse had provided. All reported feeling lonely and unsupported. Their social network (which was not mapped via a convoy model (see Section 2.3.2 above) in Stage One of the research) had diminished as many friends and relatives had died. Despite all having adult children, none of them felt able to convey their real feelings to them or be willing to negotiate assistance overtly/directly (see Section 4.3.1 above). Ron was able to negotiate support by confiding in his son-in-law about his concerns about getting to the toilet on time and hoping that his son-in-law might provide a solution, based on past experiences. All participants were

hopeful that their relatives might 'read between the lines' and to probe deeper into their lives: Ron was hoping his son-in-law would find a solution to the toilet on the first floor; Wendy was hoping her daughter would somehow learn about how neglected and helpless she felt about her granddaughter who clearly was reluctant to support her grandmother; and Luke simply hoping somehow that his children might just ask the right questions and he could tell them how he really felt. Luke's reticence about confiding in his children about what life is really like for him is framed in Matthews' research as "withholding information" (Matthews 2002:155). However, Matthews' research only focused on the views of siblings, rather than including parents' perspectives, which arguably would have provided a deeper understanding of the dynamic existing between the parties.

The unsolicited views expressed by the participants during the interviews highlighted important and unexpected issues surrounding a lack of willingness on the part of older people to negotiate informal support. However, follow-up questions which would have probed more deeply into these issues were not asked at this juncture within the research. This is because the rationale behind Stage One was to obtain an overall snapshot of participants' personal and family circumstances, support arrangements and health needs. Upon reflection, redesigning the questionnaire to provide participants with a forum within which to justify their answers arguably could have facilitated choosing Stage Two participants more easily. In addition, many of the structured interviews lasted over an hour and a half. It is likely that the length of the interviews would have doubled if follow-up questions had been posed. The three cases examined above highlight how important independence, or the illusion of independence is to older people, which has an impact on negotiating additional support.

The combined effect of wanting to portray an air of independence to the world and not wanting to be a burden would appear to indicate that some older people are potentially at risk of being unsupported even in cases where they are regularly visited by relatives. Exploring and understanding the reasons behind participants' reluctance to overtly negotiate support from those close to them will provide a richer and deeper insight into issues surrounding the support negotiation process.

6.8 Chapter Summary

This Chapter provided an overview of the results of Stage One of the field research. A profile of the participants was presented, together with a short discussion of three themes which were identified from the contemporaneous notes taken during the structured interviews, as discussed above. The following three Chapters investigate and discuss Stage Two of the research: Chapter Seven provides descriptive results from Stage Two and an account of how the data were thematically analysed, how the themes were identified and how the themes from Stage One of the research fit with the themes which were identified in Stage Two. Chapters Eight and Nine provide a thick description and analysis using symbolic interactionism of the themes identified from thematic data analysis.

Chapter 7 Results of Stage Two

7.1 Chapter Overview

Following on from the results of Stage One, this Chapter provides an overview of the results from Stage Two of the field research. A demographic profile of the individuals who took part in Stage Two of the research is presented and the themes which were identified from conducting thematic analysis of the Stage Two data are explicated.

7.2 Demographic profile of case study participants

Eight case study participants were purposively selected in light of their diverse support circumstances: two were chosen who had high support needs (Hamish and Lisa, each with scores of 9 points on the Level of Needs Scale), four with medium support needs (Barry and Leslie, each with scores of 7 on the Level of Needs Scale; Keith and Una, each with scores of 6 on the Level of Needs Scale) and two with low support needs (Luke and Petra, each with scores of 3 on the Level of Needs Scale). In addition, all eight participants reported receiving support from a diverse range of sources. The characteristics of the eight Phase One participants (age range, gender, ethnicity, marital status and support sources) appear in Table 6 below.

Table 6: Stage Two Participants

Main Case-study Participant	Marital Status	Social support network in December 2014/January 2015 (those interviewed in black bold)	Social support network hierarchy in June/July 2015 (those interviewed in black bold)
Hamish (aged 65-69), Mixed ethnicity (High needs: score of 9 on the Level of Needs Scale)	Divorced (lives alone)	**Hamish** **Carer 1** Carer 2 Daughter (living abroad) Sister (did not want to participate)	**Hamish:** support needs changed but no participants to interview as carers left Daughter Sister
Lisa (aged 80-84), White British (High needs: score of 9 on the Level of Needs Scale)	Widowed (lives alone)	**Lisa** **Carer 1** **Carer 2** **Son 1** **Son 2**	**Lisa:** support needs unchanged Carer 1 Carer 2 Son 1 Son 2
Barry (aged 80-84), White British (High needs: score of 7 on the Level of Needs Scale)	Married twice: Divorced (1st) Widowed (2nd) lives alone)	**Barry** **Carer** **Friend**	**Barry:** support needs unchanged Carer Friend
Leslie (aged 75-79) White British High needs: score of 7 on the Level of Needs Scale)	Widowed (lives alone)	**Leslie** **Carer** **Cleaner** Gardener	**Leslie:** support needs unchanged Carer Cleaner Gardener

Table 6 (continued): Stage Two Participants (source: Author)			
Main Case-study Participant	**Marital Status**	**Social support network in December 2014/January 2015 (those interviewed in black bold)**	**Social support network hierarchy in June/July 2015 (those interviewed in black bold)**
Keith (aged 90-94) White British (Medium needs: score of 6 on the Level of Needs Scale)	Widowed (lives alone)	**Keith** **Sister** Cleaner (did not want to participate) Son (did not want to participate) Volunteer (did not want to participate) Warden (did not want to participate)	**Keith:** support needs unchanged Sister Cleaner (did not want to participate) Son (did not want to participate) Volunteer (did not want to participate) Warden (did not want to participate)
Una (aged 70-74) White British (Medium needs: score of 6 on the Level of Needs Scale)	Widowed (lives alone)	**Una** **Son** **Cleaner** **Friend**	**Una:** support needs unchanged Son Cleaner Friend
Petra (aged 80-84) White Irish (Low needs: score of 3 on the Level of Needs Scale)	Widowed (lives alone)	**Petra** **Daughter** **Son 1** **Son 2** **Son 3**	**Petra :** support needs unchanged Daughter Son 1 Son 2 Son 3
Luke (aged 90-94) White British (Low needs: score of 3 on the Level of Needs Scale)	Widowed (lives alone)	**Luke** **Daughter (husband present)** **Granddaughter (husband present)**	**Luke:** support needs unchanged Daughter Granddaughter Son-in-law Grandson-in-law

Table 7: Demographic Profile of Stage 2 Phase 1 Participants							
Participant	Age	Gender	Ethnicity	Marital status	Children	Living arrangements	Tenure
Hamish	65-69	Male	Mixed	Divorced	2 daughters 1 son	Lives alone	Rented HA flat
Una	70-74	Female	White British	Widowed	1 son	Lives alone	Rented Council flat
Leslie	75-79	Male	White British	Widowed	No children	Lives alone	Rented Council flat
Barry	80-84	Male	White British	Widowed Divorced	1 son 1 daughter	Lives alone	Right of occupancy
Lisa	80-84	Female	White British	Widowed	2 sons	Lives alone	Owner occupier
Petra	80-84	Female	White British	Widowed	3 sons 1 daughter	Lives alone	Rented Council flat
Keith	90-94	Male	White British	Widowed	1 son	Lives alone	Rented HA flat
Luke	90-94	Male	White British	Widowed	1 son 1 daughter	Lives alone	Owner occupier

7.3 Phase One participants

When the interviews took place, all eight Phase One participants were living alone but all had been married in the past. All were widowed except Hamish, who was divorced. Barry's first marriage ended in divorce and his second wife died. The ages of Phase One participants ranged from 65 to 94 years.

All participants lived in the community: two were owner occupiers (Luke lived in a detached bungalow; Lisa lived in a semi-detached house); Leslie and Una each lived in Council-rented sheltered accommodation; Petra lived in a Council-rented terraced house; Barry had a right of occupancy of an upstairs maisonette owned by his deceased wife; and Keith and Hamish each lived in rented housing association flats. All participants had occupied their home for a number of years.

All Phase One participants apart from Leslie had adult children, yet the existence of adult children did not automatically mean that the latter provided regular support to their parent. Petra, Una and Lisa all reported receiving regular contact with and support from their adult children; Hamish mentioned that his children provided him with financial and material support, who all lived over 100 miles away. Keith rarely saw his only son despite

living within a 5-mile radius, similarly to Barry, who described his relationship with his daughter as distant (who also lived within a 5-mile radius) but who felt closer to his son, who lived 80 miles away as he would provide emotional support over the telephone. Luke saw his daughter sometimes, who lived within a ten-mile radius, but rarely saw his son, who lived a similar distance away, but reported he received more support from his eldest granddaughter than any other family member.

Only Hamish and Lisa reported receiving direct payments within a personal budget mechanism from the local authority to pay for their formal state care and support. Leslie received a managed personal budget and his daily support was provided by a care company which was arranged by the local authority and he also engaged a cleaner privately. Barry received informal support from a male friend and paid Carers Allowance to female friend to provide him with personal care and domiciliary care. Petra received support from each of her four adult children, engaged a window cleaner and a gardener. Una received instrumental support from her son, she employed a cleaner and received support such as lifts and help with shopping from a female friend. Lisa reported engaging two carers to meet her personal care needs, a gardener, a window cleaner, a person to do the ironing and her two sons to help out with practical tasks about her home. Keith reported that his sister and brother-in-law helped him with his weekly grocery shopping, he was visited fortnightly by a befriender volunteer and he received daily visits from the warden to make sure he was supported. Luke had occasional support from his daughter and granddaughter. All participants apart from Luke reported they were able to access a personal alarm in case of medical emergencies.

7.4 Phase Two participants

Phase Two participants were those people identified by Phase One participants as individuals who provided some type of support to them. Table 5 below shows the profile of Phase Two participants. There follows a synopsis of each case study to describe the support circumstances of each Phase One participant.

Table 8: Stage Two Phase Two Participants						
Phase One	Family	Friends	Cleaners	Carers	Volunteers	Total
Luke	2	0	0	0	0	**2**
Petra	4	0	0	0	0	**4**
Hamish	0	0	0	1	0	**1**
Barry	0	1	0	1	0	**2**
Lisa	2	0	0	2	0	**4**
Keith	1	0	0	0	0	**1**
Una	1	1	1	0	0	**3**
Leslie	0	0	1	1	0	**2**
Total	**10**	**2**	**2**	**5**	**0**	**19**

7.4.1 Luke case study

Luke was widowed and lived alone. He had low support needs. He did not need support with ADLs and could manage most IADLs. He reported that he was starting to have difficulty in carrying out some IADLs, in particular, tasks involving balance, such as standing on a ladder to cut branches and taking down curtains. Luke admitted he was finding it harder to perform heavier household tasks such as hoovering, changing the bed and cleaning. Luke had two adult children: a son and a daughter. His son had three children, now adults, who all lived within a twenty-mile radius. However, Luke only saw his eldest granddaughter, Vera, and Vera's husband regularly (fortnightly-basis), and they provided Luke with occasional support with IADLs (cleaning and gardening) and emotional support (lunch and family gatherings). Luke also received occasional support from his daughter, Lacey, and Lacey's husband with IADLs (transportation to medical appointments, gardening). Luke had a younger sister, who lived within a five-mile radius, who provided emotional support through daily telephone conversations. Luke identified Lacey, her husband, Vera and her husband and his sister as support members. Lacey (who was interviewed with her husband present), and Vera (who was also interviewed with her husband present) agreed to take part in Phase Two, but Luke's sister did not want to participate.

7.4.2 Petra case study

Petra is widowed and has four adult children: a daughter (Sharon), who lives within a five mile radius of Petra's home, and three sons (Nicholas, Charlie and Grant), who all live within a one hundred and fifty mile radius. Petra reported that all of her children provided varying degrees of support to her, so all four of her children became Phase Two participants. At the time of the first interview, Petra said that she did not receive support from anyone else. Sharon was interviewed in her home, as she lived locally. The interview with Nicholas was conducted in Petra's home, but she was not present during the interview. The interviews with Charlie and Grant took place via the telephone, as both individuals lived some distance away.

7.4.3 Hamish case study

Hamish has three adult children: two daughters and a son. His daughters both live abroad and his son lives within a one hundred mile radius. Hamish's eldest daughter provides financial advice to Hamish and manages his personal budget account via the internet from afar. Hamish's other two children provide financial and material support. Hamish also has a sister, who lives within a ten mile radius. Neither Hamish's daughter nor his sister was willing to take part in the research. At the time of Phase One of the research, Hamish employed two carers to assist him with personal care tasks during the weekdays and the Council provided carers to assist him during the evenings and at weekends. Initially, both carers agreed to take part in the research. However, one carer left Hamish's employ suddenly, therefore only one carer employed by Hamish took part in the research: namely Bev. Unfortunately, Hamish's eldest daughter, who lived abroad, who initially agreed to take part in an interview via Skype, was unable to participate owing to ill health and moving to a different part of the country. Hamish reported that he received visits from different carers during the evenings and weekends, so he did not consider that it would be feasible to include them as participants.

7.4.4 Barry case study

Barry reported that he has two adult children, a son who lives within a one hundred mile radius and a daughter who lives within a two mile radius. Barry mentioned that he seldom saw either of his children and that neither of them provided support to him, so they were

not invited to become Phase Two participants. Barry receives daily help with personal care tasks from a female friend of his former wife, Kate, who received Carer's Allowance from the state. Barry also reported receiving daily support from a male friend, Gerry, who takes his dog for a walk and buys his grocery shopping. Barry gave his permission for Kate and Gerry to be interviewed independently at his flat.

7.4.5 Lisa case study

Lisa receives daily personal care and support from two private carers, Mel and May, whom she pays from the direct payments which she receives from her personal budget. Lisa reported that she has two adult sons, Mike and Matthew, who both live within a two mile radius of her home who provide her with support, together with their wives. Lisa gave permission to approach Mel and May, and Mike and Matthew for interview. Mel and May wanted to be interviewed together at Mel's home. Mike was interviewed at his own home alone and Matthew was interviewed at his own home with his wife present.

7.4.6 Keith case study

Keith has one adult son, who lives within a five mile radius but he does not have regular contact. His sister, Dot, and her husband visit him once a week to deliver his grocery shopping lives within a thirty mile radius. Dot and her husband were willing to be interviewed and the interview took place in Dot's home. Her husband was present some of the time. Keith also employs a cleaner who visits him fortnightly and receives daily visits from a warden and weekly visits from a volunteer. Keith did not give his permission to approach his son to take part in the research. Neither Keith's cleaner, his volunteer nor the warden were willing to take part in the research.

7.4.7 Una case study

Una has one adult son, who lives within a three mile radius: Sid. Una reported that she now has regular support from her son and his family after three years of estrangement. Una also employs a cleaner, Enid, to clean her flat and to do her washing and ironing on a weekly basis. Una also receives help with shopping from her friend, Hannah. Una agreed for Sid to be interviewed at her flat while she was in another room. Sid's wife was also

present, but did not join into the conversation. Enid was also interviewed at Una's flat while Una was in another room. Hannah was interviewed in her own home.

7.4.8 Leslie case study

Leslie is widowed and has no children, which he deeply regretted. He has a sister, who lives locally, but whom he sees very rarely. He sees his late wife's sister about three times a year. He has several nieces and nephews, but only maintains occasional contact with two of the nieces: one living locally and the other living in the North.

In terms of support, he employs a cleaner, Beryl, who visits him twice a week to clean his flat and to deliver his grocery shopping. Leslie also receives personal care from a carer engaged through the local authority twice a week: Sam. Both Beryl and Sam agreed to take part in the research. Beryl wanted to be interviewed in a coffee shop and Sam was interviewed in her home. Leslie did not want to invite his sister or nieces to participate in the study because he did not want to bother them.

7.4.9 Types of support provided

This section examines the types of support which Phase One participants reported as receiving from those within their support network. Many Phase One and Phase Two participants did not equate support with meaning help with everyday tasks in and around the home. Some positioned support as receiving benefits from the state and others as financial support. In terms of how support has been extrapolated from the data, acts or tasks in and around the home environment that needed doing were identified and grouped into three categories: personal care, usual household tasks and odd jobs. Table 14 below sets out a list of tasks or actions identified by Phase One and Phase Two participants which were carried out by Phase Two participants on behalf of Phase One participants.

Table 9: Types of Tasks carried out by Phase Two participants		
ADLs	IADLs	Odd jobs
Washing	Cooking	Clearing rooms
Dressing	Hoovering	Sorting out paperwork
Using the toilet	Dusting	Redirecting post
Assistance with walking	Cleaning	Mending fence
Assistance with bathing	Ironing	Packing suitcase to go on holiday
	Window cleaning	Decorating walls
	Shopping	Fixing a mobile phone
		Fixing a television
	Gardening	Fixing curtain pole
		Writing a letter
		Getting a watch battery
		Fixing an electric heater
		Withdrawing cash

At the time of Phase One, all participants who needed regular support in place for personal care and usual household tasks had already negotiated the arrangement. Arguably, as this type of activity needs to be undertaken on a regular basis, it was a need which could be anticipated. However, it appeared that negotiating support for odd jobs presented the biggest challenge to participants. Odd jobs appear to be one-off tasks or tasks need to be carried out on an irregular basis. Often this type of need would occur unexpectedly and was therefore was difficult or almost impossible to anticipate.

7.4.10 Discussion about Phase Two participants

Nineteen individuals agreed to take part in Phase Two of the research. The majority of participants were family members (10 out of 19), followed by carers (5 out of 19), then friends (2 out of 19) and employed cleaners (2 out of 19). A total of 27 individuals agreed to take part in Phases One and Two of the research (8 Phase One participants and 19 Phase Two participants). One point to note is that although all Stage One participants were recruited via a charity aimed at helping older people in mid-to-late 2013, by the time the Stage Two interviews took place in 2015, only one of the Phase One participants

reported receiving regular contact from a volunteer. This is partly because many of the visiting services offered by the charity had been withdrawn owing to funding cuts. The one volunteer identified (Keith's case study) was unwilling to take part in the research. Most Phase One participants identified at least one person who provided them with regular support. Those identified with the highest care needs (Hamish (9); Lisa (9); Leslie (7); Barry (7)) all reported receiving help from carers. Hamish and Lisa were eligible for state support and arranged payment through their personal budget. Leslie also received state support but he mentioned that this had been arranged for him by the local authority. Barry received help with personal care and household tasks from Kate, who was paid Carer's Allowance.

7.5 Phase Three participants

Phase Three of the research took place six months after the first Phase One interviews took place, in June/July 2015. The purpose of Phase Three was to understand how support arranged by Phase One participants had changed over a six-month period (since January 2015). Over this timescale, there were no changes in the type or level of support needs for seven out of the eight Phase One participants: their support needs and the individuals with whom they negotiated their support remained relatively unchanged over that period of time. Upon reflection, this result suggests that the timescale between the initial Phase One interview and the subsequent follow-up interview was too short for notable support changes to have taken place.

7.6 Analysing the data

Thematic analysis was used to code the qualitative data and to identify themes and sub-themes throughout. The system and framework proposed by Braun and Clarke (2006; 2013) were used to guide the identification of themes and sub-themes. The reason thematic analysis was used is because the authors provided clear guidance about how to analyse qualitative data for novice researchers, such as myself. Closely following this guidance would ensure that the analysis was conducted rigorously and systematically. The aim of thematic analysis is to examine all of the data to identify "repeated patterns of meaning" (Braun and Clarke 2006, p. 86). The approach fitted well with the decision to use symbolic interactionism to search out hidden meaning within the language reported

as being used by participants in support negotiations (Charon 1995). In addition, adopting a life course perspective meant that the shared lives of the parties and events occurring earlier in the life course provided an additional contextual dimension to further understand the negotiation process at a deeper level (Giele and Elder 1998). What follows is an account of how the data were analysed using thematic analysis.

7.6.1 Level one: Getting to know the data

Firstly, each interview was transcribed word-for-word into an electronic format. This process took much longer than expected. The author considered using a transcribing service, but the idea was rejected because the author considered it important to be engrossed in the interview data from the outset in order to become familiar with the scripts and issues. Notes were made during the transcription process which enabled the author to identify preliminary codes and themes in the data. The author also listened to the interviews twice further after transcription was completed and a few minor amendments were made, to ensure that the transcripts were accurate.

7.6.2 Level two: identifying codes

Each transcript was analysed line by line to identify codes and themes and a table was created in Microsoft Word with three columns for each of the interviews. One column contained extracts from the interviews, one column contained a description of the code that the extract was placed with and the third column contained the name of the code. Each extract was coded manually because the author works better using a pen and paper and by creating a bespoke table (rather than using NVivo) helped to reinforce and remember the codes and ideas that were identified throughout the process of analysis. Some lines from the interviews appeared under more than one code, and notes were made of the rationale behind allocating text to a particular code to help the author to remember the reason for putting it there (Bryman and Clarke 2006).

7.6.3 Level three: formulating themes from codes

Once I had worked my way through every interview transcript and coded each line into my table, I then took some time to read over the codes and to consider how they could be linked together to form themes, both subjectively (in light of my research questions)

and objectively (in light of what I could identify objectively). At this stage, for several days, I was feeling slightly overwhelmed by the volume of codes and was wondering whether I would ever find patterns in the data that could meaningfully address my thesis enquiry. I decided to map the codes on a sheet of paper and draw lines between them to signify connections, which was very helpful. Initially, I viewed the data from the point of "support negotiation" as a central hub, from which I initially produced three overarching themes: "enablers to negotiation", "barriers to negotiation", and "motivations to provide support" and from each of these overarching themes were a number of sub-themes which collated many of the codes that I identified. However, some codes remained without a good fit. I was also wondering where the three themes that were identified in Stage One of my research might fit in with the Stage Two analysis ("reticence about negotiating support from family, but older people will accept help if it is offered", "conveying independence, whether real or not, is a primary concern for many participants" and "not wanting to be a bother or a burden is a recurring anxiety among respondents"). I worked on another part of my thesis for a few days and returned to the analysis with a fresh outlook.

7.6.4 Level four: rethinking the themes

Having examined all of the initial codes afresh, looked at my initial thematic diagram and considered where my Stage One themes fitted into the overall puzzle, I then realised I had been looking at the data through a different lens. When I thought about the data as a whole and what my older participants had been telling me, I realised that there were two overarching themes linked to the types of negotiation strategies that participants when arranging for a task to be carried out: "indirect negotiation" and "direct negotiation". I then re-examined the sub-themes from Stage Two and the initial themes from Stage One (see Sections 6.4, 6.5 and 6.6).

7.6.5 Level five: conceptualising the themes

Initially, two overarching themes were identified: Indirect negotiation and Direct negotiation. "Indirect negotiation" means communicating a wish or desire for support with a task to others without asking the other person outright that this is the ultimate

goal wanted. Three sub-themes were linked to indirect negotiation of support: "hinting", "not wanting to make a fuss" and "opportunity knocks".

The overarching theme "direct negotiation" means clearly communicating a wish or desire unequivocally and unambiguously to another person. Two sub-themes are linked to direct negotiation of support "asking outright" and "the unexpected". "Asking outright" means that an older person will ask a person to provide support with a task. "The unexpected" refers to a situation where an incident occurs with little or no prior warning which results in an older person directly asking for immediate support.

These themes were quite descriptive, so further analysis was conducted and the themes were further refined.

Having conducted thematic analysis of the Stage One notes taken contemporaneously during the structured interviews, the three initial themes fit in with the sub-themes identified in the following chapter. The first initial theme "Reticence about negotiating support from family, but older people will accept help if it is offered" fits well with the sub-theme "Opportunity knocks". The second initial theme "Conveying independence, whether real or not, is a primary concern for many participants" fits well with the sub-theme "Disguising unmet need". The third initial theme "Not wanting to be a bother or be a burden is a recurring anxiety among respondents" also fits well with the sub-theme "not wanting to make a fuss". This is a practical example of how important it is for a researcher to retain an open mind when coding qualitative data (Braun and Clarke 2006).

7.6.6 Level six: putting pen to paper

Having explained the themes and sub-themes above, the next level to take in thematic analysis after identifying the themes is "to tell the complicated story of your data in a way which convinces the reader of the merit and validity of your analysis" (Braun and Clarke 2006:93).

7.7 Chapter Summary

This Chapter has provided a descriptive, reflective narrative of the purpose of Stage Two of the field research. It has provided a justification of how the Phase One participants were selected and provided an overview of the demographic information of the Phase

One participants. An account of how the Phase Two participants were selected was provided and the types of support that Phase Two participants reported as providing to Phase One participants. There then followed an overview of how the data were thematically analysed, giving an overview of each level of analysis, closely following the guidance provided by Braun and Clarke (2006). Chapter Eight discusses the perspectives of older people and Chapter Nine discusses the perspectives of support members of older people's support negotiations.

Chapter 8 Older people's perspectives of support negotiations

8.1 Chapter Overview

This chapter focuses on Stage Two, Phases one and three of the field research: exploring older people's experiences of negotiating support. Interviews were analysed using thematic analysis (Braun and Clarke 2006; 2013) to search for common themes across the perspectives of older people. An inductive method of thematic analysis was employed, as the themes were identified from the data itself rather than being conceptualised in advance (Braun and Clarke 2006). Four overarching themes were found through examining and analysing the perspectives of older people when negotiating support: Negotiation Tactics, Facilitating Negotiation, Avoiding Negotiating Support and Negotiating Changes. Each of these four overarching themes will now be explored together with sub-themes which give different nuances of meaning to each of them (Braun and Clarke 2006; 2013; 2017). The meanings attributed to negotiation experiences between older people and support members was explored using a symbolic interactionist lens (Blumer 1969; Charon 1995). Where appropriate, the psychological or emotional parts of social care were drawn out throughout this Chapter, which are linked particularly to the effects of long-term health issues on mental health, such as 'a loss of confidence and self-control, which can generate…fear, anxiety and vulnerability' (Ward *et al.* 2012).

8.2 Overarching Theme 1: Negotiation Tactics

Most literature has focused on who provides support, but little is known about how older people arrange support. Gaining an understanding of different negotiating tactics used by older people is important in order to understand situations when older people could express their support needs, were reluctant to admit their unmet need or camouflaged their unmet need. Two sub-themes were identified: 'Direct Tactics' and 'Indirect Tactics' which are now explored.

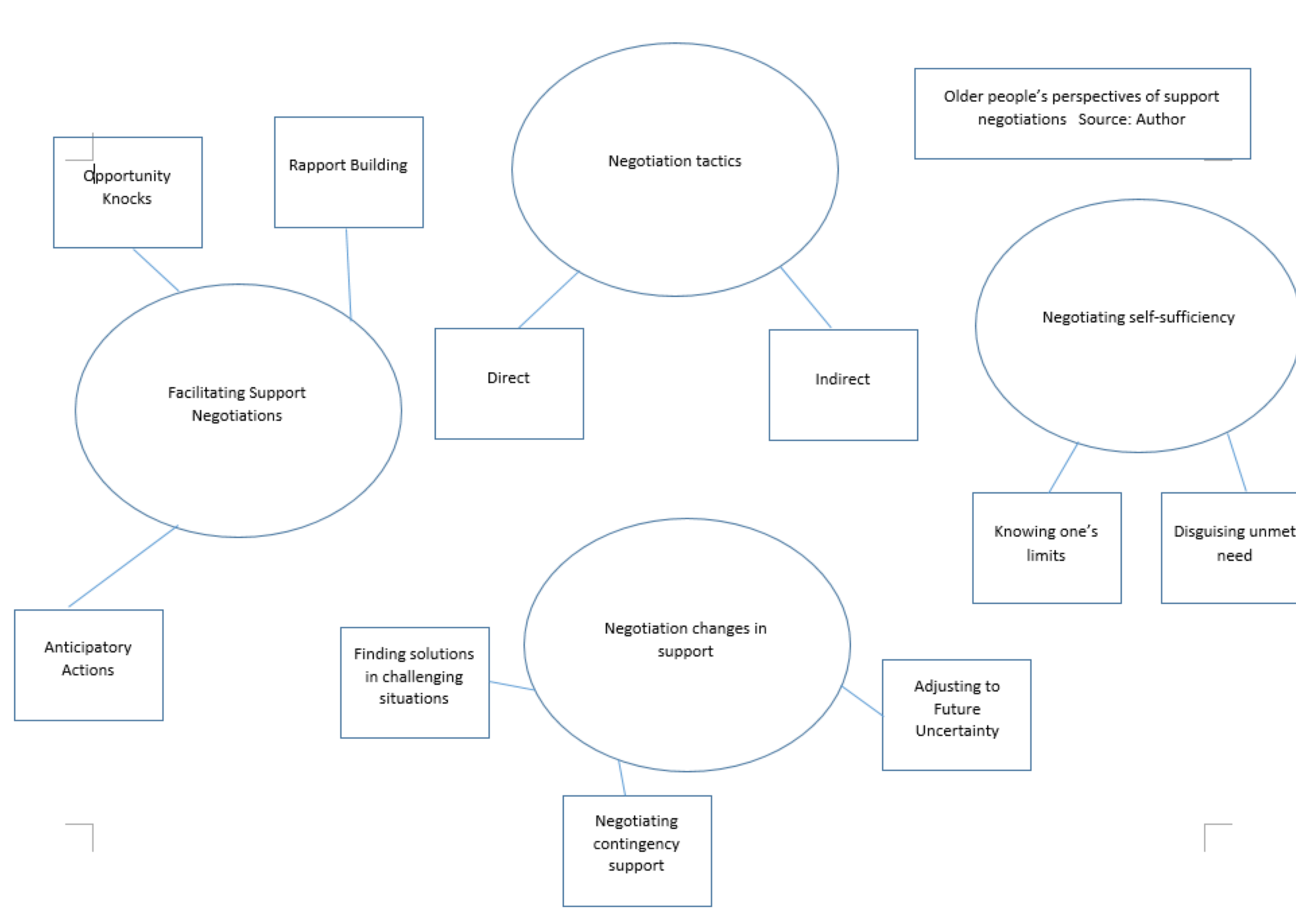


Figure 7: Thematic Diagram of Older People's Support Negotiations

8.2.1 Sub-theme 1: Direct Tactics

Direct Tactics were characterised by older people taking some form of overt approach to negotiate support with tasks from others. The most common direct tactic taken was asking directly for support. Most older people felt able to ask formal support members directly for assistance with IADLs and ADLs.

Examining how older people initially negotiated support from formal sources, most older people engaged individuals through 'word of mouth', by asking people already known to them whether they could recommend someone. When Lisa needed new carers, she explained that she was initially uncertain about what she should do, but decided to approach a friend at a Lunch Club to ask him about his own experience with his carers:

> *I knew this fellow, he had carers and I said to him that I had to change* [carers]. *And he said "I go to a very good um, care company" he said. And he gave me the phone number. So I phoned up and it was Mel* [carer], *um, who looks after me now.* [Lisa, aged 80-84]

Similarly, Una explained that when she saw an advertisement for cleaners on the notice board in the communal area of her block of flats, she asked an acquaintance for advice because she was unsure about whether she could trust them:

> *I found that…I…couldn't do as much cleaning…they come around and pinned…these adverts on our Community Board up there…so I said to her, I said "Here,* [name of acquaintance]"… *"Where's these lot from?". And she says "Oh…They're all right"…"Give her a ring"…Well, when I rang, this woman says…"I'm Enid…I'll be the one that'll be coming to you, if you want us…I'll come along tomorrow and meet you, see, you know, er, what's what"* [Una, aged 75-79]

These two extracts symbolise the importance to older people of choosing support members in a meaningful way by drawing on the opinions of those known to them to make an informed choice. This was particularly evident when there was no-one in their existing support network who could meet their need. Both extracts symbolises the participants' desire to be proactively involved in arranging for support when they recognised that they needed outside help.

For older people who were unable to negotiate formal support through ‘word of mouth’, one surprising finding was that older personal budget-holders advertised for help using Gumtree (a classified advertisement website) or on noticeboards in local shops, rather than via official routes such as the Job Centre or through the local Council:

> *I opted…to…put, er, my own advert…in Gumtree, and the way I worded it was, um, “Stroke survivor looking for, um, personal care assistant”. And I put down the details of the care that was required, the domestics, the personal care and the, what they call the emotional support type of things, like going to the cinema, and everything.* [Hamish, aged 65-69]

> *And I put an advert up in…[name of supermarket]...a notice up on the board there, for a gardener* [Lisa, aged 80-84]

The above extracts symbolise the psychological importance to participants of remaining in control of making their own support arrangements, as exemplified by placing their own advertisements for support. For Hamish, describing himself as a ‘stroke survivor’ had a dual symbolism: his internal strife to fight off the physical after-effects of his stroke and his fierce desire to be perceived by others as being actively involved in making his own support arrangements, rather than a ‘stroke victim’ waiting passively for support to be arranged for him by a local charity. Thus Hamish, he feared being perceived as a ‘stroke victim’, as he equated this to being labelled as dependent on others.

Owing to cuts in service provision, the local Council directed personal budget-holders to a local charity for assistance with administrative issues such as recruiting and employing staff, and the charity opted to use Gumtree as a recruitment resource.

Once formal support was in place, most older people felt able to negotiate directly with formal support members for additional help, particularly with personal care tasks. Barry reported that when his physical condition worsened, he now felt able to ask Kate, his carer, to carry out additional personal care tasks:

> *If I ask her to do anything, she will, she’s not like some people who say “I wouldn’t do that, I wouldn't do that”. I can more or less ask her to do whatever I want her to do, she’ll do it.* [Barry, aged 80-84]

Barry was described by Kate as an exceptionally private individual. Barry's growing familiarity with Kate, together with Kate's easy-going nature meant that on an emotional level, Barry felt able to confide in her about his incontinence issues, which he confided that he had been deeply ashamed and embarrassed about and had tried to conceal.

Other situations where older people felt able to negotiate directly was with wardens/sheltered housing managers, who checked in on them, because they were employed to provide assistance with maintaining the accommodation:

> *But it was basically, [the wardens] called to see if you if needed anything, or wanted anything doing, like I just noticed that that heater out in the hall is not working. I don't need it for heating the room, really, but I use that for when, um, my sheets get washed. And I hang them on the clothes horse round there, you see. So, I'll have to tell her about that tomorrow* [Keith, aged 90-94]

Initially, Keith felt that the warden visits to his home were an intrusion on his privacy and felt that they undermined his confidence and independence. Since his wife died two years before, he found the visits to be a good source of emotional support and helped him to maintain his independence.

Hamish directly negotiated changes within his existing arrangements with personal assistants, particularly in circumstances where there were time limits imposed by the Council. Hamish explained he would often negotiate with his PAs to rearrange their care schedule in order to create time to spend on other tasks:

> *"I've said to them "Look, um…I won't take a lunch hour, but could I combine the lunch hour with the, the morning hour?"…or I'll forgo the shower and then use that hour for the shopping"* [Hamish, aged 65-69]

A level of compromise had to be reached in order to accommodate all of the activities which Hamish wanted to do. For Hamish, negotiating with his personal assistants and substituting tasks symbolised for him maintaining his independence, in the sense that he was prioritising tasks which were more important to him, by trading having a shower for going shopping for food and groceries, and thus was not risking extra requests being rejected by asking for additional support.

Conversely, Lisa approached her PAs directly to ask them to provide extra support, as Lisa was unable to drive to the shops to buy provisions and asked her carers if they could help her:

> *I'll say "Ooh, is there any chance of you being able to take me shopping, Mel?". And she will take me. She'll arrange a day, I'll let her arrange what day is right for her, because she has other people to see to…* [Lisa, aged 80-84]

Lisa's willingness to allow Mel to choose a time which suited her symbolised her awareness that her request was beyond the remit of the negotiated arrangement and that the power to grant or refuse her request belonged to Mel. Lisa did not exhibit the same reticence about asking for extra help as Hamish. One explanation for the difference between Lisa and Hamish is that Lisa had been in receipt of formal care for more time than Hamish and was more aware of support that she might be successful in negotiating.

Likewise, Leslie planned to ask his cleaner, Beryl, if she could change his bed linen and look after his cat while he went away on holiday:

> [Leslie]… *I'll probably change* [the bed] *when I come back from holiday, I'll ask Beryl to do it. And she'll change it for me, I just need to get out the…clean sheets and she'll do it*.
>
> *Interviewer: Is that part of what she does normally?*
>
> *Leslie: Yes, well, I give her a little extra if necessary…And she's going to look after the cat for me, so er, er, she'll get extra, for that…I just give it, I just give it to her. And she's quite happy.* [Leslie, aged 76-80]

Leslie was grateful to Beryl and at the same time, mindful that his request for extra help could possibly disrupt the balance of his working relationship with her. Leslie chose to pay Beryl an additional sum of money to convey his gratitude and to compensate her for any potential inconvenience. Leslie's words and hesitant manner of delivery also symbolised that emotionally, he felt awkward about how Beryl might react to him telling her he would pay her more, but by simply handing it to her without providing an explanation, it lessened Leslie's embarrassment because the arrangement between them was unspoken.

The above extracts illustrate that older people directly approach formal support members in the expectation that they will agree to provide extra help with additional tasks. However, there was recognition that the tasks would need to be carried out on the support members' terms as they were outside of the boundaries of the usual dealings between them.

Lisa's willingness to allow the carer to choose when was convenient to take her shopping, and Leslie's intention to pay Beryl an additional sum symbolises their recognition that the requests made were beyond the boundaries of the original agreement which was negotiated. This suggests that older people wanted to redress a perceived imbalance in their negotiations with support members.

However, many older people were reticent about negotiating support directly from informal support members, equating asking for help with dependency, as Keith explained:

> *I'm so independent…I won't ask anybody, I won't ask people to, to, er, do anything, if I can possibly do it myself. Yeah, I'd have to, I'd have to be really pushed to get help. You know.* [Keith, aged 90-94]

Keith expressed pride while he was explaining that he was not reliant on anyone to help him and also that he did not approach anyone directly for assistance with ADLs. He reluctantly recognised that there could be occasions when he might have to seek outside help, but his words and strong intonation suggested that he would do everything he could to avoid it.

A further barrier to asking for help was evident in Petra's case-study. Petra had low support needs, but was finding it increasingly challenging to perform household tasks, particularly those involving an element of balancing. Petra admitted that she sometimes felt desperate, because she felt that she could not ask her children to help her because she did not want to bother them, or be seen as not coping:

> *I find the windows and the nets and things needs doing* [laughing]*, I mean, I can't ask the boys to do that. And I can't ask my daughter, as my daughter don't feel well at times, and she has enough on her plate. And I don't, I try not to complain about things, because then if they feel that, ah, it's getting on top of me, as it were, it*

worries them. So, I take the worry...I never like them to have they feel that, um, I'm wanting for anything. I just like things to just flow. [Petra, aged 80-84]

Historically, Petra's role as a mother meant that she was finding it hard to adjust to asking her children for support, because she was accustomed to providing support to her children. Petra preferred to remain silent than to be seen by her family as making a fuss. Petra admitted that she often felt emotionally overwhelmed because she felt that she ought to be able to cope with doing her household tasks, as she had always done, at the same time as feeling paralysed by her inability to admit to her children that she was not coping because she placed more value on their well-being than her own.

However, for the majority of older people, asking informal support members for help with tasks meant the possibility of being perceived as a burden, which most were unwilling to risk:

Like I say, I don't, I don't want to, [pause] I don't want to feel I'm a bloody nuisance to anybody, if that, that's the right expression. [Keith, aged 90-94]

I like to let people see I'm OK. I'm right, I'm all right. [pause] But are you though, always? [pause] You're not, you see [laughing]. Then you're a, a pain [Petra, aged 80-84]

The words used by both Keith and Petra symbolised their fear that by admitting to others that they needed help with ADLs and IADLs would mean that they felt that others would see them as 'a bloody nuisance' or 'a pain', in other words, as being dependent, which was psychologically unacceptable for them. Both were emotionally affected while saying this, illustrated by frequent pauses while they chose the right words to express themselves, and nervous laughter from Petra. The two extracts exemplify how some older people would rather not make it obvious to others that they need help because they equate the meaning of making direct requests for help with dependency. In other parts of their interviews, both Keith and Petra spoke of being brought up to be hard-working and self-reliant in childhood, which could partly explain their resistance to negotiating directly with their family for support. A further explanation for this could relate to the social norms discussed in Sections 3.2.3 and 3.2.4, where Keith and Petra have internalised a negative association in relation to help-seeking, based on the assumption that older people should be living independently and be able to cope with everyday life without

needing to rely on someone else for help. Few older people reported they would be willing to ask family members directly for support. Lisa indicated that she would ask her sons for help with IADLs, but she would not ask them to help her with personal care tasks, such as bathing, perhaps because she thought that this would exceed the psychological boundary of what they (and she) would find acceptable. However, Lisa was proud that she could ask her sons openly to help her with non-personal care tasks, as for her, this symbolised that she still played an active role in her family:

> *Anything that I wanted, you know, if I needed something do, doing, they just did it. And that was it, I mean, I've never thought of anything else other than involving them, you know. We're a family.* [Lisa, aged 80-84]

In a similar way, Keith felt isolated from his son's family because he did not feel able to ask his son for help:

> *But let's put it this way, I, I don't expect* [my son] *to* [help out]. *That's, that's the thing. And yet, in a sense, I feel* [pause] *out of it, if that's the right word. I don't feel that I'm, I'm still in the family circle, sort of thing* [Keith, aged 90-94]

For Lisa and her sons, a symbolic part of being a family meant communicating openly and providing help to each other when it was needed. This feature which seemed absent from Keith's reports of his relationships with his family, but one that seemed to be important because on a psychological level, he felt marginalised by his family. Although Keith made it clear that he did not feel that his son should provide him with support, his words symbolise a deeper meaning: if Keith's son offered to help him without being asked, it would mean that his son cared about him without needing to be asked. In addition, on a psychological level, it would also mean that Keith would not feel dependent on his son, thereby preserving his sense of self as being fiercely independent.

Direct negotiations tended to occur where there was clear evidence of reciprocity between friends. Barry and Gerry formed a symbiotic relationship when Gerry's car failed its MOT: Barry lent Gerry his car on the understanding that in return, Gerry would carry out IADLs on his behalf:

> [Gerry] *hasn't got a car and…I said "Well, you can have mine, if you can look after it", you know, if he could do a few, run a few odd jobs for me. He said "Yeah, any*

> *time". He appreciates the fact he's got a decent six hundred odd automatic car. It works both ways. I mean, I don't ask him to go out every day.* [Barry, aged 80-84]

For Barry, negotiating support from Gerry with shopping and walking the dog was based on a reciprocal arrangement. Both parties gained a benefit from the use of Barry's car as a bartering tool. Barry was keen to express that he did not expect Gerry to provide support on a daily basis, which means that he was aware that there were limits to what he could ask Gerry to do for him because on a psychological level, he was concerned about not wanting to ask Gerry to do too much, because he did not want to risk upsetting the balance of their reciprocal arrangement.

Direct negotiations sometimes took place between relatives who got on well together. Luke reported that he only felt able to ask one family member directly for support with IADLS, his granddaughter Vera:

> *When it, I find it really difficult to do things, like I'd like to get the curtains washed…I'll ask the [pause] my granddaughter, she's the only one that I could ask, really, for that.* [Luke, aged 90-94]

When asked why Luke might approach Vera rather than his other family members, he indicated that she was more approachable and empathised with him:

> *She knows a lot of, what it's like for me, and what I'm doing, you know, and the others don't seem to bother* [Luke, aged 90-94]

For Luke, it was important to him on an emotional level that he could ask his granddaughter because she seemed to genuinely care about him and she did not make him feel like any requests he made were an imposition. Whereas, Luke was apprehensive about becoming an imposition if he asked other family members directly for help, because he sensed that they did not feel the same way towards him as Vera did. Thus when Vera offered to help him, Luke did not feel dependent on her on a psychological level, because he had not had to make a direct request to her for help.

Vera herself reported that she wanted to help Luke because she felt indebted to him for raising her when her parents divorced:

I owe him a lot. Because he was there for me when I needed, if he wasn't there, we would've gone into care. [pause] *So, yeah. Yeah. So I feel like, not because I have to do it, it's just that I feel like* [pause] *you should do things like that for your, people*. [Vera, aged 40-44]

Thus, providing reciprocal support to Luke meant that Vera felt like she could repay him for looking after her earlier on in the life course. In families with a strong sense of reciprocity, older people felt more able to ask family members directly for support.

Only Lisa reported feeling comfortable when asking others directly for help, for example, from customers in a shop:

You suddenly realise that you, there are so many people about that will help you. You know, it is amazing. I mean, even when I'm out shopping, if I can't reach something off the shelf, I'll, I'll stop someone and say "Excuse me, can you help me?". You know, I'm not backward in coming forward now, I do do that. Once upon a time I might not have done, but I do now [Lisa, aged 80-84]

Thus, earlier in her life course, Lisa would not have considered asking other people to help her. As Lisa became more reconciled to living with her disabilities, she became more accepting of asking others for help because she became psychologically reconciled to the limitations which her physical conditions imposed on her. Interestingly, asking for help now did not make Lisa feel dependent on others, conversely, it symbolised she was in control of managing her limitations and enabling her to live independently. This finding is in line with Leece and Peace (2010) who also found that service users living with disability for longer had also reassessed their view of what it meant to them to be independent.

More usually, in cases where older people felt unable to directly negotiate support with non-urgent tasks from informal sources, they often paid privately for a service to meet their need. In some cases, when older people told family members that they had paid for the task to be carried out, they often faced criticism, particularly from those who had provided support with that task in the past:

Like I had all those trees cut down [pause] *there…And that cost me eight [pause] eight hundred and forty odd pound, to do it. So,* [pause] *and then my…granddaughter's husband said "Oh, you've been paying through the nose for*

that", he said. "They could have done it for about four hundred, anybody could do that for four hundred". And I said "Well, you come and have a go at it". [pause] *But he didn't do it.* [Luke, aged 90-94]

I mean, my grandson then, was getting in on the act, you see…There's my hedge and my garden, he's telling me off about this fellow [gardener]… *and they think "Oh, Mother", yeah, I said, "But leave me sort it out. Leave me sort it out".* [Petra, aged 80-84]

Older people can become anxious about the reactions of family members to their decisions to negotiate support on their own terms. The above extracts reveal that relatives were sometimes critical about how older people negotiated for support with unmet IADL needs. A judgemental reaction, particularly from family, was likely to undermine older people's confidence in their ability to negotiate support effectively. One interpretation of family members' negative reactions could be feelings of guilt, particularly where they had carried out the task in the past, and their inaction had resulted in older people paying someone else to fulfil the task.

Older people tended to ask directly for support from informal support members in (non-medical) emergency events, but often as a last resort. This is exemplified by Una's case study. During the evening, Una's curtain-rail fell off the wall, leaving her bedroom window exposed to passers-by. Una immediately telephoned her son, Sid, to ask him to help her:

I asked [Sid] *because I had to. I had to ask him, not because I wanted to [laughing] and that, you know, and er, I felt so useless because I couldn't [long pause] um [long pause] get on the step ladder for to put the curtain rail up at the other side to hold it up for the night… sometimes, I think to meself "Well, I'm wasting me time here..."…especially when you've been used to running around, going around and what have you, you know.* [Una, aged 75-79]

[on asking for help] *I think eventually, if something is so bad, it will make it that you've got to do it. If you've got to do something, you do it.* [Lisa, aged 80-84]

The above extracts demonstrate that both Lisa and Una only felt compelled to ask for help from others if they were faced with an urgent IADL task which they were unable to do themselves and which needed an immediate solution. Una in particular found it

emotionally distressing to accept that there were now limits to her physical capabilities, as evidenced by her long pauses, where she was struggling to stay composed while she recounted the experience. For Una, contacting her son to ask for help symbolised an erosion of her self-perceived role as an active and independent mother. For Una, not being able to resolve the curtain issue herself symbolised failure, as in her past, she had always been the one who would help others in a crisis. For Una, being dependent on her son Sid for help in an emergency made her feel like a failure, despite Sid being willing to help her, because for Una, being independent meant not having to rely on anyone else for help. Thus, both Lisa and Una found it psychologically challenging to accept the altered condition of their physical self and its impact on their ability to perform ADLs/IADLs, which manifested within them as feelings of dependency on others.

Interestingly, older people tended not to ask informal support members for assistance in the event of a medical emergency. All older people had a personal alarm (except Luke), which they reported using to alert the emergency services if they had a fall or felt unwell. A fear of falling was prevalent among all older participants owing to balance issues, and every participant spoke anxiously about their fear of falling, although owning a personal alarm played an important role in providing reassurance:

> *And I only just managed to get my hand in my pocket to get this, well, you know* [holding out pendant alarm] *there it is, look. I keep it there, now. I didn't use to, but I do now.* [Keith, aged 90-94]

> *I didn't like wearing this thing* [*pendant alarm*] *at one time. But I stick it round my neck now and I think "Well, it's there, in case". Because once or twice I've had to press it.* [Petra, aged 80-84]

Thus, personal alarms were important because older people could easily and directly negotiate support in a medical emergency. Although the presence of the alarm initially symbolised an erosion of older people's independence, over time, the meaning of the alarm converted to symbolising reassurance. All older participants reported feeling psychologically empowered by the presence of the alarm because it promoted confidence in carrying out practical tasks in and around the home, in the knowledge that help was nearby if needed. Thus instead of symbolising dependence, the presence of the alarm promoted feelings of independence and autonomy because it enabled older people living

alone to be confident in the knowledge that they could arrange help for themselves in the event of some form of unexpected biographical disruption to their health, such as a fall or heart-attack.

In summary, older people felt comfortable asking directly for support from formal support members, where the services provided were paid for. Negotiating directly for additional support from formal support members was usual, and there was recognition that if or when support was provided, it would be on the support members' terms. Some older people would offer additional pay to cleaners as a reward for carrying out additional tasks, in order that they did not upset the balance of their arrangement on a psychological level. Direct negotiation in this context tended to be perceived as a means of maintaining independence because it was within the boundaries of a formal arrangement, where each party would derive a benefit.

Older people only tended to ask for support from informal members where there was evidence of reciprocity, or in a non-medical emergency situation, so that a sense of balance in their relationships was maintained. Older people would ask for help directly in this context as a last resort, for example, in an emergency situation, which would reinforce feelings of dependency for them as psychologically make them feel like a failure.

In other circumstances where older people wanted to seek help from an informal support member for help with a task, they tended to adopt negotiation tactics which were less direct, as discussed in the section below.

8.2.2 Sub-theme 2: Indirect Tactics

Finch and Mason (1993) discussed through case studies and vignettes how families negotiate support implicitly. However, in that study there was limited exploration of indirect tactics adopted by older people in negotiating support from others within their support network. More recently, a Dutch study also examined indirect negotiation tactics used by formal care recipients when seeking support from informal sources (Grootegoed and Van Dijk 2012).

The most prevalent indirect negotiation tactic evident across all interviews with older people was the use of hinting. The meaning of hinting for older people was to frame a request for support without making it obvious to others that they were seeking help. In

other words, hinting was generally used to draw support members' attention obliquely to older people's unmet need. Many older people openly acknowledged that they used hints to make it known to members of their support network that they wanted them to do something, but to disguise that they were asking for help.

Some older people consciously used hinting as a tactic, believing that it successfully concealed their true intentions of making their support needs known to members of their support network:

> *Well, well, I'd be clever in a way, and say, for instance, like I, I'd say to them "Wouldn't it be nice to have one of these?" and what have you, and they would say "Oh, yes, that's a good idea, isn't it?"* [Hamish, aged 65-69]

Hamish further elucidated what hinting meant to him by recalling a recent exchange he had had with his son:

> *It's thrown out there, it's the lowdown, what are you doing now, how are you, Dad? So, I've just gone, I've just walked the length of the flat with a cup of Ovaltine and I haven't spilt it!...do you need a trolley, or something? So I got a trolley, then, and what have you. So. It's um, suggestive stuff, you know. It's playing on people, you know, on people's generosity. And seeing if you can fish it out!* [laughing]

For Hamish, dropping a hint symbolised waiting to see whether any of his support network would 'take the bait' by recognising he was making an indirect request for a trolley. By adopting this approach, he was protecting himself emotionally from any rejection of his request by his children.

In addition, Lisa recounted how she had simply told her son that her watch had stopped working and waited for him to come to his own conclusions about what he was expected to do:

> *I said to* [my son] *"My, my battery's gone in my watch". He said "Oh, right", he said "I'll be down". Because he knows what I want.* [laughing] [Lisa, aged 80-84]

Lisa's familiarity with her sons Matthew and Mike meant that she did not need to ask outright for tasks to be performed, because they expected Lisa would be calling them for help with a task in or around the home.

Keith described how he hinted about problems to the warden and also to his son:

> *I just mentioned it on the phone to him, and he was out, he said "I'll be over in twenty minutes". And he was over here, you see.* [Keith, aged 90-94]

Explanations for why hinting was a successful tactic for support negotiation in some situations were offered by Keith and Hamish:

> [referring to warden] *"I've something wrong behind my television, there…", she'd say "Right, I'll have a look". And she'll pull it out and "Oh yeah, you've got a wire out", or something like that. And she'd plonk it in. You know.* [pause] *But I didn't ask her to do it, she just done it. I know* [pause] *in the way I ask her to do it, because I said it was like it, but I didn't ask her to do it. She, she was thinking that I can help him, and she just got up and done it.* [Keith, aged 90-94]

> *It's along the lines of "Ohh, yeah, if I had this, I would er, I would be able to do that" and what have you. So, they are inspired by the way I am… inspired in a sense of this, you know, they jumped onto my bandwagon, as it were, you know. Given help me with this and that, and what have you. That's, that's how it's worked, generally. But, I've got, haven't had to batter anybody to, to help me* [Hamish, aged 65-69]

Thus both Keith and Hamish chose to believe that they were not indicating to others that they were asking for help, yet both of them vocalised a need without using words which expressed a call for help. Therefore, the success of hinting as a tactic seems to depend on how support members perceived older people. Support members who viewed older people with affection appeared to be proactive about fulfilling the task hinted at because they liked them and wanted to help out. Hamish's family were dedicated to supporting Hamish in his recovery from a severe stroke and wanted to help him to live a full life. For Hamish, his family responding to hints without him explicitly asking demonstrated that they cared about him, which helped to reinforce his positive role of living independently as a 'stroke survivor'.

Older people appeared to adopt a hinting tactic unconsciously, through describing their approach in terms of 'mentioning' or 'suggesting' problems to support members. Barry informed his son that he had been burgled, because he left his back door open so that his dog could roam freely:

> *I mentioned it to my son and that, and friends and that said I shouldn't leave the backdoor ajar* [to let the dog in]. *So um, my son gave me a Christmas present and fitted a, a dog flap in the door* [Barry, aged 80-84]

Some older people only became aware that they used hints when they recounted instances where they had made it known to support members that they needed help with tasks. Keith explained that while he was in hospital, he remembered that he needed to take his car to the garage and had spoken to his son about it:

> *Oh, well, in a way, I didn't directly ask [my son], I said [pause]…to him "I don't know whether I'm still* [pause] *whether I'm too late to have the car done". I said, as I, I thought I had told him that it had to go in for the brakes things, you know* [coughing]*…and I described where it was to him, and of course, he knew, he knows the area better than me. And, er, he said "Oh, right" he said. He said "Well, I could take it over". I said "Well, fair enough, if you would".* [Keith, aged 90-94]

However, support members did not always react positively to hints, leaving some older people disappointed and unsupported:

> *I've, I hint at things. But I don't ask outright. But I don't get no replies from it. No.* [Luke, aged 90-94]

For Luke, his family's lack of response to his hinting tactic symbolised for him that his needs were a low priority for them, which made him less inclined to seek out help from family members in the future. He did not feel that his children fully appreciated his everyday challenges, and believed his granddaughter was the only person who fully understood him:

> [Of his granddaughter] *erm, if you mention something about, "Oh yeah, I'll come and do it for you" you know. She's like that. Whereas the others, they pussyfoot around about it* [laughing] *and in the end, you say park the car, I won't bother*. [Luke, aged 90-94]

If support members did not 'take the hint', Luke reported they might provide a polite reason for why they were not prepared to carry out the task:

> *Well, I, not at the moment, but mowing the grass, but "Oh, I've got mine to do, you know, I've got mine to do down there, I'll have to do it". But yeah, I, I want mine doing* [laughing]. *But no-one says they'll come and do it, they've all got their jobs they want to do, so I let them get on with it.* [Luke, aged 90-94]

Luke's family were interviewed in phase 2 of the research and their perspectives to Luke's hinting technique is examined in further depth in Section 9.2.1 of the following Chapter.

Another form of hinting was through actions taken by older people, which was evident in Una's case study. Sid (Una's son) and Una's relationship had very recently improved as they had not been on speaking terms for many years. During a shopping trip with Sid, on impulse, Una had bought a second-hand tumbledryer. Una told Sid that the machine would be stored at his house, ostensibly to replace his machine which had stopped working. Una admitted during the interview that part of her motivation for buying the machine was because she hoped Sid would offer to dry her washing for her, as she was finding it increasingly difficult to perform this task (which he did):

> *No, it wasn't kind of me, because there was…method in me madness. Now, I do me washing, I can't hang it out on the line anymore, because I'm not steady enough, so…I throw it in, er the washing basket when it comes out the washing machine, gives them a ring, Sid picks it up…and he's always coming in with one load and taking another load out! So they tumble dry it for me* [Una, aged 76-80]

Therefore, Una's actions, whilst outwardly symbolising generosity, instilled in Sid a sense of reciprocity, whereby he felt morally compelled to return his mother's kindness by offering to dry her washing for her on a regular basis.

Therefore, older people who hinted at, rather than asked outright, for help with ADLs and IADLs did 'not [want] to be seen as imposing practical or psychological burdens on others' (Tanner 2007:25), which mirrors the policy (and social) norms of the importance of not being perceived as dependent on others for support (see Section 3.2).

One reason for support members reacting positively to hinting was linked to their ability to assume "the role of the other" (Charon 1995:104). In other words, the extent to which support members were able to empathise with the older persons' situation. Thus, hinting tactics generally yielded successful outcomes when support members had positive

feelings towards, or a positive emotional connection with older people, such as admiration, affection or empathy, which appeared to make them more receptive to reacting to the hint and providing support. In cases where relationships, particularly with family members were strained or more distant, support members were less likely to be psychologically aware of, or receptive to hinting as a potential support negotiation tactic. In addition, tasks involving physical exertion or which were time-consuming were less likely to be fulfilled than easier solutions, such as buying an item. Hinting can therefore be seen as a risky tactic because it can be legitimately ignored by a support member, which could potentially leave older people at risk of harm if they attempted to carry out tasks that they felt unable to perform safely.

8.3 Overarching theme 2: Facilitating Support Negotiation

Having examined Negotiating Tactics described by older people, the sub-theme of Facilitating Support Negotiation highlighted conditions that enabled older people to negotiate support with ADLs or IADLs from support members. In addition, circumstances were explored where older people did not need to negotiate support because support members had taken some form of pre-emptive action. Three sub-themes were identified: Rapport Building, Anticipatory Actions and Opportunity Knocks, which will now be discussed in turn.

8.3.1 Sub-theme 1: Rapport Building

The ability to foster a meaningful dialogue with support members facilitated older people with negotiating support from others, particularly from formal support members, such as paid carers or PAs. The potential to develop a rapport was a particularly important consideration for older personal budget-holders when recruiting PAs. Drawing on Hamish's case-study, Hamish's main criterion when selecting potential candidates was based on whether he thought he could build a rapport with them:

> *So you make up your mind, you know, with a little bit of piecing together the jigsaw about the qualifications and their experience and also generally, what the person is like. You know, their, their personality and everything. You want to get on with somebody who is working for you. It's also someone you want to bully and send*

> *around* [joking/laughing], *rather than somebody who looks, er, very stubborn and obstinate and er, you can't get them to do something* [Hamish, aged 65-69]

For Hamish, establishing a rapport with a PA candidate was particularly important because they would be interacting together on a daily basis. He wanted to appoint someone amenable and trustworthy, with whom he talk openly and could share important details about his life.

> *But you know when you have somebody that's caring for you, you, you establish a rapport, and you, you know, you get in each other's arena, you tell each other about the week* [Hamish, aged 65-69]

Keith also shared a similar view, when he was describing his relationship with the warden:

> *I, I don't mix with my words, really. But er, we talk about anything and everything, sort of thing.* [Keith, aged 90-94]

It was important for older people to feel able to converse comfortably with formal support members so that they felt at ease not only if they needed to ask for help, but also when carers or PAs were carrying out intimate personal care tasks. For Hamish in particular, the ability to be light-hearted was perceived as an important tool with which to build rapport, particularly for Hamish, who needed support with intimate personal care tasks:

> *The biggest thing, of course, is, initially is you have to establish this elementary relationship with those persons that come out to you. You, you're letting them into your home and everything…you're undressing in front of them, and they look at your [pause] goodies, and everything, you know. So, each one is adjusting…I'm lucky with the two girls that I've got. They're, they're professional, and they're wise enough. They're, they've got a good sense of humour and…they're human, you know.* [laughing] [Hamish, aged 65-69]

Humour was also important to Leslie, as was being visited by the same carer. Rapport between older people and support members was usually created gradually over time when the same individuals bonded with each other through shared experiences:

> *It will be the same carer. She's very good. Very good. We have a laugh and a joke together and that when she come in, and I always leave the door unlocked for her, when I know when she's coming.* [Leslie, aged 75-79]

However, a negative aspect to rapport building emerged when the balance shifted between what was considered appropriate and inappropriate conduct between older people and formal support members. One consequence of building a rapport over time was that the roles assumed by support members and older people sometimes became blurred, because one party might take advantage of the more permissive relationship. Hamish recounted a time when Bev, his PA, asked him if she could bring her children to his home during the school holidays. Hamish's multiple roles as Bev's employer, as her friend and being a parent himself brought into play conflicted feelings, as the extract below exemplifies:

> *I put myself out a little bit for Bev, because she brought the two children. Who brings their children to work?...so I said "OK, let's put a plan together". OK, we'll take the children. At some risk, mind you. Because if we went to [name of place], and…there was an incident where it was a choice between looking after me and er, looking after her children, well, for sure she was going to look after her children. So, it was a gamble, right? And also, there's the liability, what happens if the child, if the children had an accident there, or something like that? I don't have an insurance cover, to cover those things.* [Hamish, aged 65-69]

Additionally, there was a risk of one party overstepping the professional boundary by oversharing information about personal issues. Hamish explained that he felt obligated to adopt the role of confessor to Bev to provide her with emotional support when she told him about her personal issues:

> *You feel, in a sense, that you, you owe them, really, at least an ear, you know, if they've got a problem "Oh, why don't you do this?" I would say, or "Why don't you do this", you know. And you know, in friendship, more than anything else, you know.* [Hamish, aged 65-69]

Hamish's case study exemplified that older people sometimes felt obligated to acquiesce to unwelcome changes to support arrangements because the professional relationship

had metamorphosed into a form of friendship. Hamish's role changed from employer to friend, and he felt obliged to respond in kind to Bev.

Thus building a rapport meant that older people felt secure interacting with formal support members, which was especially important for older people who received help with personal care tasks. A good rapport also increased the chances that older people might feel able to vouchsafe issues of concern and highlight awareness of unmet need to support members. Conversely, over time, a rapport could also mean that support members took advantage of the familiarity and renegotiate the professional boundaries of the support relationship. Older people may feel obliged to respond in kind or risk withdrawal of support, potentially placing them in a vulnerable position.

8.3.2 Sub-theme 2: Anticipatory Actions

Several older people mentioned the importance of support members being able to anticipate what support they needed with ADLs and IADLs without being asked. This observation is in line with the first step proposed by Tronto (1993) in terms of noticing that older people need some form of support (see Section 3.2.3). Support members who took pre-emptive actions were described by older people as being able to "think ahead" and to "plan in advance". Older people perceived an ability to pre-empt their support needs as being a quintessential characteristic of a paid carer, as Hamish explained:

> *I've got an electric shaver and I've got um, I've got an electric toothbrush. So, OK, I've got these two things, but they need to be charged, again, so you have to anticipate that tomorrow morning, he's going to brush his teeth, he's going to have a shave.* [Hamish, aged 65-69]

Several older people perceived the ability to anticipate a person's support needs was an innate quality, rather than a skill which could be taught. Older people considered individuals to have polarised characteristics: individuals who had a natural instinct to anticipate others' support needs without needing to be asked, and individuals who were oblivious to the possibility that others might need support. Hamish and Keith shared this view:

> *NVQs are a, a relative thing, but, and there's certain things also that you can't teach people, you know what I mean? They're just inherent in their person… So they're*

> *[pause] they know you're going to take a walk…to the bathroom, and they give you your stick and you're, you're going, you know…* [Hamish, aged 65-69]

> *There's two differences, one who, who can see you need a problem done, and will do it.* [pause] *And those who* [pause] *don't know you've got a problem* [pause] *and you've got to ask them* [Keith, aged 90-94]

An ability for informal support members to anticipate support needs could be based, in part, on the level of affection felt for the older person. Hamish gave examples of where his son had bought labour-saving items without asking, to help make Hamish's life easier:

> *Well, again, I'm lucky, because um,* [pause] *well it,* [pause] *I don't know. Sometimes, they just spring off the board themselves, you know, and they jump into the pool at the deep end. I mean, like my son. He bought the televisions there and there* [pointing around the room]. [Hamish, aged 65-69]

Hamish also explained that his daughter was able to anticipate his needs:

> *And* [Hamish's daughter]…*she looks at her husband and then you know, she does that* [nods head back and forth]*, and he knows straight away, like "Bring, get him a chair to sit on and everything", you know. It was, so, like, a…a silent movie...Really, they just move their head and it's "Move his chair, do this"…But, that understanding, I don't know, it's, there's no written book for it, isn't it?* [Hamish, aged 65-69]

For Hamish, although he reported that his son was able to anticipate what he might need in terms of household or leisure items, his daughter's ability to anticipate his care needs had a greater meaning for him, in terms of how she communicated what she thought that he would need at a family gathering to her husband. For Hamish, this symbolised that not only did she care *for* him, but that she also cared *about* him.

Petra described her youngest son as highly perceptive of her support needs and would often carry out maintenance tasks and housework for her because he noticed they needed doing, such as painting and vacuuming. This was in stark comparison with her other two sons, whom she would need to ask directly for help (but chose not to):

> *And Grant, yeah, I think it's, er,* [pause] *in you do things, don't you? You know, you don't have to be asked or anything, if it's in you to do it.* [Petra, aged 80-84]

One explanation offered for the difference in attitudes was that her two older sons were living in rented property, but Grant himself was owner-occupier of his property. Petra therefore considered Grant more likely to be attuned to the types of tasks which needed to be carried out in and around one's home. However, being related to a person who pre-empted support needs did not necessarily mean that other close relatives would follow suit.

Hamish thought that the ability to anticipate the need for support was gender-related, expressing the view that women were more likely to pre-empt support needs than men:

> *It's always the, the female, whether it's a daughter or somebody that always looks after their, or the niece, or somebody that looks after the. Men are a little bit, um, shy of, looking after their parents and everything. Or they just don't care or but they don't even think about it, you know.* [Hamish, aged 65-69]

Females being more suited to caring has been a dominant theme in the literature on care and also in policy assumptions because of their 'natural' tendencies to display caring characteristics towards others, particularly to older people and children (Section 3.2.3). Yet two fathers, Barry and Luke considered their daughters incapable of anticipating their support needs. Barry described his daughter as having little patience and a dominant personality, and concluded she was not well-suited to caring for others:

> *Yes, see, she'd never make a nurse. She's got, she can blow her lid up… She's too bossy. Well, er, you see, er, she doesn't make a good nurse.* [Barry, aged 80-84]

Luke expected his daughter, Lacey, to want to anticipate his support needs and felt hurt when she did not, as this symbolised she did not care about him. Luke attributed Lacey's lack of caring nature to her being childless. He compared Lacey with his (more caring) granddaughter (who had two children):

> *They're different. But I can't say how different.* [Granddaughter's] *more* [pause] *understanding, I suppose that's what it is. She's got a family of her own, she's got two children. My daughter hasn't got any, and I wonder if that's some of the cause of it. She's got no idea, really, in that way.* [Luke, aged 90-94]

Adopting a lifecourse lens here sheds some light on Luke's assumption about females. His own mother had taken care of him and his sister, as well as both of her parents, and his wife took care of their two children, as well as her own parents and his parents, so his values were nested within the social context that was relevant for him throughout the Twentieth Century.

Keith gave an example of how he thought his son incapable of pre-empting his support needs:

> [Son]…*would come and pick me up to take me across, to where he was living to, for Sunday lunch? And when we got out of the lift downstairs, he would grab hold of me and almost make me feel as though I was running, you know. And I used to have to say to him "Steady, steady". And he'd say "I'm not a very good carer, am I?". And I would say "No, you're bloody not"…*[pause] *he wasn't very sympathetic towards you. You know, oh, I didn't want sympathy, but I wanted a little bit of care, sort of thing…anyways, he, he can't help it, actually.* [Keith, 90-94]

For Keith, feeling rushed by his son symbolised a lack of empathy of what it might be like for someone to experience mobility problems. Similarly, Luke considered Lacey was incapable of understanding of what life might be like for him because being a mother symbolised having a caring nature. Luke's views notwithstanding, the above extracts demonstrate that the gender of informal support members did not appear to determine who was capable of anticipating support needs. Some female informal support members were identified by older people as being unable to anticipate needs, while some males possessed anticipatory traits, and vice versa. Two older males believed that their daughters ought to anticipate needs because they were female, however, most older people believed that the propensity to care was an inherent personality trait linked to gender.

Several older people articulated the importance of formal support members to be able to anticipate their support needs without having to be asked, so that they did not feel dependent:

> *That, that having that knack to be able to enable somebody is also having a certain amount of* [pause] *to pre-empt everything, you know, and to think through things*

> *and what you need to do to make it possible for that person to* [live]. [Hamish, aged 65-69]

> [Of carer] *Because she cared. And she took an interest in you and in her job. She did her job right.* [Una, aged 80-84]

Participants tended to have a polarised view of support members: those who were capable of anticipating support needs and those who could not. The ability to anticipate support needs without being asked was perceived as innate. In addition, the ability to anticipate support needs tended not only to symbolise for older people that the support member 'cared for' them, but also that the support member 'cared about' them. This suggests that for optimum care and support to be delivered, both facets of 'care' should be present. However, some older people believed that 'being caring' should symbolise an embodiment of what it means to be a female, thus reinforcing a social norm regarding women being 'natural caregivers' (McKie *et al.* 2001). However, while some female support members were described by participants as 'being caring', others were not. In addition, the findings suggested that being female and being related to an older person did not necessarily mean that she would provide care and support. Thus, the accounts of older people suggest that 'being caring' is innate within a person, regardless of whether they were male or female. 'Being caring' depended mainly on the quality of the relationship which existed between the older person and the support member. Support members who enjoyed a positive relationship with an older person meant that they were more likely to 'care for' and 'care about' them. In addition, living locally did not always mean that children would provide support, and living at a distance did not necessarily mean that support would not be provided. The next sub-theme explores the third aspect of Facilitating Support Negotiation: Opportunity Knocks.

8.3.3 Sub-theme 3: Opportunity knocks

This sub-theme discusses situations where support members made an offer to provide support with ADLs or IADLs without being approached by the older person for help. Older people did not always feel able to ask support members for help with tasks, or support members might not be available or willing to provide help. As discussed in Section 3.2, older people are generally reticent about asking others for help because they do not want to be perceived as being dependent. However, if someone offered to help them

unexpectedly, or happened to be nearby, most older people tended to take advantage, for example, in situations where someone visited them or happened to be nearby. There were few instances in the interviews where older people reported that support members made an offer of help. Therefore, there are not as many extracts to illustrate this sub-theme as there are for others. Nevertheless, this is an important facet of the overarching theme "Facilitating Support Negotiation" because the finding revealed older people were minded to accept help if it was offered. One example recounted by Keith, when a formal support member asked him if he needed other support while she was there:

> *She said "What can I do for you?", so I said if you want to do anything, you can make me bed for me. Because that…is a problem now, you know, well, it's not easy.* [Keith, aged 90-94]

Keith's then explained why he was happy to accept help if it was offered:

> *And people are, they don't, I don't ask them to do it. But they volunteer to do it. That's different.* [pause]…*It's different because I haven't had to ask for them to do it.* [Keith, aged 90-94]

For Keith, being asked *by* someone symbolised that he did not have to ask *for* help because it meant that he did not feel dependent on others. Keith believed that his son should offer to help him, rather than Keith asking him for help:

> *I think if* [my son] *really* [pause] *if he really wanted to know what I was doing, and how I was, and all the rest of it, he would ring me and ask me if there's anything I wanted. Or, could he do anything. That would be my attitude as father and son business.* [Keith, aged 90-94]

Therefore, for Keith, part of the role of a son was to feel an obligation to ask a father whether he needed help. However, most examples of offers of support were made to older mothers by their sons. When Lisa's son noticed during a visit to Lisa that she was receiving an unprecedented volume of junk mail and begging letters from charities, he offered a solution to help her to stop it. Lisa admitted she was relieved when her son offered to help her, as she had been unwilling to tell her family that she was finding it hard to cope:

> [My son] *said "Would you like me to help you with this, Mum?" he said "This is becoming a bit too much, isn't it?". Because every day, I was getting piles of post like this* [demonstrating with her hands]*. And he said "This is ridiculous"…and I said "Yes, I would like you to sort it out for me". And so he did.* [Lisa, aged 80-84]

When Petra's son, Grant, visited Petra, he noticed that her windows and curtains were dirty and he offered to help her to clean them:

> [Grant] *said "What about washing the curtains, net curtains?". So, we did, and we cleaned the windows and. This is him, you see. You know what I mean? Because it was all done in a matter of an hour. And cleared up and he catched the hoover…He suggested it. He is, you know, he's like that about things, You know, he could see they were grubby. I said "I know they are". [laughing] "But I can't get up to do them myself"*. [Petra, aged 80-84]

These extracts emphasise that older people sometimes opt not to ask for help with tasks that they cannot do, but when support members offered to help them with a specific task, then older people tended to accept that support. One reason for feeling able to accept help is because older people have not had to ask outright for help and therefore do not feel like they have placed an obligation on their family to provide support to them. This symbolised that they have maintained their independence by not needing to ask for help. Older people also feel emotionally valued, as for them, it symbolised that they were being cared for.

Older people tended to prefer socialising with family, rather than getting support with tasks which needed doing:

> *If they offered, I'd, I'd let them do it. But the time is so short when they come down…And I want to be out and about. I want to be out of the house. So I'll forget about the curtains and the windows and everything then, when they come.* [laughing] *When they go again, I think "Blinking windows"* [laughing] [Petra, aged 80-84]

For Petra, spending quality time with her family was equally, if not more important to her than them carrying out tasks for her. However, because time was limited during his visits,

Petra felt torn between socialising with her son and allowing him to carry out tasks which had been worrying her.

The next overarching theme will examine how older people negotiate changes in support over time.

8.4 Overarching Theme 3: Negotiating changes in support

It is widely recognised that support needs change over time and how older people might choose to renegotiate the support that they needed was an important aspect of the research. Older people were interviewed twice during a six-month period to understand whether they renegotiated support and if so, how. However, during the timescale, all older people's support needs remained at a similar level and members of their support network remained unchanged, with the exception of Hamish. Hamish's two personal assistants both left during that time and had not, at the time of his second interview, been replaced. The theme is discussed in relation to two themes: Adjusting to Future Uncertainty and Finding Solutions in Challenging Situations.

8.4.1 Sub-theme 1: Adjusting to Future Uncertainty

All older people expressed some level of uncertainty about what their future might hold. Most participants who did not have a close relationship with their family felt that the support in place at that time was temporary and would inevitably need to be renegotiated at some stage in the future. Two reasons were attributed to why older people might need to renegotiate support. First, older people's health needs fluctuate and accordingly, support would need to increase or decrease. Second, support members, particularly formal support members, may no longer be able or willing to provide the same level of support to the older person. This concern was exemplified in Barry's case study, Barry considered his support needs were met, but expressed uncertainty about how long Gerry and Kate might continue to provide him with support:

> *Oh, I get by at the moment...If anything happened to Kate or she couldn't, or didn't want to do it anymore, or Gerry, I would just have, I've have to consider, I'd have to go back and see the Parkinson's nurse and er, sort something out. And if I, if I couldn't cope, well, I would either have to pay [pause] people so much each day, it's*

> *terrible there's all these people that come round with* [the local Council]*, it's a farce. The lady downstairs, somebody comes in for about quarter of an hour in the morning. Yeah. You, you know, that's all you get, the bare essentials.* [Barry, aged 80-84]

When interviewed a second time, Barry explained that the level of support provided was the same, but expressed concerns that Gerry's declining health might affect his ability to continue providing support:

> *So…things er, about how I run my life is [pause] more or, more or less the same, Gerry and Kate.* [pause] *Trouble is, Gerry* [pause] *Gerry has got, um, a type of cancer, but he's, they take little pieces out here and there. He, he still drives, he, he's still on my car insurance…* [pause] [and] *goes and gets the shopping. So, everything's basically, all the time I've got those two in there, fit and well, things are basically how, how, how I've been living.* [Barry, aged 80-84]

In addition, Kate was due to retire a few months hence, which meant that her financial circumstances would improve and she would not need the additional income from caring for Barry. Barry also considered a decline in his health as being inevitable and consequently, anticipated needing additional support. Accordingly, he expressed apprehension about his future and resignation about not feeling in control of his support arrangements:

> *But* [pause] *I just live from day to day and just hope things will be all right. I mean, I've got to face up to things, that certain, certainly in the future, but whether it will be through ill health or have a, some serious illness, or there's nobody to look after me, I, I've just got to wait for that to come. Well, I don't see there's much I can do at the moment.* [Barry, aged 80-84]

For Barry, who was retired from the forces, accepting he could do little to plan for his future was frustrating. When he was working, he held a responsible role, managing staff and making advance plans, so he found it hard to adjust to living with uncertainty.

When considering negotiating support which might be needed in the future, most older people perceived the only option open to them was to enter some form of residential care setting if they became increasingly unable to manage at home. For Leslie, who was

the only childless participant, he viewed residential care as almost inevitable if his health worsened:

> *Well, I've either got to go into a home, or er, er, go into hospital, but the hospital first and the home after, I don't know. Which I wouldn't want. But then, I've got no choice, have I, then, have I? There's nobody else to look, look after me, so.* [Leslie, aged 76-80]

Surprisingly, most other participants (with at least one adult child) also viewed entering residential care as the most viable option for their future should their health deteriorate and their support needs increased. Most older people did not want to live with their children for a variety of reasons. Barry was adamant that he would prefer not to live with his daughter because of her domineering nature:

> *Oh, er, I wouldn't want to live with my daughter, I don't think.* [pause] *She's too bossy. Well, er, you see, er, she doesn't make a good nurse.* [pause] [Barry, aged 80-84]

One barrier for Luke to living with his family was a fear of being unwanted:

> *Yeah, but I don't like [pause] getting in other people's way.* [pause] *I might be to them, I don't know. Ah, I don't know.* [laughing] [Luke, aged 90-94]

The sub-text of these extracts generally suggests that older people would not want to become dependent on their family for help, as they did not want to become dependent on them and in the worst case, feared becoming a burden to them. In addition, they feared a loss of control as there was a risk that they could become dependent on family members that would prefer not to live with.

All older people expressed strongly negative views about residential care:

> *That's the only thing that frightens me is getting stuck in some horrible home. Where there's, you hear about what goes on in some of them* [Barry, aged 80-84]

> *I don't want to go into a home. I don't. I've seen, er, I've heard about, well, I haven't seen, well, I have seen, but I've thought some of these homes I wouldn't like to be in there. All sat round there, er, er, outside the wall, er, er by the wall, and windows, just* [pause] *doing nothing.* [pause] *Who wants to sit there?* [Leslie, aged 76-80]

> *Everything would be different, yeah, yeah. I wouldn't be able to do a lot of things I like to do. Yeah, it would, well, they take your money, don't they? So no, I definitely wouldn't want to go. I want to keep my money! Have it around so I know where it is. Not where, where they er, take it and give me so much a week for er, pocket money.* [Leslie, aged 76-80]

> *I don't want other people telling me what I've got to do and not do. I'm a very independent person and I want to keep me independence...Because everyone's telling you what you can do and what you eat and what you don't do and when you go to bed, and all the rest of it, I couldn't stand that.* [Lisa, aged 80-84]

It can be seen that entering residential care symbolised captivity, passivity and loss of autonomy and freedom. Interestingly, many older people did not consider the option of exploring receiving care and support in their own home to meet any changed level of need. Almost all older people perceived their entering residential care as inevitable and perceived it as something to be dreaded:

> *I'm thinking about selling up and going into somewhere where they look after you. But I don't know what that's like… somewhere where they cook as well, you know, get the meals and look after. Course, that's the next move. It's all I can think about, anyway. I, I don't like it.* [Luke, aged 90-94]

Yet it was evident that older people wanted to stay at home for as long as practicable. Remaining in their own home was important for all older people, because it symbolised independence and control over their own environment (Section 3.2).

Many older people who had unmet need at home found solutions to challenging situations as discussed in the sub-theme below.

8.4.2 Sub-theme 2: Finding solutions in challenging situations

This sub-theme explores how older people approached negotiating support in situations where there was no-one available to provide help. Two broad areas where older people reported needing support was help with IADLs and opportunities to socialise.

As most older people spent a vast proportion of their time alone in their home environment, they were frequently reminded of IADLs which were outstanding. In

particular, tasks requiring physical exertion, such as gardening, shopping for heavier items, ironing, changing the bed and emptying the washing machine, which presented an ever-constant source of frustration. Both Petra and Luke, with low support needs, were worried about how to negotiate support to maintain their garden:

> *Well, for the first thing, um, to mow the grass out there. Then some of the trees, bushes and trees round there wants trimming out. So, [pause] yeah. It's getting a bit too long.* [Luke, aged 90-94]

> *And the hedge, I've got a great, big hedge…it's lovely, but it does need doing* [laughing]. *I wish it would go away, sometimes!* [Petra, aged 80-84]

What is interesting about these two extracts is the wording that Luke and Petra use to indicate that they needed support with gardening. Both Petra and Luke had low support needs, but were becoming increasingly unable to manage heavier tasks, particularly in the garden. Interestingly, both participants described the task in the passive tense as something that 'wants' or 'needs' doing, which suggests it is important for Petra and Luke not to be seen to ask for support and they distanced themselves from appearing dependent. In the interviews, it became evident that Petra and Luke had hinted for support from their family (as family had helped them with gardening in the past), but no help had been forthcoming. Therefore, both negotiated help privately, and both had had a negative experience (a substandard service or being overcharged). In addition, they received criticism from their family about the solution they found, which made them feel less confident about engaging a private firm again. Both Petra and Luke felt desperate because they did not want to ask their family for help, and did not know of anyone else who could perform the task or recommend someone.

Most older people reported adapting their everyday lives with a view to meeting their support needs:

> *And er, you, you find that you can adapt to doing things which you probably wouldn't have thought about.* [Keith, aged 90-94]

> *Yeah, when you get to my age, mate, you've just got to take anything life throws at you and throw it right back again, I think.* [Una, aged 80-84]

When Hamish realised after his carers had left that they had forgotten to give him his medication one morning, he needed to find a solution, as he knew his health condition would get worse if he missed his dose:

> *So I was wondering what to do…and I was looking out of the window and saw one of my neighbours passing and I knocked on the glass and said "Please will you pop these tablets for me?". So the chap popped them out for me* [Hamish, aged 65-69]

In particular, older male participants with higher (medium and high) support needs gave examples of innovative and sometimes risky solutions in order to meet their needs. Keith, who had limited mobility explained:

> *If I drop something, for example, and it goes underneath the table, I've got a shoe horn over there, which I get and I hack it out underneath and pick it up…if it's…small things…if I dropped a tablet on the floor, I'd have a job…But what I would probably do is wet my finger…the tablet sticks to me finger for a brief second while I lifted it up to me mouth* [Keith, aged 90-94]

> *I leave my stick behind sometimes and I, I go round the house trying to hang on to furniture, rather than use my stick and things like that. Which is silly, but there it is. You do tend to do it.* [Keith, aged 90-94]

For Keith, continuing to carry out ADLs and IADLs was of particular importance because he believed the Council would place him in a care home against his will if he could not:

> [Toileting] *I had to get out of bed, and what I did was, I normally used to make, try and get to the bathroom? But er, but it was usually [pause] a near miss, when I did get there, and er, I finally got a pail, which is like a plastic bucket, er, [pause] and I was trying to use that. Er, which* [pause] *under the circumstances, I had to balance myself ag, against a…support they'd put in, to get in and out of bed. I had to balance my backside against the, that, and hold the pail er, at the same time, sort of thing, you know.* [Keith, aged 90-94]

Several older people reported that family members very often gave an impression of being occupied with work, family or other commitments, which meant that older people tended to feel unable to approach them for support:

> *Because [my son] starts work at, what, seven o'clock in the morning, sometimes. And he doesn't finish til seven at night. [pause] But…that's why I wouldn't ask him.* [Keith, aged 90-94]

> [My family's] *got their lives to lead, they got their jobs to do. They don't want to mess around with me, do they? When they got all that, to do.* [Keith, aged 90-94]

> *But* [my daughter's] *always too busy and she doesn't come over very often. And she'll, she'll talk to me on the telephone, but she's got two young children, so I, I leave her to get on with it.* [Barry, aged 80-84]

As a result, there was a perception that support members often considered their own commitments to take precedence and were too busy to help:

> *My daughter, er, she, she works, and er, by the time the weekend comes, she's got all her housework to do that hasn't been done during the week. And that sort of thing. So she's always, sort of busy, hasn't got the time, I give up in the end.* [Luke, aged 90-94]

> *They're all, everyone is busy. Occasionally, they'll come here, do you know what I mean? But not as much as I'd like them…you can't demand to anybody to kind of come, can you?* [Petra, aged 80-84]

Older people interpreted 'busyness' as meaning that informal members were disinterested in them and did not want to make time to visit them or provide support with IADLs.

> *Always, er, er, as a young man, I always chose, er, er, I helped people out, but, er, then they don't want to help you, they've always got to find an excuse why they can't do it.* [pause] *No. They're busy, or something like that.* [Leslie, aged 76-80]

In addition, older people did not feel justified in asking for support with IADLs from informal support members because they knew they also needed to do the same kinds of tasks:

> *They're always moaning that they don't have enough time to do their own jobs, so. I just let them get on with it. You know. If you can't do it, you can't do it for me either. So yeah.* [Luke, aged 90-94]

Therefore, some older people tended to remain silent about their support needs. Consequently, many older people interpreted their support needs as having a lower priority than the needs of younger family members. In particular, both Barry and Hamish appeared to endorse the view that younger people's needs should take precedence over their own:

> [My son has] *got a career and a life to live. Whereas I'm getting near the end of mine, you know.* [Barry, aged 80-84]

> *I said [to (ex)girlfriend] "Look, you're wasting, you're wasting your life. You're much younger than me and I think it's, it's, um, it's a good thing for you to, I feel like you're in, er, in this virtual cage of my, my stroke condition and it's a cage where you're a bird that can fly and I'm keeping you in a cage with my things so, you know, I think it's better that you find your way and enjoy your life* [Older male, aged 65-69]

The above extracts demonstrate that some older people with higher support needs were concerned about being perceived as a burden by informal support members. Both Barry and Hamish appear to have internalised an ageist view that their needs were somehow less important than other's needs. A further barrier for Keith was the prevalence of ageist attitudes in the outside world, particularly in shops, which compounded his unwillingness to seek support from others:

> *Like I said, I won't ask if I, if I, unless I've really got to. I've got to be really [pause] desperate for [pause]. But [pause] I feel they compromise you by talking in a ridiculous, I mean, they're obviously changing their voice just to [pause] because you're an old person. They think that they've got to talk to you in that manner.* [Keith, aged 90-94]

Another area of unmet need identified was a lack of opportunities to socialise with others when older people wanted to. Evenings and weekends were times when many older people wanted to socialise, but there were few opportunities available:

> *I like company…I , I don't like being on me own [pause] and that. Yeah, and as I say, it's the weekends I hate.* [Leslie, aged 75-79]

> *Well, it'd be nice to have company in the evenings but…it's something that, you can't, you've got to learn to adapt to life as well, haven't you?* [Lisa, aged 80-84]

> *Well, all I'd like is if* [my family] *were to come up a bit more. That's all. The rest of it's all right. But the way I look at it, is there's not anything else I can do, so I've got to put up with it. So, that's the way I think about it.* [Luke, aged 90-94]

A few older people expressed disappointment that there was no-one to provide them with general emotional support, to 'run something past' and seek reassurance about concerns:

> *It'd just be, just nice to know that there's somebody there if you want some advice or if you urgently need something that they'll back you up.* [Barry, aged 80-84]

> *Yeah. Like I said, if people…could ring me up more or come to visit me, I er, I, er, I love it.* [Leslie, aged 76-80]

In particular, older people missed having someone in their life who took a genuine interest in hearing their news. Leslie recounted a recent telephone conversation with his sister when he announced he had his fall:

> *I, I told me sister that I, er, she knows I had a fall, but, er, er, I tell her when I ring her "Oh, I had a fall last week". "Oh, did you?". And she ain't very well herself. And that.* [Leslie, aged 76-80]

Leslie felt hurt that his sister had not taken more of an interest in his health, but justified her lack of concern with the knowledge that she was also experiencing poor health. Being visited by volunteers was not perceived by older people as an ideal solution to a lack of opportunity to socialise with others. Only Keith reported a fulfilling interaction with his Befriending volunteer. Most older people expressed disappointment about the nature of the volunteer relationship. Many had built up a meaningful interaction with volunteers, only for them to leave unexpectedly and without explanation. Petra explained:

> *It was very puzzling, really [laughing]. But, there was probably a reason. And, I wish I knew…Because, ah, I thought he might finish properly and say "Well, I'm coming next week, and next week is my last time". Like they all do. But, he didn't. He, just, vanished.* [Petra, aged 80-84]

For Petra, she felt that she had built up a meaningful relationship with her volunteer and was devastated when he left. In the absence of any other explanation, Petra blamed herself for his departure:

> *You know, because I…know [name of volunteer] so well, you see, well this is it, maybe he got really fed up with me.* [Petra, aged 80-84]

Leslie considered being visited by a volunteer to be a waste of time, because the timescale was too short for him to develop a meaningful interaction:

> *Well, er, er, it's all right them coming. But they only come for an hour, and that's it. Gone. It's no, it's no good to me. No good to me at all. You know.* [Leslie, aged 76-80]

The above extracts indicate that older people want to develop a meaningful connection with others, rather than a temporary interaction with an individual who visits occasionally and who may leave at any time. Negotiating socialising at weekends was also challenging for Hamish. During the weekends, he received support with ADLs and IADLs from a care company three times a day, which was arranged for him by the local Council, rather than from a PA. However, this arrangement proved restrictive for Hamish because if he was invited to spontaneous family gatherings, he would need to cancel his care visits. Hamish was warned by the Council that he was at risk of his care arrangements being terminated:

> *I was going on this visit down to see my daughters. And, er, [the care company] reported it as, that I was cancelling too many calls. And um, um, I was warned by…a supervisor or something that said to me "If we cancel too many calls, social services will take it away from you". So it was like a, like a threat on er, on my part.* [Hamish, aged 65-69]

8.4.3 Subtheme 3: Negotiating contingency support

This sub-theme examines how older people in receipt of a personal budget renegotiated support when it became necessary. This theme was identified in Hamish's case-study. Hamish already had support arranged via a PB at the time of the first interview: he employed two PAs to attend him during weekdays. At the weekend, the Council arranged for carers from a care company to visit him three times a day to carry out ADLs and IADLs.

When Hamish was interviewed six months later, he explained that both his PAs had very recently left his employ suddenly (one because of suspected theft and the other because she was unwilling to negotiate changes to her working times):

> *Oh, I haven't got any carers now, Bev walked out on me…I'm at my, at my wits end trying to decide what do I do. Do I go to the, the Care Quality Commission and report her? Or what do I do? You know what I mean. She's done me wrong, you know, she's, she's left me pretty vulnerable and you know, it's a serious crime, in care terms, you know.* [Hamish, aged 65-69]

Hamish had been given no contingency provision in his PB, had no care support worker allocated to his case and had been given no advice by the Council about what to do in such situations. In addition, Hamish's PB had not been reviewed since it was set up almost three years' previously, which should have been reviewed every six months:

> *When you've not had an assessment of any kind since you got your first one in place, and you've not had a care, a care support worker allocated to you, then you really are in a dire situation.* [Hamish, aged 65-69]

Hamish explained that he had received no on-going assistance from Social Services once the PB was in place. Each time he made contact with the Council to ask them what he should do, he was unable to speak to someone who could help him:

> *I picked the phone and I, I called the old social support worker that I used, was appointed in the first three years…and she said "Look, I don't deal with you any more so I'm not going to deal with you". And I phoned again "Oh, this lady's…working from home today, so I can take the message and what have you"…"I'll…put you forward to the review team". But it's lost in the ether, really* [Hamish, aged 65-69]

Hamish made direct contact with the care company which the Council used and with which he was familiar, and arranged for them to provide him with support cover with ADLs and IADLs during the weekdays, which was more expensive than paying his PAs. He then received a call from a Care Manager at social services, who told him that he had acted inappropriately and that he would need to arrange cover with a different care agency and bear any additional cost himself:

I requested the…five days morning call, just to make sure that…I'm out…of bed and…I'm dressed and everything. And I've had a shower. And um [pause] I was told I made a mistake and er, um, it was wrong for me to make my own er, request for straight from the, the care agency…and she gave me other care agencies that were a lot cheaper than the care agency that I am with...But then, you know, I was expecting rather than she or somebody at the social support workers was supposed to [pause] really handle the, the authorisation and the, the er, [pause] engaging of the care agency, I was going to have to do it on my own. You know what I mean? Which I thought was a little bit harsh…I have to pay a care agency as an additional cost, because the care agency is more expensive than what I normally pay the, the personal care assistant. So, the added cost needs to be…catered for in some sort of way. And this is what I was trying to explain to the Council. But they didn't seem to catch [pause] the gist of what was the implication of it. [Hamish, aged 65-69]

Hamish felt unsupported and desperate because there was no plan built into his PB to address emergency situations. In addition, social services did not offer him any support in making alternative arrangements:

You know, just the carers are not there anymore and they're for their own reasons, have left. You're caught in this no man's land…you put in a request, you know, and you're assuming that social services will come back and try and make some effort in trying to sort your problems…And then, [pause] it's all about the care, and the cover and the additional cost, and there's not a contingency plan in place, so, or arrangement in place by social services to…cater for these out of the ordinary circumstances. [Hamish, aged 65-69]

Hamish positioned himself as being self-sufficient, but admitted that he found the situation challenging to negotiate, but thought that people who were less capable would find it impossible to do so:

And I think, well, my case is, I can understand things and I'm still able in all, in a way, but when complications become a difficult thing for some other users, you would think that they really are in a big, big mess. And they going to have a lot of difficulty being able to solicit…not only funds, but services from the social services [Hamish, aged 65-69]

In summary, Hamish's situation highlighted a major gap in coverage in PB coverage, which could have far-reaching consequences for older people who were potentially unsupported:

> *There's a big gap in, in emergency support and if there was a call like, if it was like the fire brigade, or, er, the ambulance services, where they come and do something for you. But it's not, it's not a…do or die thing…but it's just that* [pause] *gap for just* [pause] *you need help for things, that if you don't eat, or you don't take your tablets…you are going to suffer in the not-so-distant future…*[Hamish, aged 65-69]

The next section focuses on how older people negotiate self-sufficiency, in terms of recognising their limits in performing ADLs and IADLs by themselves, or presenting an image to others of being self-sufficient.

8.5 Overarching theme 4: Negotiating self-sufficiency

This overarching theme explores how older people negotiate self-sufficiency, which will be discussed in relation to two sub-themes: Knowing One's Limits and Disguising Unmet Need.

8.5.1 Sub-theme 1: Knowing One's Limits

Almost all older people mentioned that they would only seek help from others if there were no other choice open to them. Luke was adamant he would attempt to carry out a task first rather than ask someone to help him:

> *But, er, I never ask them to come and do it. It's only if I'm forced to do it, will I ask.* [Luke, aged 90-94]

Some older people attributed their reluctance to negotiate support to their earlier life course experiences:

> *"Don't let anybody know, think that you, we've bred a gibber* [a coward]". *That's what* [father] *said. I've always remembered that. Whether or not that was the, the thing that's made me so, er, er, determined, or stubborn, or whatever the right word is, I don't know.* [Keith, aged 90-94]

Keith, in particular, had a strong sense of pride and desire to live independently, which he attributed to his father's worldly advice: it was more important to him to keep silent about his needs, than appear dependent.

For some older people, negotiating support from others was not always sought or a possibility. Similarly to Barken (2017), carrying out ADLs and IADLs without negotiating support from others was perceived as a positive achievement, mainly because it reinforced feelings of not being dependent on anyone else. There were no discernible patterns in negotiating tactics according to older people's need. Almost universally, older people reported wanting to carry out ADLs and IADLs, while recognising there were limits to what they could do. Most older people knew when it was appropriate for them to negotiate support from others:

> *Oh, I like, I like to be independent. And I also like [pause] like to have some relatives and no person's an island on their own, like I couldn't be totally independent any more.* [Barry, aged 80-84]

> *Well, that's what it is, that's why I've never bothered. I can, if I can do it meself, I just as well do it meself. It's only when it comes to doing something I can't do, that I will want somebody to help.* [Keith, aged 90-94]

Examples of tasks with which many older people negotiated support were help with household shopping, particularly bulky items:

> *I mainly ask her to bring me things like tinned soup, tinned beans, and all that sort of stuff. Which is heavy, and I can't bring from the car, with two sticks… if I run out of milk, and I have to get a couple of pints, in [name of supermarket]…but two pints of milk, or even one pint of milk, in a bag, that is hanging down by the side of a stick, is, is heavy.* [Keith, aged 90-94]

Cooking was another task which older people would negotiate help with from formal support members:

> *She brings my meal, because I'm frightened I can't get things in and out of the oven properly. I'm frightened of burning myself. Same as I'm frightened of making a cup of tea for myself.* [Lisa, aged 80-84]

Therefore in each of these cases, older people recognised their limitations and negotiated support with tasks where they feared for their personal safety, in particular, in order to avoid serious injury caused by falling or burning. The extracts suggest that independence for older people did not mean a complete absence of support for others, but a recognition that for them to live independently, that there was an element of interdependency on others.

Some older people also recognised that their support members were best placed to identify their limitations and suggest or provide additional help which was needed. Hamish mentioned that his eldest daughter negotiated his support needs because she wanted to make sure that he was properly looked after before she emigrated:

> *She was aware of it all the time, so she would send me stuff, even if, or what have you…But before she went* [abroad], *she decided "Oh, let me put my, er, or in a sense, let me put my Dad in good, in a good way".* [Hamish, aged 65-69]

When first interviewed, Lisa and Hamish (with high support needs) received support paid via a PB. Both reported feeling in control of their support arrangements because they were paying someone to carry out support tasks. Lisa's adverse experience in the past of receiving a care package symbolised dependency for her because she had no control over which carers would come to visit her and when:

> *I didn't like it because…they started coming at seven. And I said "There's no way that I want to be made ready for bed at seven o'clock. I want to be able to go out in my garden if I want to"…And that was why I was glad enough to get my own, because then I could tell them what time I wanted them to come and, you know, like that. And of course, when you're paying them yourself, they're more, um, able, they feel more that you've got to do what you tell them more, you know. Whereas the others are answerable to their, their company, aren't they?* [Lisa, aged 80-84]

For Hamish, describing himself as a 'stroke survivor' rather than a 'stroke victim' symbolised his perception of being self-sufficient. Interestingly, Hamish reported receiving support with ADLs and IADLs from a girlfriend in his past, but now paid for the same types of support via his PB. Hamish made an insightful observation about the difference between receiving informal support and formal support:

> *And um, you know, if you get somebody that's paid for, you know, in the way like with social services, or even, or you're contributing to the, to the payment of them, you feel it's a service that you're getting, and it's a, it's a, it's a good arrangement to be in, you know. You're paying for a service and it has to be done, you know, you're not begging for it, or anything like that.* [Hamish, aged 65-69]

For Hamish, "begging" for help symbolised dependence, but further, indicated a level of uncertainty about whether his girlfriend's support might withdrawn, as her motive for doing so appeared to be based on altruism. Thus Lisa and Hamish's role as 'employer' gave them a level of control over their support arrangements which had been absent when they received similar support from a care company or partner, as there had been no certainty of when (in Lisa's case) or if (in Hamish's case) support would be provided.

One explanation might be the 'expectation' of support is acceptable when it arises from negotiation of formal paid support because it is provides a level security and control. By implication, 'expecting' informal support in the role of a 'boyfriend' symbolised being a burden and feeling that his (ex)girlfriend was obliged to provide him with support.

However, support negotiation on behalf of an older person was not always welcomed, particularly support negotiated by health professionals. One older male recounted an episode while he was at hospital, where he was given an ultimatum of being allowed home if he received daily visits from a care company, which he reluctantly accepted:

> *"But we insist that if you go home, we've got to make arrangements with [name of care agency] whatever they call them". So I said "Well, if it's a must, all right, that, you know".* [Keith, aged 90-94]

It can be seen from these findings that older people appear more accepting of support arranged for them by people who know them best, rather than imposed on them by people separated by professional distance.

There were some limits on the types of support which older people would be prepared to negotiate. Whilst all older people were prepared to negotiate support with practical tasks, accepting financial assistance from others in their family support network was considered to be unacceptable:

> *I'd never ask my children for money. No. It's not right. Their money, their money's got to see them through. They, I mean, you shouldn't have to ask your boys for help like that. Not in my opinion.* [Lisa, aged 80-84]

A determined attitude was demonstrated by several older people with moderate to severe mobility issues to maintain control over their everyday lives. Keith, with high level needs refused to allow carers to come into his home to help him with activities of daily living because he was intensely determined to improve his ability to walk by increasing his exercise levels:

> *Oh, yes, I'm still fighting it. I leave my stick behind sometimes and I, I go round the house trying to hang on to furniture, rather than use my stick and things like that. Which is silly, but there it is. You do tend to do it.* [Keith, aged 90-94]

In this case, Keith symbolises his daily struggle to improve his mobility as something to battle with on an everyday basis.

Another example was an older male who positioned himself as being determined to retain his independence for a long as possible:

> *Well* [pause], *for me, I, I just er, the way I look at it is that I [pause] the more something is thrown at me like that, then the more wah, determined I am to really look after myself. You know, just make sure that like I can try and find some way of popping my tablets, or making a cup of tea, or something like that. So, hence, all the things that I've got are sort of a gadgety, you know, so I can open a, a, I've got a, I've got a* [pause] *I've got um, a jar opener, I've got a tin opener, and they're all electric and everything.* [Hamish, aged 65-69]

Several older people decided to recruit their own carers rather than involve others in the decision and reasons ranged from maintaining a sense of self:

> *No, I wanted to pick them out myself…Because I am an independent bitch.* [laughing] [Older female, aged 80-84]

Another reason for wanting to recruit participants was in response to frustration with the recruitment service offered by social services:

> *So quite honestly, I mean, that's when I decided "Ok, I'm even going to interview the staff" er, er, interview persons prospective carers would be in my own responsibility and just go ahead and, and I was, was mindful of the fact that you, the way you advertise yourself as, do you put this, do you put stroke victim? Or do you put stroke survivor, you know [laughing]. So I put stroke survivor, you know* [Hamish, aged 65-69]

A few older people expressed reluctance at some aspects of being self-sufficient, suggesting that they would prefer to share the responsibility with particular tasks. In particular, one older male indicated he was not comfortable dealing with his finances, as his late wife used to manage their shared bank account:

> *Yeah. Well, there's no-one else here to do it for me. So I've got to.* [pause] *I got to keep, keep a tab on it all, the, er, er, the money, where it goes and what's what.* [pause] [Leslie, aged 75-79]

Most older people who paid support members to provide assistance with ADLs felt more in control of meeting their support needs and expressed a preference to receiving paid care over receiving support from informal support members:

> *Like it is now, it's different, people are actually paid to look after me and, er, it's, um, it's a good situation because you expect something and there are actually, terms and conditions to, er, under which they are employed and they fulfil, specific duties, you know, rather than relying on a kindness of somebody.* [Hamish, aged 65-69]

Interestingly, most older people felt able to ask paid support members for help with tasks which were beyond the remit of their contractual arrangement :

> *I'd just say to her "Oh, I need so and so, is there any chance of you doing it?". Because we're very close, now...I don't mind asking that. Especially as I'm paying, you know.* [Lisa, aged 80-84]

Older people tended to feel that the financial relationship with a paid support member made a difference to and gave them the ability to ask for extra support with tasks which they were unable to fulfil themselves. The quality of the relationship also mattered in

terms of whether an older person felt comfortable enough to ask a paid support member to provide extra support.

8.5.2 Sub-theme 2: Disguising Unmet Need

One important sub-theme identified in the interviews with older people was wanting to present a facade of being able to cope with their lives to others. Most older people with children did not want to be perceived as needing help, particularly with IADLs, so they did not make their support needs known:

> *I don't want them forever lasting calling me up and saying to me "How are you doing, Dad? Are you all right, Dad? Do you want anything, Dad?". And I don't want that. I don't want that. So if I don't ask, in the first place, they think I'm all right.* [Keith, aged 90-94]

Keith's extract suggests that he would rather pretend to others that he was coping with life rather than openly admitting that he needed help, which for him, would mean he was conveying an impression of dependency. For Keith in particular, he internalised the advice that his father gave to him when he was a young man about not showing fear or uncertainty, which could be reinforced by the policy messages aimed at promoting living independently as being the goal which older people should aim for (Section 3.2).

Some older people would also conceal health conditions so that their children would not worry about them. Petra developed agoraphobia after falling outside a few months before and was fearful every time she left her house in case she fell again. She did not want to tell her children because she considered it was showing weakness, which came into conflict with her role as a mother:

> [My daughter] *will come and tell me, you know, how she's feeling and this and that and the other thing. But I won't say anything about myself.* [pause] *Because I feel if I do, that upsets her. She'll be worse. And, er, I feel, er, I'm her mother, so I should take it all.* [pause] *Maybe I've taken too much on the chin.* [Petra, aged 80-84]

Una's role as a mother to Sid was also important to her and meant that she, too, was reticent about asking him for help:

> *I just don't like asking people to do things, or you know, take me anywhere, or do anything for me, if I can help it. I mean, my idea is um, [pause] I mean, he's my son, so really, I'm here to look after him, in a way, you know, I should be looking after him, not him, you know, ringing him up and doing this, that and the other.* [Una, aged 80-84]

Petra also hid her disappointment when her sons were unable to visit her because they made other plans:

> *Because I can be bubbly, I can forget everything, when I meet people. I can be out the front joking and no-one would ever think, you know. Because that's how I want it to be, I suppose. And that's just me…I just think about the summer and I think "Well" [pause] you know, the boys are going away on holiday, they have to go on holiday. You know, I think they felt a little bit, when my, Nicholas said it to me. But I said "You have to go on holiday". [pause] I said "Don't feel [pause]". I said "It's only for ten days". [laughing] Well, it will be two weeks, by the time I see them again.* [Petra, aged 80-84]

Petra's priority had always been putting her children's needs above her own needs. However, she admitted that not only was she finding it challenging to cope with tasks in and around the home, but also keeping up with her sons when they took her out for the day. Petra faced a dilemma as her own needs were in direct conflict with her need to protect her children:

> *I don't want to upset them. [pause] Because they have to go out to work every day. And if they're thinking "Oh, there's Mum down there and she's not very happy". And I think they do like to think I am happy. Because I've always been that kind of a person. But they have to realise, now, that I'm older now. And I'm not doing the things like I used to do. Going into town and spending all day in there, and going off. But, how do I come around that, without upsetting them?* [Petra, aged 80-84]

In addition to conveying independence to others, in the sense of not outwardly seeking or asking for help, some participants believed that their role as a parent came into conflict with asking their children for help. Una and Petra in particular, felt that their role as mother meant that they should continue to care for their adult children. By admitting that they needed help undermined their sense of sense and what 'independence' symbolised

for them. Thus, providing an illusion to family members of being self-sufficient was a symbol for some older people that they were coping with everyday life, which also helped them to feel more positive about themselves.

Older people also presented an illusion to formal support members, as exemplified by Keith. Keith was only released home from hospital on the proviso that he would be visited by carers each day to help him to get up in the morning and go to bed at night. Keith awoke early each day and made sure that he was already washed and dressed when the carer visited him in the morning, and he refused to get ready for bed in the early evening when the carer arrived:

> *Two days, they came night and morning. The third day…the woman came and said to me [pause] "We're signing you off…you didn't want us to do anything for you". I said "Why do I want you to do it? I didn't", I said "I told them in the hospital" [pause] I said "That they insisted that they engaged you…I'm not a, I don't want people to wait on me", I said. If I can do it, if I'm home, I'm happy to do it myself. If I can't do anything, I will ask, you know.* [Keith, aged 90-94]

For Keith, presenting an illusion of independence in this case stemmed from a different motivation than Petra and Una. Keith was aware that his failing health meant that he was finding it increasingly challenging to perform ADLs and IADLs, and he admitted that he was terrified that 'the authorities' would force him to go into a care home. In his flat, Keith had made many home-made adaptations to his flat and had calculated different ways in which he could perform ADLs and IADLs in order to avoid being seen as not coping at home. Thus, older people tended to be self-sufficient where possible, and recognised their limitations with tasks that they were unable to fulfil. Where possible, they negotiated support with tasks from others, but for some older people, it was more important to present an illusion of coping so that they were not perceived as being dependent, or so that they did not cause distress to their family.

8.6 Chapter Summary

Four overarching themes were identified from older people's accounts of how they approached the negotiating support from others. The themes centred on Negotiation Tactics, Facilitating Negotiation, Negotiating Change and Negotiating Self-sufficiency.

Negotiation tactics adopted by older people were discussed under three sub-themes: Direct Tactics, Indirect Tactics and Building a Rapport. The findings indicated that most older people felt able to negotiate directly for support with personal care tasks with paid support members, such as carers, PAs and cleaners.

Positive aspects of negotiation tended to centre on how successful an older person was in fulfilling a support task without involving others, or accepting minimal help from others. Negative aspects of negotiation highlighted through were related to older people's accounts of their feelings about the extent to which they were able to negotiate support from others.

These four overarching themes encapsulate a range and diversity of negotiation scenarios and illuminate circumstances where older people might be prepared to approach others directly, or indirectly, or not at all. The following Chapter 9 focuses on the other side of the negotiation interaction: how support members perceive the negotiation tactics which older people use to arrange support. The results of these two chapters are discussed together in Chapter 10, where similarities and differences to existing literature are critically examined.

Chapter 9 Support members' perspectives of older people's support negotiations

9.1 Chapter Overview

This chapter focuses on the results from Stage Two, Phase Two of the field research: exploring support members' perspectives of how older people approach support negotiations. Again, data were analysed using thematic analysis (Braun and Clarke 2006; 2013). In particular, perspectives of how support was arranged have been examined to identify common ideas present in the data (Braun and Clarke 2013). In addition, support members' perceptions of negotiation strategies adopted by older people when arranging for support with everyday tasks were explored, together with negotiation tactics employed by support members themselves. The meanings of negotiation for participants were explored using symbolic interactionism (Charon 1995).

Four overarching themes were found through examining and analysing the perspectives of support members on how older people negotiate support: 'Older People's Negotiation Tactics', 'Facilitating Negotiation with Older People', 'Negative Experiences of Negotiation' and 'Motives to Negotiating Support'. Both positive and negative perceptions of support negotiations were pervasive throughout the majority of interviews with support members, and different negotiation strategies used by support members were identified through interpreting their accounts of interactions and negotiation experiences. Motives for older people negotiating support became evident through exploring support members' narratives when they described their feelings about providing support and the meaning it held for them.

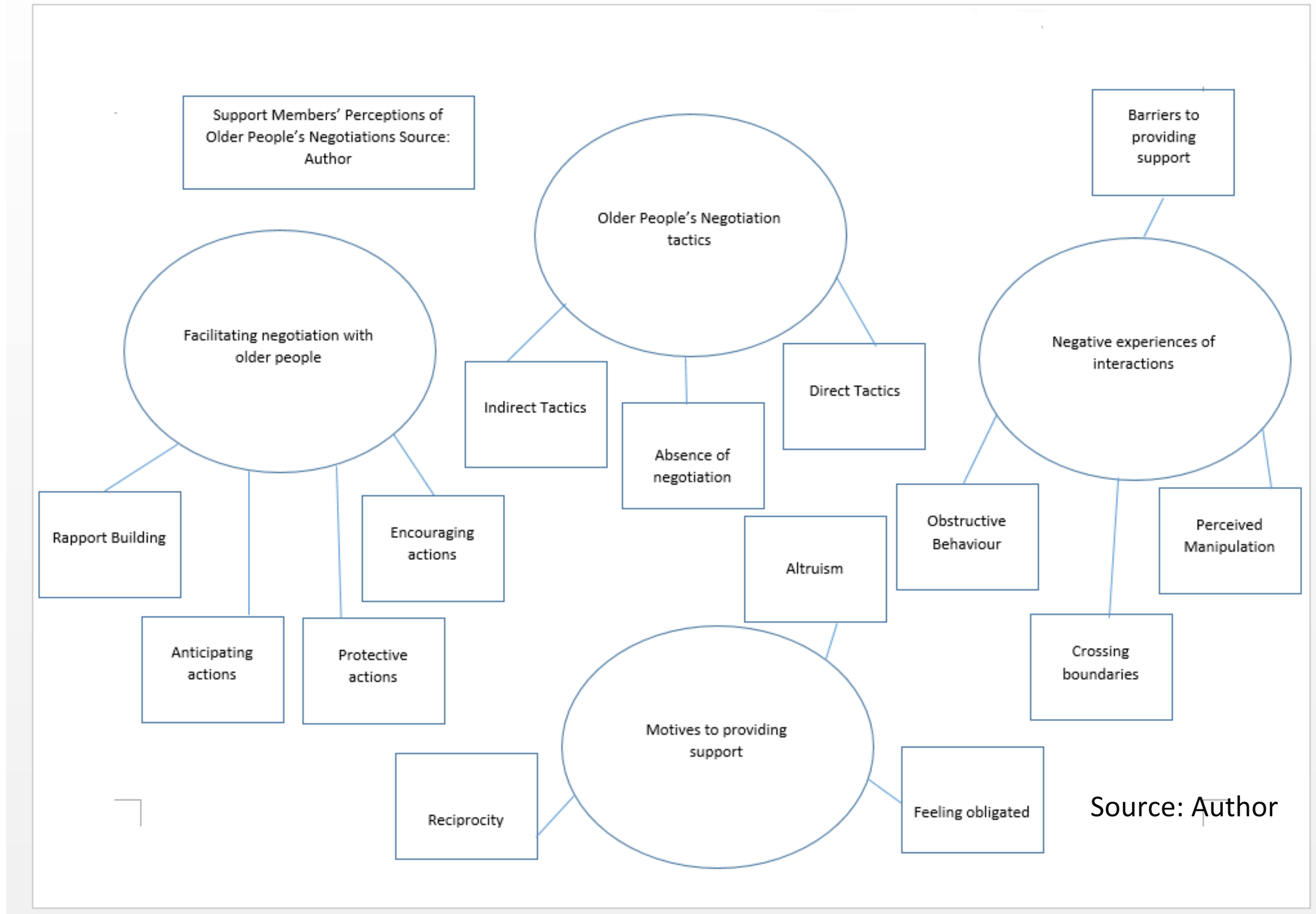


Figure 8: Support Members' Perceptions of Older People's Negotiations.

9.2 Overarching Theme 1: Older People's Negotiation Tactics

The first key theme explores support members' perceptions of negotiation tactics which older people adopted when entering into negotiations with them to provide support. The tactics identified are discussed under three sub-themes: 'Indirect Tactics', 'Direct Tactics' and 'Absence of Negotiation'.

9.2.1 Sub-theme 1: Indirect Tactics

Many informal support members identified that older people chose to ask them indirectly about tasks which needed doing without asking outright for support. Informal support members explained that they often needed to work out the hidden meaning of what older people were saying. Luke's son-in-law explained:

> [Mimicking Luke] *"Oh well, my, my grass is getting tall", or "My trees are overhanging" "Oh, I need to get them cut down. I'm going to have to pay someone to get those done". So it's like, click, click, click. Oh, so he wants us to come over and help you, "Well, if you can". Yeah, great, you know. So, and, er, that's what's happened in the past, isn't it? He, he doesn't say directly, he says it in a roundabout way.* [Son-in-law, aged 50-54]

Linking this to Luke's extract in Section 8.2.2, Luke had explained that he had had to resort to making his own arrangements to cut down the trees, because no-one in his family had offered to assist him. Although his son-in-law recognised that Luke hinted about tasks, he did not like Luke using this tactic to draw attention to tasks which needed to be done and was resistant to reacting positively to them.

It became evident from support members' narratives that older people often used an indirect approach when support was needed with tasks they felt unable to do themselves and when they were uncertain about whether the person they asked would be prepared to provide support with it. The use of the dysphemism 'moan' was prevalent in support members' descriptions of interactions with older people who did not ask for support directly. The negative connotation associated with the word 'moan' belied how some support members felt about the older person and their request. It appeared that support members who felt less affection towards the older person tended to perceive hints as

complaints rather than requests for help. Luke's daughter Lacey (who had a difficult relationship with Luke) explained:

> *He'll never ask you for help. He'll just moan that it's not getting done and he can't do it anymore. But he'll never say "Will you help me?". He'll just moan that he can't do it. So you say "We'll do it". Or "We can help"…I would prefer it if he asked, really.* [Lacey, aged 50-54]

When probed further, Lacey believed that the reason Luke did not ask directly was because it symbolised dependency. For Lacey, she would prefer to be asked directly, because she felt awkward about not being able to discuss the issue openly:

> *I think he feels he's being a burden if he has to ask. I don't* [pause], *that's the only thing I can think why he wouldn't ask you directly… I just wish he would. But he, yeah. That's all I can think, he doesn't* [pause] *want to burden you. But he'll make you feel guilty about it.* [Lacey, aged 50-54]

Lacey rationalised that Luke did not want to appear to be reliant on her for help. By making his request indirectly, Luke was rationalising to himself that he was not explicitly making a request, which therefore protected his own view of himself as being independent within his own definition of what 'being independent' meant.

'Moaning' was also ascribed to a situation where an older person might tell another support member about a task which they had wanted someone to do, but which remained outstanding. The rationale behind this 'hinting' tactic was to prompt the support member to intervene on the older person's behalf. In the following extract, Sharon, Petra's daughter explained that Petra was unhappy because she had wanted to ask her son, Charlie, to change the bed linen at the end of his visit, but she had not felt able to ask him. Sharon was equally frustrated with Petra for not asking for support directly, and frustrated with her brother for not offering to help:

> *And I don't know how many hours it takes, either. It must take her hours. Because of her shoulder, her arms, her hands, everything. But she moans about it, that they should be doing it. But what I say to her is "They're* <u>*men*</u>*. They can't do it, unless you tell them to do it. And you need to be quite specific about it"*. [Sharon, aged 50-54]

For Sharon, framing her mother's (Petra's) hinting behaviour as 'moaning' symbolised her lack of patience with Petra, as she felt that Petra ought to adopt a direct approach with her brothers and to instruct them to change the bedlinen. Sharon blamed Petra for her brothers' shortcomings. Sharon was the only daughter of Petra's four children. When Sharon was a child, Petra would ask Sharon to help her with household tasks, but not her brothers, which Sharon always felt was unfair. Sharon's strong reaction to her brothers' lack of help in the house could be attributable to a longstanding resentment of her brothers, as she was brought up in a gendered household, where her father was the breadwinner and her mother stayed at home to look after the house and to raise her children. As children, she and her brothers were brought up to adopt similar values, which Sharon resisted whenever she could. Therefore, Sharon interpreted the meaning of her brothers' failure to act to a lack of awareness or anticipation of their mother's needs as a gender issue' which was deeply entrenched within their specific family unit over the life course, rather than to a general unwillingness to provide support to Petra. Petra herself endorsed this gendered view of household tasks, as she did not think it would be appropriate to ask her sons to help her with washing the net curtains, but suggested a different barrier to asking her daughter Sharon, based on Sharon's long-term health condition (Section 8.2.1). Sharon advocated the importance of adopting a direct approach with males generally when negotiating support, rather than taking a subtle approach.

A hinting strategy was usually successful when the task being hinted at was framed by informal support members as a legitimate need. In the extract below, Lisa's son Matthew expressed irritation when he realised his mother, Lisa, was expecting him to make her a hot drink when he visited her:

> *She'll say "Are you coming up?". "Yeah, I'll come up and see you, Mum". You go up there, get in there, and the first thing is, uh, "Are, are you going to have a cup of tea?". Because of course she wants you to go and make her a cup of tea. So, if she can be lazy, she will.* [Matthew, aged 55-59]

The above extract shows that Lisa's son, Matthew, symbolised his mother's reticence about making him a cup of tea as being 'lazy', but Lisa herself reported that she was worried about making a cup of tea because she was scared that she might scald herself with hot water (Section 8.5.1). It was evident that Lisa had not voiced this fear to

Matthew, perhaps because she did not want to be perceived as being weak or dependent to her son because this eroded her sense of self as a mother.

Several adult sons described how their mothers made remarks about practical help needed with plumbing or decorating in the hope that they might offer to come to fix it. However, these tasks were sometimes viewed as being trivial or of low priority by informal support members. Una's son, Sid recounted an example of Una's hinting:

> *She would, er, get on the phone, and she'd say something like "Oh, the tap's getting on my nerves", and we'd continue talking, and she'd say "Oh, the tap's really getting on my nerves now". And then I would say "Well, what's wrong with it?". And then she would turn around and say that "Oh, the one in here is dripping" or whatever…She'd in a roundabout way do it.* [Sid, aged 45-49]

To understand Una's perspective, she recounted a different emergency situation where she had had to ask her son, Sid, directly to come to help her (a broken curtain rail) and reported feeling powerless and dependent because she was incapable of fixing the problem herself.

Similarly, Petra's son, Grant recalled:

> *A recent example is…in the lounge, above the…window at the back…there's some flaky paint, where…some water had been, had been getting in from the outside, when the er, guttering was down….it's kind of flaking off and…it needs scraping off and painting.* [pause] *So that's er, that's the latest example of things that get, get mentioned occasionally, which need doing, but, er, they're not a priority.* [Grant, aged 50-54]

Grant intimated that his mother, Petra, tended to adopt an indirect approach to highlighting issues in and around her home which needed addressing, which Grant perceived as being non-essential tasks, but were evidently important to Petra because she was unable to perform them herself. Petra had had two falls in recent years, and although she made a good physical recovery from them, she was psychologically affected and was fearful of walking outside or of doing any task which involved balancing (which would be needed to redecorate the wall above her window). Turning to Petra's perspective, she admitted that she would never ask outright for help, because she felt

very strongly about not wanting to be seen as a burden on her children or to cause them to worry on her behalf (Section 8.2.1).

Therefore, in cases where either an older person was perceived as being capable of carrying out a task, or if informal support members considered the task as being low priority, they were less inclined to fulfil it. Support members tended to focus on the urgency of the task itself, rather than considering why their parents did not feel that they could ask them outright to perform the tasks and what this might symbolise to them: a clear admission of dependence on others.

Interestingly, informal support members who felt affection for older people tended to describe older people's indirect requests for support in more neutral terms, such as 'mentioning'. Keith's younger sister, Dot, who regularly went grocery shopping for him described the initial conversation where Keith hinted he was finding it hard to lift his shopping bags:

> *He happened to say how awkward it was, trying to carry heavy stuff. And I said to him, "Well, we, if we're coming down, like we do", I said, "Just let me know and I'll get whatever it is you can't carry". You see, and that's what we've been doing ever since.* [Dot, sister, aged 80-84]

In this case, Dot knew Keith well enough to be able to interpret the meaning when he commented that he was experiencing difficulties in carrying items and importantly, Dot was able to reassure Keith that it would not be an inconvenience for her to go shopping for him. This was particularly important for Keith to know, because he was fearful of being viewed by his family as a burden. Keith was very keen to emphasise that he would not ask anyone to provide him with help, particularly his son and grandchildren, but that he accepted his sister, Dot's, offer to go shopping because it was Dot who made the suggestion, and therefore Keith felt that he was not being burdensome to her (even though Dot and her husband lived almost thirty miles away from Keith, a sixty mile round car trip to deliver his shopping) (Section 8.5.1).

Older people would use indirect negotiating tactics with formal support members, in particular, euphemisms, to alert carers that they needed additional support with tasks that they felt uncomfortable discussing. Barry's carer, Kate, described when Barry had initially alerted her to his incontinence issues in an oblique way:

> *Because he, he, he gingerly was mentioning things. You know, "I had a bit of an accident", I said "Oh, did you?".* [Kate, carer, aged 60-65]

From Barry's perspective, over time and as he grew to know Kate, he felt able to ask her for help with personal care tasks, which Kate explained had been particularly challenging for Barry, as she described him as a private, proud man, who had retired from the forces. Kate's nursing background facilitated her to react to Barry's hint that he had urinary incontinence in a non-judgemental way, which in turn, served to normalise it for Barry. This gave Barry the confidence to express his needs directly without seeing them as being burdensome, which helped him to adjust smoothly to the gradual deterioration in his physical capabilities owing to a wasting disease (Section 8.2.1).

Therefore, older people generally used indirect negotiation tactics with informal support members for help with tasks that they were unable to perform, particularly in situations where the successful outcome was uncertain (that is, the task being carried out). Informal support members who felt affection for the older person were more likely to describe the indirect tactics used as 'mentioning', whereas those who held less affection tended to construe the meaning of hinting as 'moaning' or express irritation at the tactic. Some informal support members expressed the view that they would rather be asked outright, because they felt guilty when they were unable to discuss fulfilling the task openly. Formal carers tended to report older people using indirect negotiation tactics in situations initially where the subject matter of the task was embarrassing for them to raise.

The next sub-theme identifies situations where older people use direct tactics to negotiate support.

9.2.2 Direct Tactics

It was more commonly reported that older people used direct tactics to negotiate additional support from formal support members. One reason for this might be because of the contractual nature of the help. Una's cleaner, Enid explained:

> *If it was, she needed something at the shop, or something, she'd say "If you're going to the shop, would you get me such and such?"* [Enid, aged 65-70]

Una and Enid had had an interesting relationship. Enid had been Una's cleaner for some years, but Una and Enid had a disagreement about the quality of Enid's work, and Una discharged her. However, Una was even more dissatisfied with the replacement cleaner, and after a month, asked Enid if she would clean for her again, which Enid agreed to. The relationship between the two women' although contractual, had become closer to the nature of friendship over time because they had built a good rapport. Una therefore found it easy to ask Enid to buy her a newspaper or pint of milk from the local shop on her way to clean. And both Una and Enid reported that Una would often give Enid food items or perhaps give Enid a small gift which she chose when she went shopping with her son and daughter-in-law, to help to balance the unspoken arrangement.

A formal support member was asked for help with a task outside of the remit of their negotiated agreement:

> *Well, I don't just go in, and wash his back, his legs and his feet and, and put the cream on. And his stockings and shoes. And leave. I make him a cup of tea. You know, I chat to him. He started to do a letter today, to this hotel company, um, summat about his money. And could I read it through? So I just amended the spelling for him, and, and said "Don't put that". You know. It's about your money, they don't need to know that. Um, and he'll write it out properly…* [Sam, Leslie's carer, aged 55-60]

Leslie reported that he and Sam had built up a good rapport with Sam because she had provided care to him for a number of years. By Leslie asking Sam to help him symbolised the easy nature of their relationship, as well as evidence of trust, as he had discussed his finances (unnecessarily) in the drafted letter.

Conversely, a different carer, Mel, was not prepared to provide extra support to Lisa when she asked for help to complete an application for a reassessment of her personal budget entitlement:

> *I had to be nasty, I said "You've got Matthew, you've got Mike. And you've got yourself". Unfortunately, I'm not going there. "I don't <u>want</u> to know what you've got in the bank. I don't <u>want</u> to know what money you've got to play around with and what money you haven't got to play around with. All I want to know, is the hours that you need.* [Mel, carer, aged 66-70]

Interestingly, the carer symbolised her lack of willingness to assist Lisa as being 'nasty', which suggests that she did not feel comfortable refusing to help. Lisa's views of her carers was that as she was paying them, her carers should do what she asked them to do (Section 8.5.1).

Considering the two extracts above, one possible explanation for the disparity in willingness to provide extra support was that in the first example, Sam knew that Leslie was widowed and childless and had a limited support network to draw upon for help. In the second example, Mel considered Lisa's request exceeded the boundaries of their negotiated arrangement because Mel felt that owing to the private nature of this task (involving Lisa's finances), she felt that it would be inappropriate for her to help Lisa. Mel considered that help ought to be the responsibility of Lisa's sons, as both of them lived locally and had historically provided support to Lisa.

Turning to informal support members' reports of older people's direct negotiation tactics, older people tended to ask family or friends outright in cases where there was some form of reciprocity which was evident in their relationship:

> *And I say "Of course I, I won't mind, I'll do it for you". And I do, but* [long pause]. *And I have to laugh, because if we do it, he says, he forgets sometimes and then we're just as we're going and he'll say "I haven't paid you". And I said "Oh, next time would do". But he keeps on about it, he keeps ringing up and saying "Don't forget I haven't" and I said "No, all right! When I come down next time"* [laughing]. *But I mean, if he didn't offer it, I wouldn't get upset with him, because it's just one of those things. I mean, he'd do it for me if it was the other way around. I'm sure he would, so.* [Dot, aged 80-84]

Keith and his sister, Dot enjoyed a close sibling relationship, which was evident from their descriptions of each other. Keith positioned himself as being fiercely independent and only relied on Dot to bring him heavier groceries. Dot recognised the importance to Keith of retaining independence (on his terms) and her extract symbolises a deeper meaning where she would not tell him that he owed her the money for the shopping to protect his independent sense of self.

Another example of reciprocity in informal relationships was evidenced in Barry's case study and the extract below shows that Barry negotiated with Gerry explicitly about the parameters of the use of his car (Section 8.2.1):

> *I had an old car* [pause] *and I, I knew it was packing up. And Barry said "Listen, that old car of yours, it's, it's not going to go through an MOT, is it? I said "No". I said "It's had it now, Barry". He said "Why don't you use mine?"…* [So in return] *I do the shopping. Er, what else? Take him to the vets if he needs to go, the dog. Because I've got the car, you see…I takes* [Barry] *for a little trip here and there, which is, keeps him going*. [Gerry, friend, aged 80-84]

From Barry's perspective, Barry had been told by the doctor that he was no longer safe to drive his car owing to his degenerative health condition, which was a blow to his sense of self, as driving had been an integral part of his work in the forces. Thus, for Barry, negotiating with Gerry regarding the use of his car would still mean that Barry could retain a sense of independence, as the conditions of Gerry's use of the car meant that Gerry could run errands for him, such as shopping and travelling to and from medical/dental appointments. This form of arrangement protected both men's sense of independence: Gerry because he had access to a car, which meant that was still able to drive (Gerry lived some distance from amenities, so access to a car was vital for him and his wife) subject to albeit providing transport-related support when Barry might need it. And Barry, as discussed, had negotiated his own private chauffeur arrangement with Gerry to take him wherever he needed or wanted to go (Section 8.2.1).

One informal support member identified a potential barrier for older people to feel able to ask for support directly from family, which was because such requests had been ignored or refused in the past. Sharon reported that her mother, Petra, had asked her sons for support in the past, but that Petra no longer felt able to ask:

> [Petra] *says, at the moment, that she does ask them to do things, and they say "Yeah, I'll do it later" and they never do it. So, she can't be bothered, now. That's what she now says.* [Sharon, daughter, aged 50-55]

Sharon seemed disbelieving of Petra's assertion that she asked her sons for support, but appeared to indicate that Petra chose to be silent or adopted an indirect negotiation strategy such as hinting with her brothers. Possible explanations for this misnomer could

be that older people tend to say what they think their children want to hear, or adopt different strategies depending on with whom they are negotiating support from. Examining this from Petra's perspective, Petra admitted that she would be prepared to accept help from her children if it was offered to her (Section 8.3.3), but that her usual tactic was to hint rather than ask directly. Another explanation for the contradictory view of Sharon and Petra could be that Petra believed that by hinting to her sons, that she had made her needs known (in other words, in her mind, she made a request for help), but her hinting tactic was unsuccessful, or that Petra wanted to appear assertive to her daughter, so she told her what she thought that she wanted to hear.

In another case, Matthew indicated that his mother, Lisa, would generally ask him to help her when he visited her, but that he might not always fulfil her request. Matthew seemed confident that his mother was capable of negotiating the support which she needed from another source if he was unable or unwilling to provide it:

> *She'll ask me, once I'm there, if Oh, I could do so-and-so, and so-and-so and yeah, I could say, Yeah, or if I say No, she don't take offence at that, she'll find some other way of getting it done. Maybe me other brother. Whatever. Or her carers, or whatever. Yeah. Yeah.* [Matthew, aged 55-59]

From Lisa's perspective, she was confident that she would be able negotiate the support that she needed from either her sons or from her paid carers, especially if it was a task which was within the remit of the care and support tasks which she paid her formal carers to provide (Section 8.5.1).

Some informal support members perceived older people as only adopting a direct approach in cases where there is a non-medical emergency in the home. Sid explained:

> *But yeah,* [my mother would] *just basically ring me, and say "Oh, I need this doing, I need that doing urgently" and if I'm in, I'll do it, and if not, Minnie will do it.* [Sid, aged 45-49]

From Sid's mother's (Una's) perspective, Una would only ask directly for help in an emergency situation (Section 8.2.1), but would more usually adopt an indirect approach to negotiation, such as hinting at unmet need.

In the examples, it can be seen that older people felt able to negotiate support directly from others in certain situations. In particular, formal support members identified that older people often asked for additional help with tasks which were beyond the scope of the support terms agreed. Depending on the type of task and on the support available to the older person, formal support members were inclined to provide help with a task if they felt that it was appropriate and if they considered there was no-one else in the support network who was better placed to provide support. Older people usually used direct tactics in support negotiations when they were confident that their request would be fulfilled, or if the interaction was based on past or present reciprocity. Informal support members also reported that older people tended to negotiate support directly in non-medical emergency situations.

9.2.3 Absence of Negotiation

Another negotiation strategy which was evident from support members' narratives was an absence of negotiation, which was characterised as a support member taking some form of unilateral action or decision on behalf of the older person. This was conceptualised by support members as 'taking away control' from the older person. Sharon explained that she 'took over' reluctantly when it became evident to her that her mother was unable to negotiate meeting her support needs:

> *So in the end, I've even gone, I even have to go online and buy her a lamp online because she'd been to a couple of shops. She couldn't find the one she wanted, where she sits there, she wanted it in the antique brass, so I found one, online, at* [name of store]. *I told her I ordered it. "Oh" she says, "That's good". So then it came, and then she's happy. I have to take it away, sometimes, I have to take away from her, which I don't really like to do. Because, but I'm the one who has to listen on a daily basis* [laughing] *to "I need this, I need that". And I think, "God, you know, she told me that two months ago and she still hasn't got it".* [Sharon, aged 50-54]

Therefore, 'taking over' in this context meant that Sharon considered she was undermining her mother's (Petra's) independence, which Sharon felt reluctant to do, because she did not want to increase her mother's dependence on her. Conversely, some male informal support members perceived 'taking over' as a strategy to enable an older

person to retain, rather than lose, their independence. Matthew felt that by intervening on his mother's behalf, it meant that she was able to live independently:

> *Um, if I see something that's not right, well, I immediately address it, it's got to be done. It's as simple as that, you know. That's what keeps Mum going. So, and she wants her independence, so she lives on her own.* [Matthew, aged 56-60]

Lisa's perspective on negotiating support needs, particularly from her sons, Matthew and Mike, was that she would generally ask them directly for any support that she needed. In a situation where Lisa felt out of her depth, when she had vast numbers of 'begging letters' from charities, Matthew offered to help her by taking on the task and writing to each organisation to request them to stop writing to his mother. Lisa did not perceive this as dependency, but to facilitate her to live independently.

Tactics used by some male support members to ensure that an older person complied with their requests included a form of coercion to ensure that their views were taken seriously:

> *So, yeah, so we tell her off, make her listen, and she's all right. Yeah...so that's what we do with Mum, we have to* [pause] *iterate it, get it into her head and make her see, sometimes, you know* [Matthew, aged 55-59]

> *I actually, didn't have a row with her, but literally ended up telling her off like a, a little naughty school-girl* [Mike, aged 55-59]

Interestingly, Lisa did not mention that he sons adopted a paternalistic approach to conversations which were linked to her support negotiations. One example given was that Matthew was highly concerned about the amount of money that Lisa had paid to numerous charities and foreign organisations who had requested payments from her and was concerned about the legitimacy of the organisations that had been writing to her. Lisa did not mention this when she was explaining how Matthew had taken away her worry about the unmanageable levels of post she had received, perhaps because she was concerned that it would reflect badly on her that she might have been the victim of fraud (Section 8.3.3).

Another son, Sid, explained as he knew his mother, Una, very well, he felt he would be able to take over if he thought that she was finding it hard to cope with everyday tasks such as shopping and housework:

> *I would, me and my Mum's relationship is that I would just come out with it. Because, I mean, there's no beating around the bush, you know. If I don't say something to her, she won't even think about it. You know, so I think it's best just to come out with it, and say "Look, Mum, you know, you're struggling. You know, why struggle, when someone else will bring it in?"* [Sid, aged 45-49]

Sid's proposed intervention was in response to knowing that his mother, Una, would not ask him for help if she needed it because she would rather try to cope with everyday tasks by herself to maintain her sense of independence.

Another type of absence of negotiation was evident when support members discussed matters affecting an older person, but without including them in the conversation. One example of this type of negotiation took place between two sons, who contacted their mother's carer to ensure that their mother took her mobile phone with her when she went out so that she could be contacted:

> *And Mel will listen to me…I'll phone her up and say "Look, Mel, do me a favour, will you? And make sure she takes that phone".* [Matthew, aged 55-59]

Lisa mentioned that her sons had tried to contact her on her mobile phone when they had no reply from her landline. Lisa had been invited out unexpectedly one evening and had not told them or taken her mobile phone with her. Her sons had been extremely worried, thinking that something bad had happened to her. After this incident, her sons were insistent that she took her mobile phone with her whenever she went out, in case they wanted to contact her to know that she was safe. Although the sons wanted Lisa to maintain her independence, it is arguable that they were fostering dependency on them by being overly protective of Lisa. Lisa was resistant to taking and using her mobile phone, because she did not like it.

In summary, there were several instances where support members acted unilaterally without including older people in the support negotiations, which appeared to be motivated by the belief that they were acting in the older person's best interests. Some

male informal support members adopted a paternalistic approach, particularly with their mothers, in order to ensure that they complied with their requests. Other support members tended to act unilaterally or to address the issue directly with the older person without conflict.

9.3 Overarching theme 2: Facilitating negotiation with older people

The second key theme highlights evidence of perceptions of positive aspects in support negotiations with older people. Facilitating aspects were defined in terms of the ways in which a successful outcome of negotiations with older people became evident. Three sub-themes were identified: “rapport building”, “anticipating actions” and “protecting actions”. Each of the three sub-themes will be discussed in turn.

9.3.1 Sub-theme 1: Rapport Building

The importance of the ability to communicate well with older people was mentioned by the majority of support members providing formal support as being essential to foster openness and trust in support negotiations. Building a good rapport with an older person with formal and private support members included having ‘a banter’, ‘a chat’, ‘a good old natter’, ‘a giggle’, or ‘to take the mickey out of each other’. Support members who considered that they had established a good rapport tended to describe older people in fonder terms, such as being ‘mates’, ‘friends’ or ‘like family’. Formal support members perceived building a rapport as an important diversion to help people to overcome the embarrassment of being washed intimately:

> *I talk a lot. I chat. And, and people relax when you chat. Don't they? You know. If you go in with a smile and a lot of chat, and you know, rah-rah-rah, and how long have you lived here? Oh, all right. Do you have any children? Oh, do you? Yeah. And then they’ll ask me that question, and then I’ll answer. And then, as time’s going on,* [pause] *they’ve forgotten what’s happening to them. And it’s like “Oh, you're done, now”.* [pause] *And that’s, that’s the way I do it.* [Sam, carer, aged 55-59]

Some formal support members indicated that their perception of the role had evolved over time, changing from being just a job to becoming something more meaningful as a

result of creating shared experiences and memories, as well as becoming increasingly familiar with the older person's personality:

> *So, basically, it's um, and we've become mates now, you know. We can chat about different things, and it's a pleasure going to* [Leslie]*. You know, which is why I can't stop doing it, bless him.* [Sam, carer, aged 55-59]

Leslie shared a similar perspective of Sam, speaking very fondly of her and evidently enjoying the easy and fun friendship and mutual trust they had built up together over time (Section 8.3.1).

One privately engaged cleaner, Beryl, explained how her interaction with Leslie had evolved over time into friendship, symbolised by him entrusting her with the keys to his home:

> *He's got used to me, he's, when he's been away on holiday, after, he's given me the keys and I'm, I used to go in every day and feed his cat, I mean, that's trust between us, you know. So, I like that, that's nice.* [Beryl, cleaner, aged 65-69]

Leslie's perspective mirrors Beryl's view of their relationship, that he trusts Beryl and feels able to ask her to do additional tasks for him, but is mindful of the parameters of their arrangement (Section 8.2.1).

An important reason identified by several formal support members for building a rapport was to foster an atmosphere where older people felt able to voice requests for support openly and without fear of being belittled or judged. Enid vocalised:

> *Yeah, she don't, she'll ask me whatever she wants, yeah, I don't mind. Yeah, oh yeah, I think we're definitely comfortable together, we have a right laugh, yeah.* [Enid, cleaner, aged 60-64]

Several formal support members emphasised the importance of continuity of care in fostering an atmosphere of trust where an older person felt able to raise issues openly. A meaningful relationship was considered something which can only be developed properly over a period of time, in particular, to help to identify whether health issues were affecting an older person's abilities to perform ADLs and IADLs. One carer felt that it was

important to normalise embarrassing issues such as urinary incontinence rather than to provide sympathy to older people, which helped to establish a rapport:

> *Yes, yeah, because you build up a relationship, you're not just in and out. Of course, he could ask me anything, I mean, I've washed, I mean, when I first started,* [lowering her voice] *he didn't want to admit he had some incontinence problems, he didn't want to admit certain things, now that, in itself, can lead to pressure sores, etc…However, I'm really relaxed about it, I said "Oh, we all do that, oh, we all have accidents". You know, and it's just generally stuff like that. I keep saying that to him now, that he has to wear an incontinence pad all the time. However, he's more relaxed now. And he's not so anxious, he's not always thinking "I'm going to have an accident and I've got nothing" because that was what was stopping him going out in the past. Now he can go out. It's all sorts of things. And that's only by building up a relationship. And you can't build a relationship in half an hour.* [Kate, carer, aged 60-64]

The importance of openness in communication extended both ways, as for some support members, a good rapport meant both sides feeling able to voice worries and concerns. To Gerry, part of the meaning of having a good rapport with Barry was being able to speak light-heartedly him to cheer him up, especially when Barry was feeling despondent:

> *You've* [pause] *got to step in and have a go back at him, sometimes. Or, take the mickey out of him, when you can, you know. Tell him he's a silly old bugger and that.* [Gerry, friend, aged 80-84]

Formal carers tended also to adopt a similar approach when talking to older people, particularly in circumstances where they considered older people were complaining without justification. There was a sense that sometimes, formal support members felt that older people needed help in putting matters into perspective:

> *But I, she's, to me, she gives me the opinion, though, if he's having a whinge about something, she'll say "Oh, come on, you know, don't be silly", that sort of thing…but they take note of that, you know, rather than sympathising with them all the time. You can get through to a person by, you know, and she's got that sort of air about her, that, would do that. With me, I just sympathise with him, you know.* [laughing] *Yeah.* [Beryl, cleaner, aged 65-69]

Beryl's words symbolise an ageist attitude towards older people as a homogeneous group, by her use of the words 'they' and 'them', which could lead to a danger in trivialising older people's genuine concerns. The above extract seems to stereotype older people generally as having a tendency to complain, rather than articulate genuine support needs.

9.3.2 Sub-theme 2: Anticipating actions

In addition to building a rapport, support members also talked about the importance of being able to pre-empt support that older people might need to function in their daily lives without the need to negotiate. Anticipating was particularly evident amongst formal support members, some considering the ability to pre-empt support needs without always being asked or without asking as being an essential and integral part of their role. Lisa's carer, Mel explained:

> *You know what their needs are, you know what they feel, you know when something's wrong. If you don't, you're not good at the job. You know, and I don't know, you just pick up these signs and you think "Oh hang on a minute, this is not right". And you investigate.* [Mel, carer, aged 66-70]

For Mel, being a 'good carer' is symbolised by her observation about the importance of being able to tap into her emotional responses and intuition to sense the moods and situations of older people, in addition to the usual five senses.

One formal carer admitted that she unofficially changed the order of the client schedule she was given by her supervisors because she knew her clients' preferences. She considered planning older people's support to anticipate their needs more important than complying with a rigid work schedule:

> *You do, you get your times that are on your sheet. But, I know all these people so well, that* [lowering her voice] *I don't stick to what's on the sheet.* [pointing to various names] *Because I know she'll go early, he has to go at seven because he's a disabled lad who goes to work…who has a Day Centre, so you know that if they have Day Centre that day, you need to be there early, so they're washed and dressed. And you know who doesn't really like getting out of bed. So they're quite happy. And also, I know who has medication in the morning, at lunchtime and you have to think*

> *they have to have a certain amount of gap between their morning, morning medication to their lunch medication. So you also have to work out that they've got enough time.* [Sam, carer, aged 50-54]

The ability to anticipate older people's daily support needs was identified as being particularly valuable in unforeseen circumstances, such as when a carer knew that they were unable to provide usual cover. Anticipating support for some formal support members meant thinking ahead to ensure that the older person could still function throughout the day. Bev explained:

> *You know, and I just made sure I had everything set out, so that [Hamish's] day was left as easy as possible with the things he finds difficulty with. And then he could still carry on from there.* [Bev, female, aged 35-39]

Hamish appreciated Bev's ability to ensure that she laid out all of the items he would need each day in order to be able to function, and made sure that his electric shaver and toothbrush were fully charged for the following day (Section 8.3.2).

Anticipating help with everyday tasks was also evident among formal support members, where often, additional tasks were carried out above and beyond the scope of the initial engagement. A typical example was Enid anticipating how a health condition might impact on Una's ability to carry out simple tasks throughout the day. :

> *It's all of these things, she's got a bad back, hasn't she? She can't do it, she just can't get down there. Like, I always make sure she's got her shoes on and things when I go, because she can't do that either. Just silly things, like putting a pair of shoes on, you know?* [Enid, cleaner, 65-69]

Una praised Enid's propensity to think ahead to identify what she would need that day and attributed this ability to Enid genuinely caring about her, which in Una's view meant that she performed her role correctly (Section 8.3.2).

If it became clear that an older person was experiencing new difficulties in performing tasks, formal carers might anticipate what additional support an older person might need and commence negotiating extra formal care on their behalf:

> *Then I would go back to my office, and say "I think that Leslie probably needs a little bit more help". You know? I'd chat to him about it first. You know, "Have you had your shower this week?" "Did you manage all right?". Because he showers himself, um, and then I'll take it from there as to what he said.* [Sam, carer, aged 55-59]

However, some support members considered that negotiations could not always be planned in advance. Negotiations needed to be navigated with skill to ensure that support needs were met in a way which suited each party. One formal support member, Bev, suggested understanding how to negotiate support was a gradual process, which became easier once a relationship with Hamish became established and the extent of his support needs and preferences was known:

> *But, um, to be fair, with Hamish's needs, it's one of those things that you have to start with, and you get to know him, and you progress through and you do that judgemental yourself, does that make sense? Obviously, still with um, help and advice if you need it from* [name of daughter] [Bev, carer, aged 35-39]

Hamish considered that Bev's ability to pre-empt his support needs was something that was inherent within her. He also considered that it was more 'natural' for women to demonstrate this attitude towards caring (Section 8.3.2), a view which was not shared by Petra, who considered this was a trait exhibited by people and not limited to women (as the only one of her children to pre-empt her needs was her youngest son). In addition, Luke did not think that Lacey, his daughter, was particularly caring and he attributed this to her not having any children, a view which Lacey found to be highly distressing. Similarly, Barry thought that his daughter (not interviewed) was very domineering and short-tempered and was not well-suited to providing care to him (even though she had two children) (Section 8.3.2).

Even informal support members considered it important to conduct support negotiations cautiously to manage older people's expectations, as exemplified by the following:

> *And yeah, Mum was very much involved with that. And I, I didn't want to raise her hopes either. It's very er, er, treading on eggshells there, I didn't want to say look, I'm coming, so, er, you know, will you be happy, or, er, it was like, it might happen, and it hasn't happened.* [Charlie, aged 50-54]

> *It something, I mean, to me, it's,* [pause] *it's second nature to me. In that I can, I can think what she's going to think before she thinks it, sometimes. Yeah, I know, that's sad, isn't it? But no, you know, I mean, I didn't, well, I've been a, I didn't think that me and my Mum were that close, but I think we are. You know, thinking about it, I think we are. Mmm. But then, that's not, that's not a bad thing. I would say in her hour of need, she knows where I am. Yes.* [Sid, aged 46-50]

In the accounts from support members, facilitating aspects of negotiations are framed as helping older people to clearly communicate their support needs or to meet their needs by pre-empting what support is needed. Support members who had a close relationship or bond with an older person were in a better position to be able to anticipate the level and type of support which is needed. Interestingly, based on their personal experiences, some support members considered that women were 'naturally' caring in the sense that they were more able to pre-empt older people's support needs before being asked, which suggests an internalisation of societal norms about gender (Section 3.2.3). However, one participant felt that this was a trait exhibited by people, regardless of gender. Some male participants who did not enjoy a close relationship with their adult daughters suggested that they were not best placed to provide care to them. The next sub-theme examines a further way in which support members facilitate support negotiations.

9.3.3 Sub-theme 3: Protective actions

Actions which both protected and supported older people were evident among informal support members. Being protective meant 'looking after' an older person, helping them to 'feel safe' and supporting them because they 'wanted to' and rather than out of a sense of obligation. Although the actions taken differed between each case study, the fundamental aim was to help to meet older people's unmet need. Sid perceived his mother as needing more opportunities to socialise so that she did not feel isolated:

> *Um, I just want my Mum to be happy, really. And if that's the way to do it, I don't want her to be on her own too much. I don't want, erm, I want her to feel safe, um, and if that's what's needed, then I'm, I'm, I'm, I'm happy to do it.* [Sid, aged 46-50]

While Sid respected his mother's (Una's) decision to live alone, he was mindful that Una might feel unsupported or become lonely, so he telephoned his mother most days and

was willing to visit regularly to deliver and collect Una's washing when she bought the tumbledryer for him and his wife, Minnie (Section 8.2.2).

To protect older people's self-esteem when offering to provide support, several informal female support members recognised the need to reassure older people that they were genuinely willing to perform the support task and did not offer out of a sense of duty. Dot described helping her brother, Keith:

> *Well, he, he, he thinks he's being a bother. And you've got to convince him that he's not being a bother. You know, you're doing it because you want to do it. But he says, he says "Sorry for being a nuisance". I say "You're not a nuisance. I come down because I want to. Not because I think I should. I come because I want to". I said "If I didn't want to come, I wouldn't". And that's it. So, he knows it, I'm not doing it just to satisfy him, I'm doing it because I want to do it. And that's it.* [Dot, sister, aged 80-84]

Keith often equated receiving help with being dependent, and out of all the participants, was the most vehement proponent of wanting to remain independent. Keith needed constant reassurance from his sister that in doing his fortnightly shopping, she did not feel that it was an inconvenience to her (Section 8.2.1).

For Sharon, the meaning of protection was to try to avoid a situation where her mother would be reminded of her agoraphobia and its impact on her ability to leave her house. Sharon could empathise as she had experienced a similar condition herself:

> *Because then she'll go home and she'll say "Oh, I forgot to get my…jam". You know, and there's little things. And I can't, they don't sell it on-line when I was doing my shopping. So I can't go and take her to get that. So then she's got to wait another fortnight for it. And I know that must be quite awful for her. Not, not awful that she hasn't got her jam, but awful that she realises that she can't go on the bus to Sainsbury's and get it herself. Yeah. And I don't really want her to realise that all the time…Because I know from my own experience that, that, it is um, it makes you worse inside. It really makes you dislike yourself and feel a failure. So I don't want her to always have those sorts of feelings.* [Sharon, aged 50-54]

Sharon therefore could empathise with her mother on one level, because she also had been diagnosed with agoraphobia and could understand the deeper meaning for Petra of not having her jam, because it signified a loss of independence and a feeling of helplessness.

Protective actions also manifested themselves in ways where an informal support member attempted to negotiate additional support with a third party who was not currently an active member of the support network, without first consulting with the older person. The motives behind negotiating support appeared to be twofold. Most importantly, the motive stemmed from a perception that an older person needed additional support which a support member was either unable to give, or to sustain the same level of support which was currently provided. And secondly, there was a perception that the third party ought to be providing support owing to the nature of their relationship with the older person. This is evidenced in two cases, outlined below.

In Una's case study, Una and her son had not spoken for a few years. When Una's health began to deteriorate, her friend, Hannah, found herself taking on additional support responsibilities. Hannah reluctantly admitted that she was struggling to cope with her own ailing health needs as well as providing support with shopping and other household tasks that Una needed. For Hannah, a meaningful solution was to intervene and approach Una's son, Sid, without Una's knowledge to persuade him to form a reconciliation with his mother and provide her with support. From Hannah's perspective:

> *Well, I, I think, I thought he needed to go and see his mother. Because she was quite poorly, you know. I, I don't know how much longer she's got left. I mean, when they said it was something wrong with her…I thought "Well, you, you don't know, do you?". So I thought he'd be sorry if he didn't go round and see her and something happened*. [Hannah, friend, aged 80-84]

Similarly, Vera and her father had not spoken for many years. When Vera's grandfather, Luke, needed additional support which she was unable to provide owing to other responsibilities, Vera approached her father to try to persuade him to start to provide support to Luke (his father) because she felt that it was her father's duty to do so:

> *So, um, yeah, so we, it's a bit more pushed for time now and that's why it's frustrating for me that I think my father should do some of the stuff…I did make*

> *aware to my father that we were going through a situation…and he didn't make any attempt to help out with anything. Not a thing. And he still hasn't done anything.* [Vera, granddaughter, aged 40-44]

In light of the above, support negotiations tended to be more successful where there was past evidence of a close relationship between the older person and the support member. From Sid's perspective, he was happy to provide support to Una because he felt affection for her. In contrast, from Vera's perspective of her father's relationship with her grandfather, her father left home at sixteen and had not formed a close relationship with either parent. Thus, duty in itself is not always a deciding motive to provide support, as the nature of the pre-existing relationship between the older person and the family member is also important.

Some male informal support members felt it was their role to protect their mother. Matthew recounted a recent incident where his mother, Lisa, had a fall while she was out shopping with him:

> *So, it's like this business of when she fell down in [area of city]. I felt as though I'd let her down. I felt hurt myself, you know. Because she's in my charge. And she says "Don't be stupid. I'm an adult". I said "No, no, no, no, when you're out with me, I'm there to look after you. And now you've fallen over, I feel that I've failed".* [Matthew, aged 55-59]

Matthew's words symbolise his view that he ought to protect his mother, Lisa, when she went out with him. For Lisa, Matthew's over-protective manner towards her symbolised that he was treating her like a dependent child.

Protective actions tended to be more prevalent from male support members towards their mothers. The next sub-theme explores encouraging actions which support members take to facilitate support negotiation.

9.3.4 Sub-theme 4: Encouraging actions

A fourth sub-theme identified through the narratives of the participants were actions which support members took to encourage older people to negotiate ADLs and IADLs with which they had difficulty. Encouraging actions were reported as being prevalent

amongst both formal and informal support members and differed from protecting actions as their purpose was to motivate older people to perform ADLs and IADLs.

In many instances, both types of support members recalled specific examples of encouraging actions aimed at helping older people. Bev described how she believed it was important to be supportive of Hamish to encourage him to carry out tasks that he wanted to achieve:

> *Um, he does have a go, every now and then. Um, the thing with Hamish is* [pause] *he, in his head, he's still completely and utterly able, and he does as much as he possibly can, um, to be able to do that…and to be fair, I try to encourage him to do that, because the minute you turn round and say, right, I've, me, he gets a little bit* [pause] *frustrated, is probably the better word. He gets very frustrated. So, sometimes, as much as it might take…an extra five, ten minutes, if he wants to try and put his socks on, I'll let him try and let him. Other times, most of the time, he's quite happy for you to do it, but every now and again, he's like "I want to have a go" and I'm all for that…*[laughing] [Bev, carer, aged 35-39]

Hamish himself was determined to carry out as many tasks as he could for himself, because for him, finding a way to take his medication or to make himself a hot beverage symbolised that he was exercising independence and proved to himself that he was not completely dependent on others (Section 8.5.1).

And similarly, another formal carer described the process of providing encouragement as being gradual. It was also important to observe an older person's capabilities and gauge their feelings, then gradually negotiate the next steps at the older person's own pace:

> *So you're not pushing, you know, so you find out the information and take in all the information, and then start kind of wheeling her around to "You can do this. You, you haven't got to sit there", you know. So, but now, she's just getting herself, there. She was over the moon last night, she managed to sit on the bath. On her bath seat to get into the bath. She thought "I did it". And I said "See?", I said "If you're not going to try, you're not going to know".* [Mel, carer for Lisa, aged 65-69]

Lisa herself admitted that she was apprehensive about carrying out household tasks and tasks which required balance, as she was afraid of hurting herself. Mel saw the process of

building up Lisa's confidence as being a gradual one, but one that was important in order to help Lisa to become more self-sufficient (Section 8.5.1).

Informal support members also reported that they used encouragement as a negotiation tool to help older people to feel confident to walk outdoors and to feel able to extend themselves in a secure environment. Sharon explained that she had been encouraging Petra to walk to the shop:

> *So, I thought "Oooh. That's worked quite well, hasn't it?". But I do, I am quite blunt, I'll say to her, like, er, you know, "You can't wait for* [name of support worker], *even though you've rung them, because, you know, you're just going to be stuck in every day". I said "And you know now, yourself, what you have to do. So, just a little bit, every day". And then, one day, she said to me, I said "Are you bored?" Because she said something and she said "Yeah, I'm bored with doing that bit". "What a good thing, then" I said, and she was surprised by that. And I said "Yeah, but if you're bored, you're now ready to move on". And she didn't realise that. I have to tell her that. And then, when she actually told me she went to the shop, I said "That's absolutely fabulous. That's amazing". "Is it?", that's what she said to me on the phone, "Is it?", I said "Yeah, course it is".* [Sharon, daughter, aged 50-54]

Equally, giving an impression of being encouraging and supportive was also highlighted as being important to help to motivate an older person. As Sharon explained:

> *So, I think, I need to sound like that to her as well, because I don't think my brothers are like that, they're not that kind of people. Because I don't think she realises how well she's doing, otherwise.* [Sharon, daughter, aged 50-54]

Petra had lost confidence in herself as a person after her two falls, in particular, walking outside, but she was determined not to reveal how she felt to her children, particularly her daughter, because she did not want to be seen as a burden. So Petra's reluctance to admit that she was 'doing well' could have been a part of Petra's act to try to appear as if she felt fine, while out walking with her daughter (Section 8.2.1).

Some formal support members considered it was important to ensure older people carried out as many tasks they felt able to do safely in order to discourage dependency:

> [Leslie's] *fine, at the moment. I believe that, um, independence is important. And if you can do it, do it, as long as you're safe. If you feel you're not safe, then you need to say. Don't put yourself at risk. You know, unnecessarily.* [pause] *But it's bad to have someone come in and do everything for them. He can get his breakfast. I'll make him a cup of tea. If he's running late, and I go, and he hasn't had his breakfast, then I'll quickly do his cereal and his banana and his toast and everything. You know.* [pause] *That's not a problem. But I won't do it every time, it's not on my* [patting the schedule] *my list of things to do. Because he can do it. And if I do it every time for him, he will lose it. You know, if you don't use it, you lose it.* [Sam, carer, aged 50-54]

Sam's words symbolise she aims to strike a balance when supporting Leslie, between promoting his self-sufficiency, at the same time as maintaining his quality of life, as exemplified by making his breakfast if he needed to go to his club or leaving him to make his own breakfast if Leslie did not have any scheduled commitments that day.

This perspective was mirrored by informal support members who felt that it was important for older family members to maintain their independence:

> *So she needs to, you know, to prolong her own self, isn't it? And that's why she's got that particular calendar, she's now got her memo board, she has got her pad by the phone. It's all in place, whether it all gets used all the time, but she's getting. She actually is, yeah, it's like training her.* [Sharon, daughter of Petra, aged 50-54]

Petra had confided that she felt as though she had lost confidence in many aspects of her life, not least because of her inability to socialise because of her agoraphobia linked to her fear of falling again and becoming injured. From Sharon's perspective, she felt guilty that she was not able to visit her mother more often because of her own limiting health condition, and felt that by offering practical solutions to what she saw as meeting Petra's needs, she was able to assuage her guilt and help Petra to maintain her sense of self.

Providing encouragement for an older person to achieve a particular activity or task was also seen as promoting a meaningful way of facilitating negotiation of a specific task or activity. Kate noted:

> *So, er, our aim now, is to, because he's having a new chairlift put in, is to get him out, now the spring's coming. You know, to give him a focus. And, and to be more*

> *mobile. Because of being in, in, in the flat all winter, he's got, you know, there's no chance of real exercise. He's, he used to have a physio come up to do exercises, er, he does them generally, that, but there's no real* [pause] *motivation there. But if you start going out, it gives you more motivation.* [Kate, carer of Barry, aged 60-64]

For Kate, the most important aspect of independence that she perceived for Barry was to give him a goal to aim for. Kate's previous profession as a nurse meant that she viewed Barry's needs through a medical lens. Thus for Kate, facilitating Barry's independence meant building up his physical strength and flexibility to enable him to leave his flat to socialise.

Sharon thought it was important for Petra to work towards a treat such as having her hair done at a hairdresser's as motivation for her to help to combat her fear of walking outside:

> *And I, I said to her "Wouldn't it be lovely" I said "If you could have a goal, and then you could have your hair blow dried?". And then she'd be sat in the salon, with other people. Even though her hairdresser comes, she only comes every six weeks, but if she felt like having her hair done, because obviously, she's not able to do it herself, with those hands. And I'm not able to do it like I used to do it for her. So, I think it would be, and then it would be something to aim for, wouldn't it?* [Sharon, daughter of Petra, aged 50-54]

Although Sharon was not a trained as a health professional, it was important to her that her mother, Petra, should set herself an objective to work towards in order to increase her confidence in walking so that she could maintain her independence. Sharon herself had received treatment for agoraphobia earlier in her life course, so she recognised the value of being motivated by a reward.

Most support members considered it important to help older people to negotiate ADLs and IADLs in order to help them to be self-sufficient, in order to maintain or build upon their independence levels. Having examined actions which facilitated older people support negotiations, the following theme examines evidence from the interviews with support members of negative views of older people's support negotiations.

9.4 Overarching theme 3: Negative views of older people's support negotiation

The third key theme highlights evidence where negotiations with older people have been impeded. Examples of impediments in the narratives were grouped into the following four sub-themes: "obstructive behaviour", "crossing boundaries", "manipulation" and "barriers to providing support", which will each be examined in turn.

9.4.1 Sub-theme 1: Obstructive Behaviour

Negative perceptions surrounding older people's behaviour when negotiating support with everyday tasks were commonly held by support members. In situations where older people chose not to ask for support directly, some informal support members interpreted it as an inability to be assertive. Many support members identified older people as exhibiting behaviours which symbolised a barrier to negotiating support from others, such as being 'too polite', or being 'too proud', 'too stubborn' or 'taking offence easily'. Vera described Luke as a person who did not articulate his support needs because he did not want to be a burden:

> [He's*]…too much of a gentleman, he don't always say stuff.* [Vera, granddaughter of Luke, aged 40-44]

Luke's admission that he tended to hint and thus did not tend to ask outright for help was recognised by his family (Section 8.2.2). For Vera, Luke's indirect tactics symbolised politeness, rather than an awareness that he wanted to conceal any dependence on his family for help.

Some informal support members tried to understand why an older person might choose not to negotiate support directly by imagining how they themselves might feel in similar circumstances, thus adopting "the rôle of the other" (Mead 1934:372). A different explanation was offered by a few informal support members which suggested that older people might be less inclined to ask for support because they were determined to prove to themselves (as well as others) that they were still capable of carrying out everyday tasks. Sid described his mother:

> [Una's] *a bit stubborn. In that she will try and do something herself, and if she can't do it, she'll keep trying, and then when she gives up trying, that's when she'll ask for help. Yeah, she will, she likes to persevere. She likes to try and try, and try and try.* [Sid, Una's son, aged 45-49]

For Sid, Una's actions symbolised her determination not to give up and to be seen to be as independent as possible. Sid's perception of his mother accords with Una's own description of herself, where she would only ask for help as a last resort (Section 8.5.2).

Another informal support member (Hannah) described Una as having a volatile personality. Hannah interpreted Una's disposition as being shaped by her difficult experiences earlier in the life course (two traumatic marriages), which Hannah attributed as posing a barrier for Una in negotiating help from formal support members:

> *Well,* [Una's] *had all sorts of carers going in, but she's paying for them, I think. I think she had some through the* [pause] *social, but they didn't work out. But, Una, bless her heart, takes offence very easily. I think it's because of the life that she's had, bless her heart. And she takes offence very easily and I mean, she's got rid of several of the cleaners.* [Hannah, friend, aged 80-84]

Hannah believed that events which took place earlier in Una's life course had an influence on how Una reacted to life events. Hannah mentioned that Una had had two unhappy marriages and had a low patience threshold.

One older formal support member talked about her relationship with her own family to illustrate her point:

> *And quite often, I need to go and get stuff…Which means going to [name of shop], or places like that. And, you see, gurrrr, and they know this, and you think "Ohh, God, I could do with a lift". And they know you could do with a lift. But they won't offer, so I think "Well, I won't ask"* [laughing] *it's like that, I think "Well, if you can't offer, well, I don't want one, then"…I think it is that, though, pride, with old people.* [Enid, Una's cleaner, aged 65-69]

Another older formal support member offered a similar view in relation to observing how older people react when visited by new carers:

> *So, I understand from his point of view, I have empathy with what he, what his needs are, as regards to if somebody was coming in every day, who was a complete stranger, you don't always remember to tell people things. And then you don't want to bother them, elderly people are like that.* [Kate, carer, aged 60-64]

Interestingly, in both extracts, the support members made the same general assumption: that a characteristic of all older people is to be unassertive. In addition, both used words which distanced themselves from older people (who were only slightly more advanced in years than themselves).

9.4.2 Sub-theme 2: Crossing boundaries

One negative side-effect of building an effective rapport with older people reported by formal carers was a propensity for some older people to challenge the boundaries of the existing support relationship. Older people sometimes asked formal support members for help with tasks beyond those which they were engaged to carry out. Pervasive throughout the interviews was a sense that an invisible line was crossed in the relationship between support members and older people, particularly where there was a tendency to perceive older people more as kin than as clients:

> *If anything happened to Lisa, it would be a very sad thing. And nothing to do with money or anything else of that thing, because she's become part of the family, she's like a grandmother, like May said. You know, she, you're involved with her. So you take on all her ups, her downs, what's important to Lisa* [Mel, carer, aged 65-69]

Thus for Mel, building a good relationship Lisa meant that Lisa was symbolised as being an extended member of her own family. Lisa also reported that she felt close to Mel and her daughter, May. However, there were limits to how far Mel would tolerate Lisa's request for extra help, which meant that it was easier to impose limits owing to the contractual nature of their relationship.

A few formal support members expressed strict boundaries of the type of extra support they would and would not be prepared to provide. If the request for support was different from the tasks already being provided, formal support members tended to negotiate in terms of finances in order to re-establish the boundaries of the formal relationship. This was evident in Lisa's case study, where her formal carers provided

support with personal care tasks and cleaning, and she asked them to provide her with extra help to clear her spare room:

> *And I turned round and said to her, I said "Well, if you come into that rate, Lisa, I might have to charge at the hourly rate. We do an hour, I can do an hour, no problem". I said "Past that hour, I might have to charge".* [pause] *"I'll think about it". Think before you act. And that's the only way we can do it. Because she's also got to realise she's not Number One.* [Mel, carer, 65-69]

From Lisa's perspective, because she paid Mel for the care she received, she felt able to ask for extra support outright (Section 8.5.1). There were some extra tasks that Lisa asked for that Mel was happy to provide (cooking meals). However, when Lisa asked Mel to clear out her spare room for her, Mel considered that this was beyond the boundary of an acceptable request and reminded Lisa that she would need to renegotiate the terms of their existing agreement if she wanted help with this task.

In addition, one cleaner made it clear that she would not feel able to provide additional support such as personal care or administering medication:

> *But I don't do any personal care,* [pause] *(a) because I'm not trained, and um, I know for a fact* [pause] *by working in the office,* [pause] *domestic and personal care, we didn't do. Because of the medication, and things like that. There's no way I would do that. Because we don't know what they've already taken, you know.* [Beryl, cleaner, aged 55-59]

Some informal support members felt that the more tasks they carried out on behalf of older people, the more older people demanded additional assistance or expected them to provide extra help with little warning:

> *But I would do it anyway. It's not even a, I don't even* [pause] *because sometimes, I do get annoyed, we've had it where, like, you'll get a phone call the night before "Oh, I've got to go to the hospital tomorrow". And you're like "Ohhhh". And you say* [laughing] *"Twenty-four hours' notice is not long enough", you know. Um, but it's kind of like that's, it's kind of expected of us, but I would do it anyway…* [Lacey, Luke's daughter, aged 55-59]

The perception that older people tended to make assumptions that others would provide them with extra support was common amongst support members generally:

> *I kind of, er, you can't be, with my Dad, you can't, you kind of can't start doing something because if you start doing it and he, and he thinks it's a routine, and he'll expect it of you. And he gets very upset, if you don't do it [laughing]. Which he has done with me and Vera.* [Lacey, daughter, aged 50-54]

Lacey's two extracts show that she was upset because her father made an assumption that she would provide him with help, particularly at short notice, which for her, symbolised that he did not value her or her time.

Knowing the support boundaries were negotiable worked to older people's advantage in many cases because they felt able to approach formal support members directly for assistance with tasks which they were not specifically engaged to do. Formal carers reported being open and willing to carrying out additional tasks, particularly when they were aware there was no-one else available to provide support with these tasks. In addition, older people expected informal support members to provide them with support at short notice, because they were relying on their goodwill to help out.

9.4.3 Sub-theme 3: Perceived Manipulation

Support members sometimes perceived older people used manipulation as a tool to orchestrate support negotiations. Terms used by support members to describe manipulation included "being a bit sly about things", "twisting a situation", "scheming and conniving" and "doing the crafty". Older people's perceived manipulative behaviour was constructed as manifesting itself in different ways. There were reports from some support members who felt "played off" against each other, or older people displaying "attention seeking behaviour".

Older people were perceived as manipulating informal support members if they negotiated support with tasks which would benefit them, in particular, tasks which involved some form of exertion, or tasks which they would rather not do. Matthew suspected his mother carried out manipulative behaviour:

> *Because sometimes, she don't want to do things that you want her to do. So she tries to twist it so that she can get it her own way…because sometimes, she don't want to do things that you want her to do.* [Matthew, son, aged 55-59]

In response, informal support members also exhibited manipulative behaviour to achieve the outcome they wanted to achieve from older people, in particular, to prevent older people from acting in a particular way:

> *There's been occasions where I've had to go and say to her "If you persist with this, Mum, I won't come up and see you no more". Job done. Now she ain't going to risk that for nothing. So she'll stop doing what she's doing.* [Matthew, son, aged 55-59]

Being familiar with different personalities of informal support members was perceived as an advantage to identify instances where manipulative tactics were suspected, as exemplified by Matthew:

> *But I know that's where it's going. I mean, yeah, I mean, when you live that close, when you're that close, well, I know how she thinks. I know how she works. She knows how I work. She knows how my brother works, and I know how my brother works. And so on. That's how it is. That's what,* [laughing] *that's what being part of a family unit's all about. It's a big game, innit?* [laughing] [Matthew, son, aged 55-59]

Some informal support members perceived manipulation as a motive to prompt support members to visit older people to negotiate support with a particular task. To two brothers, their mother's request for support was interpreted as a ploy to initiate a visit in order to combat loneliness, rather than a request for help:

> *She's an attention seeker, she's very much an attention seeker. Because she's alone, she's a lonely old lady.* [Mike, son, aged 60-64]

In addition, the two brothers considered that their mother was idle, and suspected she used tactics to manipulate others to provide her with support she needed with tasks:

> *However, when it comes down to now, she's just lazy, she won't look after herself properly. Um, and she's really lazy, as I say if I go into the house…I'll walk in the door and she'd say "Do you want a cup of tea?", and I'd say "Yes" and she'd say "Oh well,*

> *can you make me one at the same time?". She wouldn't get up and go and get it for you.* [laughing] [Mike, son, aged 60-64]

Based on past experience, the sons were reticent about providing their mother with help whenever she asked them. The sons interpreted the real meaning of their mother's request as scheming for a social visit, rather than considering that she might have a genuine need for support, either with a task or because she was very lonely, which meant that they were less inclined to help.

The above extracts suggest that both Matthew and Mike consider that their mother's (Lisa) actions means for them that she was either lazy or attention-seeking when she asks them to do tasks in and around her home for her. Lisa's sons perceived their mother as being undeserving of their help because they thought that she is still capable of performing most non-strenuous usual everyday tasks, such as making a cup of tea. From Lisa's perspective, owing to her mobility issues, she reported that she was very apprehensive about cooking and preparing hot drinks, because she was fearful of burning herself. Although Lisa mentioned that she felt that she could ask her sons to do anything for her, from examining her sons' perspectives, it appears that Lisa's requests were not always fulfilled. This message was not conveyed by Lisa. Examining both the perspectives of Lisa and of her sons is insightful because they demonstrate the complexities behind why support members might or might not choose to offer to provide support to older people and thus gives a deeper understanding behind older people's unmet need.

'Playing off' was another manipulative tactic perceived by informal support members, which involved an older person who deliberately encouraged a support member to be in opposition with another support member, with the aim to gain an advantage for themselves:

> *But you and Vera* [pause], *your reaction to your Dad, is identical. Your frustration with him, is equally as frustrating with Vera's, with him as well. They're both frustrated. And they both can see through what he's saying. And then, when you two talk, you can see "Yeah, we know that". You, you can feel.* [Ted, Luke's Son-in-law, aged 50-54]

> [Luke] *can, he's* [pause] *very naughty. He can play us off each other, you know? And when we do meet up together, we* [pause], *we don't, sort of like, "Well, he says this*

> *and she, he says" like this, we kind of, um,* [pause] *comf, I say comfort, I wouldn't say it's comfort, that's a little bit too strong a word. But we sort of* [pause] *find something that we, we can see what he's doing.* [Lacey, Luke's daughter, aged 50-54]

These actions can be perceived as a form of manipulation, with the aim being to cause a rift between two people in order to increase the level of control in a situation where an older person felt that they had less power. From Lacey and Ted's perspective, Luke tends to resort to psychological tactics between Lacey (his daughter) and Vera (his granddaughter) to provoke a reaction based on guilt to motivate them to provide support. Luke had told his daughter that she did not think that she was very caring because she had not had children of her own and did not anticipate his support needs. Luke compared her unfavourably to Vera (Section 8.3.2), and when Luke mentioned his view to Vera, she then met with Lacey and told Lacey that she should be doing more for Luke. Lacey felt hurt and unjustly judged by her father and Vera and felt resentment towards them both, which made her feel less willing to provide support to Luke.

Some formal support members admitted they were sometimes sceptical when older people told them they were finding it hard to manage ADLs and IADLs. One reason put forward was because they thought that older people exhibited attention-seeking behaviour, for example, exaggerating or pretending to be in pain to negotiate extra help from them:

> *We judge what mood she's in, how she's reacting, if she's OK, sometimes we do know that she puts on a bit. Which ninety-nine percent of old people do. You know, "I can't do this, this is very painful". And you think "Yeah, OK". And you just get on and do it. And ignore it. If you make a fuss of it, that's wrong. Because while you're making a fuss, like a child, they'll carry on. So you don't make a fuss, you just kind of come outside of that reasoning and think "No, I'm not doing that, I see your plan in that. No, you can do it yourself".* [Mel, carer for Lisa, aged 65-69]

From Lisa's perspective, she admitted that she struggled with cooking and preparing hot drinks. The main reasons were because she feared for her personal safety and did not want to take any risks because she wanted to avoid injury, and also because performing these tasks gave Lisa pain because of her mobility issues (Section 8.5.1). Therefore, there

is a danger that if carers do not take older people's needs seriously that this could means that older people are even less likely to admit they need help and could result in them taking risks when attempting to perform tasks themselves.

Interestingly, several formal support members shared the view that most older people adopted attention-seeking or infantile tactics to negotiate extra support from them. Accordingly, they tended to react to perceived manipulative behaviour less positively and were often unwilling to provide extra support because they felt it was unwarranted or unnecessary. The following sub-theme discusses barriers identified by support members to providing support to older people.

9.4.4 Barriers to providing support

There were several barriers identified through the interviews with support members to providing support to older people, such as time restrictions, proximity restrictions and older people's unrealistic expectations. Most informal support members of working-age needed to take time off from work to provide older people with transport to health-related appointments, which was not always possible:

> *Well, I try to get along about once every few, every month or two. Um, it's a, it's a bit haphazard really…I mean, I do get a lot of annual leave, but the problem was er, we used it, we had to use up a lot of it for um, her medical appointments.* [Charlie, aged 50-54]

The two extracts below exemplify how informal support members considered older people to have unreasonable expectations of support which they thought should be provided to them. Matthew observed that his mother, Lisa, always seemed to find additional tasks for him to do in and around her home whenever he visited:

> *Um, so, er, you go up there to do one job and you end up with about five others. Which makes you a little bit reluctant to go up and do the first one. You know where I'm coming from? Because, like I said, I've got my life to lead as well. So you get over there, and you think "Oh, I've got a ten minute job to do", and you end up being there all afternoon. It's just a ruse to keep you there. You know where I'm coming from? I ain't stupid.* [Matthew, aged 55-59]

Una's friend, Hannah, observed that Una had expected her son, Sid, to help her too much, in the past. Hannah believed this had been the primary cause for Una and Sid's relationship to break down two years previously. Hannah gave an example of the type of instance that had precipitated the rift:

> *Well, I mean,*[Una]…*phoned* [Sid] *and said she had a spider on the floor. This is, and could he come round and but you see,* [Sid's wife] *was objecting to how much time…he was giving to his mother, I suppose. And that stopped, and er, as I say, they didn't see each other, I don't know how long it was, but this is about the second time that they've, this has been, happened, you know.* [Hannah, friend, aged 80-84]

In both extracts, it appears that older people sometimes ask informal support members to visit to provide support with tasks as a pretext for socialising. Informal support members perceived the main reason older people might ask for help was because they wanted company because they were lonely, rather than experiencing unmet need.

Another barrier identified by informal support members was a perception that older people sometimes expected too much from them. Lacey, Luke's daughter, considered it necessary to manage the expectations of older people, particularly when providing emotional support:

> *I think that um, what happens, with* [Luke] *at the moment, is that um, where* [Vera]*, kind of, um, went to see him every weekend, he kind of got used to it. And now she's realising that it can, you know, you can't have a life doing that, you, you, she couldn't go out, she wasn't going out weekends, and of course, he gets a bit upset, that we don't go over every weekend.* [Lacey, aged 50-54]

In the above extract, Luke's disappointment symbolised he was expecting too much from Vera, because she had been visiting him regularly but had recently reduced the number of visits to him. Lacey's words 'you can't have a life doing that' appear to indicate that she believed Vera visited Luke out of duty, rather than because she genuinely enjoyed his company. Therefore, Lacey considered Vera was justified in choosing to decrease the support she provided to Luke because she was doing him a favour.

Another barrier to providing support was a fear of doing a support task the wrong way, which was a reason cited by a few informal support members. Older people were

sometimes perceived as having high expectations about standards of performing a task and wanted it carried out in a specific way. For example, when describing her mother's attitude to carrying out tasks, Sharon noted:

> *She feels that she's got to be behind them all the time, or they don't do things properly. I think the only person who ever did anything properly was my Dad. And she doesn't think anyone else does it properly. I don't even think that if I did it, it would be done properly. So, I think then you'd feel like you don't want to do it for her anyway.* [Sharon, aged 50-54]

Another barrier mentioned to negotiating support mentioned by both formal and informal support members was the perception that older people had unrealistic expectations, particularly in relation to formal support members:

> *But she can be like any other person, hard work though sometimes. Sometimes, like a lot of old people, she's not the only one, expects more and unfortunately, you can't give more. You know? So.* [Mel, carer, aged 66-70]

There were several barriers identified by support members which affected their willingness to provide support to older people. Many support members tended to perceive older people as being manipulative and seeking more support from them than they were willing to provide. The following theme explores the reasons why support members chose to provide support to older people.

9.5 Overarching theme 4: Motives for providing and seeking support

Motives for support members choosing to provide support to older people varied across the different case studies. Studies have focused on exploring three main motivations to explain why family members provide support to older people: filial obligation (Stuifbergen and Van Delden 2011), exchange in the form of reciprocity (Grundy 2005; Lowenstein *et al* 2007) and altruism (Alessie *et al* 2014). Although there was evidence of each of these motives across the cases examined, interestingly, support members also expressed multiple and conflicting views about why they were willing or unwilling to enter into support negotiations. Each of the motives will be explored in turn: "feeling obligated", "reciprocity" and "altruism".

9.5.1 Feeling obligated

Some daughters tended to feel obligated to provide support because they felt that it was something which had to be carried out regardless of whether or not they wanted to do it:

> *And then we had to stay with him, fortunately, the way it worked out was I then stayed with him, brought him back here, the next day, so we had to be with him constantly and then put drops in his eyes.* [Lacey, aged 50-54]

> *The chiropodist comes to her, now...because I was starting to take her, then I started to feel so unwell…so, it's all right saying she only does this once a month, or whatever, but I may not be well, on that day. And how can I? Then I feel obliged and I have to do it.* [Sharon, aged 50-54]

In both of the above cases, the daughters had explained that they had a difficult relationship with their parent, in different ways. Lacey explained that her father, who had low support needs, had always been very judgemental towards her, which made her feel defensive. In the second extract, Sharon felt that her mother, Petra, had become too dependent on her for support with everyday tasks, in particular, with transportation, despite Petra having low support needs. Both daughters described feelings of guilt because the relationship with their parent resulted in a reluctance for them to enter into support negotiations.

Closely aligned with obligation was the sense that close family support members who provided little or no support to older relatives ought to do more. One illustrative example was where Vera, who was a main source of support for her grandfather, felt that her absent father should share some of the support tasks which she carried out:

> *And that's what's more frustrating with me and my father. Because I think he's a disgrace. He should do this stuff "He's your Dad. It's your Dad. You should do these things". Sometimes I feel like shaking him* [Vera, aged 40-44]

Vera perceived her own father to be neglecting his duties as a son because he was not willing to enter into support negotiations with his own father. Vera explained that she had confronted her father, arguing that he should feel obligated to provide support to his own father on the basis that he had been cared for by him as a child:

> *"But he needs your care, he looked after you". It's like a, um, you, you, as a parent, you bring your children up and then you, when you, when they need you, you're supposed to step in and go "OK, that's all right, I can do that".* [Vera, aged 40-44]

This account resonates strongly with the hierarchy of care proposed by Qureshi and Walker (1989) because the view of the granddaughter is that a child should provide support to their parent where there is no surviving spouse.

9.5.2 Reciprocity

Linked closely to the feeling of obligation is the idea of reciprocity in support negotiations. Reciprocity was more evident in sons' narratives, who perceived their willingness to enter into support negotiations with their mother as a form of repayment for the care and support which had been provided to them earlier in the life course:

> *Um, but then, that sort of flips over, the flip side of the coin, when something happens to them, doesn't it? So, you know, you can't refuse what they've given you. That's how it works. You know, it's give and take. Two way traffic, innit? It's not a one-way street* [Matthew, aged 55-59]

> *Because usually, I'll think to meself "Well, she did for me when I was little, you know", so it's for me obviously to do for her when she's old now. Yeah, that's the way it is, isn't it? She's looked after me, I suppose I've got to look after her, now, switch roles.* [Sid, aged 45-49]

Therefore, willingness to enter into support negotiations with older parents perceived as a form of role reversal, where informal support members would provide support to parents because it had been provided to them as children in the past.

Interestingly, a form of general reciprocal empathy was mainly evident in accounts from female support members, both formal and informal, who framed their willingness to negotiate support with older people on the basis that they were likely to be in a similar position later on in the life course:

> *And, like I say, it could be me one day. You know. I don't know, it's, it's, whatever he asks me, it, it's, it's not hard. It really isn't hard. And I, I know he can't do it* [Beryl cleaner, aged 55-59]

> *And I'd hope, well, I hope that my two* [children] *will do something like that for me. Because we're all going to get to that age, and we're all going to be at that stage.* [Vera, granddaughter, aged 40-44]

> *One day, that will be me, you know, with my daughter and I don't want my daughter to make me feel like a complete idiot!* [Sharon, daughter, aged 50-54]

Therefore, it appears that males may be more inclined to provide support to older people on the basis of past behaviour. By contrast, females seemed more inclined to provide support because they are more able to empathise with and understand the support needs of older people by "taking the role of the other" (Blumer 1969:10).

9.5.3 Altruism

Altruism was present in the interviews with support members, but was evident in conjunction with other motives linked to support negotiations. In addition to receiving payment for care and support tasks, altruism was also a motive for a few formal support members:

> *But you know, because of how he is, and he's such a nice man, you do more for him, do you know what I mean? You want to do it.* [Beryl, cleaner, aged 55-59]

> *Because I like looking after people. But that just about sums it up. I like doing my little bit. Yeah.* [Sam, carer, aged 55-59]

The above extracts suggest that individuals who were willing to negotiate paid support did so not only for payment, but also because they genuinely wanted to help older people.

The interviews with some informal support members revealed that there was more than one motive present in providing support. This was exemplified in the extract below, where Matthew describes what it means to negotiate support with and for his mother:

> *So, yeah, um,* [pause] *it's not just duty, it's, duty's a wrong thing to say. No, it's not a wrong thing to say, it is duty, but it's duty through love. Care. Because I love my Mum, of course I do. Love her to bits...So, it's neither one thing or the other. Not*

> *more than each other, it's just, it is the same, the duty and the love bit, it's the same.* [Matthew, aged 55-59]

Therefore, motives to provide support were not always easy for support members to conceptualise. This is because support members may experience different feelings towards older people at different times, which might affect how they view support provision at a given point.

9.6 Chapter Summary

Four overarching themes were identified from support members' narratives of their experiences of negotiating support with older people. The themes centred on negotiation tactics, positive aspects of negotiation, negative aspects of negotiation and motives for providing support. Negotiation tactics adopted by support members were discussed under three sub-themes: direct approaches, indirect approaches and absence of negotiation. Positive aspects of negotiation tended to centre on how support members felt about how to conduct successful support outcomes on behalf of older people. Four sub-themes were identified: "rapport building", "anticipating actions", "protecting actions" and "facilitating actions". Negative aspects of negotiation identified how support members perceived the meaning of behaviour within the negotiation process, crossing boundaries in the support negotiations, how older people were perceived as being manipulative and barriers to providing support. The final key theme explored some of the main motives for support members to provide support to older people, such as feeling obligated, reciprocity and altruism.

These four overarching themes encapsulate a range and diversity of negotiation scenarios and illuminate circumstances where support members might be prepared to provide support to older people or not. The following Chapter 10 discusses the results from this chapter and the previous chapter, where similarities and differences to existing literature will be critically evaluated.

Chapter 10 Discussion, Conclusion and Policy Recommendations

10.1 Chapter Overview

This Chapter contains a discussion of the research findings presented in the previous two Chapters 8 and 9, emanating from the inductive thematic analysis of the data from the interviews with older people and their support members. The research findings are interpreted and discussed with reference to existing literature focusing on support negotiation in addressing the four research sub-questions posed in Section 1.2 in Chapter 1. A discussion of how the theoretical issues such as convoy model, lifecourse, accumulation of advantage/disadvantage, biographical disruption and symbolic interactionism have enriched the findings will be provided. Limitations of the research are identified and recommendations for policy-makers are presented in light of the discussed findings.

The purpose of the study was to explore how older people negotiate support with tasks which are needed to be carried out in and around the home environment and from whom. Although some studies have focused on older people and what type of support they receive at home (Nocon and Pearson 2000; Barker 2002; Sims-Gould and Martin-Matthews 2010; Jacobs *et al.* 2016; Coleman *et al.* 2016), little attention has been paid to the negotiation processes which older people contend with when approaching others for help with carrying out ADLs and IADLs (Finch and Mason 1993; Horton and Arber 2004; Dunér and Nordström 2006; Grootegoed and Dijk 2012). Even fewer have explored how older people's negotiation tactics are perceived by support members (Finch and Mason 1993; Horton and Arber 2004). Eight older people, together with members of their support networks (totalling 19), were interviewed separately in order to gain an in-depth and holistic understanding of the negotiation process, in particular, negotiation tactics employed and motives underpinning support negotiations. Negotiations taking place within the home environment were dynamic and were subject to change based on the perceptions of the parties involved, the nature of the support which was the subject of

the negotiation and the unwritten conventions which each party built up over the course of prior dealings (Coeling *et al.* 2003).

10.2 Contribution to knowledge

This section will draw out my contribution to knowledge and understanding by identifying the originality of my findings and discussing them in conjunction with the care discourse and key debates on social norms, negotiation and independence, which have been explored in earlier chapters of this thesis.

An extensive examination of the literature revealed that most research focusing on social care support and older people investigated *who* provides support, rather than *how* that support has been negotiated (Silverstein *et al.* 2006; van Gaalen *et al.* 2008; Willyard *et al.* 2008; Lashewicz and Keating 2009; Sims-Gould and Martin-Matthews 2010; Grundy and Read 2012; Tetley 2013). Most recent research which has explored how older people approach social care support negotiations has been conducted in the Netherlands (Grootengoed and Van Dijk 2012) or in Sweden (Dunér and Nordström 2006). There are few qualitative studies focusing on social care support negotiations involving older people within the context of England and those which were identified are at least fifteen year old (Finch and Mason 1990; Finch and Mason 1993; Horton and Arber 2004). The research also builds on the findings of more recent quantitative studies relating to unmet need, such as Vlachantoni *et al.* (2011), Dunatchik *et al.* (2016), Vlachantoni (2017). No studies were located which examine how older people negotiate support with unmet need together with how support members perceive older people's negotiation tactics.

Therefore, this thesis makes two main original contributions overall to knowledge and understanding: it provides a unique insight into the underlying meaning of negotiations which take place between older people and members of their support network for help with social care support. The second original contribution to knowledge and understanding that this thesis exposes is in highlighting the importance for local authorities to build in an emergency plan in the event that the usual arrangements made within a Personal Budget are either terminated, or are significantly disrupted for reasons which are beyond the control of the Personal Budget holder.

The paragraphs below will provide specific evidence to support these two assertions.

Turning to the first main contribution, the majority of existing studies have focused on older people's care and support needs from either a single perspective, from a dyadic perspective or from multiple perspectives. Within the research examining a single perspective, most studies have been conducted from the standpoint of the person who provides care and or support to an older person (such as Pohl *et al.* 1997; McGrew 1998; Pecchioni 2001; Hartmann *et al*. 2016). The older person's perspective has been explored in some studies (such as Zechner and Valokivi 2012; Breitholz *et al*. 2013a; Breitholz *et al*. 2013a;), just informal support members' perspectives (such as Finch and Mason 1990; Matthews 2002; Finch and Mason 1993; Connidis and Kemp 2008), just formal members' perspectives (Olaison and Cedersund 2006; Dunér and Nordström 2010) or perspectives of the care dyad pairing (Qureshi and Walker 1989; Horton and Arber 2004). The unique contribution to knowledge of this thesis is that the research explored the perspectives of *both* older people *as well as* formal and informal members of their support network (beyond simply a dyadic pairing) within the English context.

By examining *older people's perspectives* of support negotiations, this thesis extends knowledge and understanding by revealing that older people in England tend not to explicitly ask others for support with help because presenting an outward appearance of independence was more important to them than acknowledging to others that they were struggling to cope with ADLs and IADLs. The interviews with older people revealed that they would rather conceal feelings such as desperation, distress and frustration arising from being less able or unable to manage everyday tasks than admitting that they needed help. An incidental finding within a Dutch study revealed that people generally tended not to ask outright for help with ADLs and IADLs and used tactics such as 'masking' and 'hinting' (Grootegoed and Van Dijk 2012:687). This thesis extends knowledge and understanding of circumstances when older people feel able or unable to negotiate support from others. Applying the lens of symbolic interactionism (Blumer 1969) (see Section 2.3.1) as a theoretical approach extends the findings of Grootengoed and Van Dijk (2012) because it uncovered the deeper meaning of how participants used language and symbols during their interviews when recalling and recounting past conversations relating to support negotiations (Blumer 1969). Participants interacted with each other 'on the basis of meanings they have for them…[which] are derived through social interaction with

others; and [are] managed and transformed through an interpretive process that people use to make sense of…their social worlds' (Blumer 1969:2). An analysis of the language used by older people revealed commonality that older people consider that their own needs and lives are somehow inferior to younger support members. This meaning was expressed through older people's insights of 'not wanting to bother or upset them', a perception that 'they have their own lives to lead' and appreciation of how 'busy' they were. Exploring this meaning through symbolic interactionism suggests two interpretations: first, that older people may have internalised ageist attitudes held by society that their lives and needs are less important than younger age groups. Second, that older people have internalised a perception that younger people hold ageist or a negative attitudes towards them, as a societal group. This finding concurs to some extent with existing knowledge elsewhere, for example, a study by Cahill *et al.* (2009), conducted in the United States, where older people expresses fear of 'burdening' their children with their support needs, but the main focus of the study was to compare responses from different ethnic groups, rather than exploring older people's reasons for being reticent about seeking support from support members. Therefore, older people tend to conflate the meaning of asking directly for support with being dependent because one strong message from the findings was that older people were reticent about making their support needs explicitly known, particularly to informal support members, in case they were seen as being burdensome to them. This finding suggests that older people have internalised the policy norms which embody the aspiration of self-sufficiency such as "lead[ing] an active and independent life" (Secker *et al.* 2003) (discussed in Section 3.2).

By examining how 'individuals use language and significant symbols in their communication with others' (Carter and Fuller 2015:1), symbolic interactionism thus extended knowledge and understanding of how older people communicated with others to convey an indirect request for help. Older people generally resort to using indirect negotiating tactics with informal support members, rather than voicing overt requests for help. Older people tended to interpret the meaning of hinting as a negotiation tactic as an acceptable way *for them* to communicate unmet need, in particular to informal support members, because they felt that they could preserve their independent sense of self by convincing themselves and others that they were not overtly expressing a request for help and thus were not at risk of being perceived as dependent. For older people, asking

outright symbolised an admission to the world that they were either unable or becoming unable to cope with ADLs or IADLs and thus in danger of being perceived within the frame of societal norms as being a 'failure' (Sixsmith and Sixsmith 2008). Older people described their hinting tactics as 'mentioning', rather than 'asking' or 'telling'. A successful use of hinting as a tactic (that is, when the subject of their request was achieved) symbolised for older people that they had been 'clever', because the meaning of hinting for them was not only to achieve the desired practical result, but also to sustain and reinforce a positive sense of themselves as not outwardly showing dependency. Another contribution to knowledge was that although most older people were cognisant of using hinting as a tool to indirectly highlight their need for help, others recounted memories of negotiation scenarios where they had hinted with a member of their support network about their support needs, but did not recognise that they used hinting as a negotiation tactic. This suggests that some older people use hinting subconsciously as tool when negotiating for support in situations, particularly where they were unsure of whether the outcome might be successful.

Another contribution to knowledge and understanding was in uncovering two situations where older people felt able to approach support members directly for help. Older people who could pay someone to provide formal support to them meant that they felt able to make a direct request for help or to negotiate extra support from them. This finding concurs with existing studies (Lang *et al.* 2009), but furthers knowledge by understanding the meaning for older people of asking outright for help. Older people felt able make an explicit request in situations where the nature of the support relationship was characterised by clear reciprocity, which symbolised, for them, a balanced relationship based interdependence, where both parties made a similar contribution of some sort of support to the other (Lang *et al.* 2009). The contribution stemmed from a clear understanding of a well-defined, reciprocal arrangement with formal support members (payment for services), which meant for older people that they were not indebted or beholden to others and helped to maintain a perception of independence (Sixsmith and Sixsmith 2008). In a similar way, a recent or current reciprocal arrangement arising from an interaction informal support members also symbolised a lack of indebtedness for older people, because each party could derive benefit from the arrangement and neither party felt disadvantaged. A second situation when older people would ask outright for support from informal support

members was in non-medical emergency situations. The findings showed that older people sought help reluctantly, usually as a last resort, in cases where they were unable to find another solution to meet their needs. Older people reported feeling negatively about themselves, as this type of situation highlighted for them feelings of dependency on others.

This thesis also extends knowledge and understanding by revealing that older people would be willing to accept help from informal support members who offered to help with tasks without being asked. Unsolicited help given by support members made older people feel valued because it meant for them that they did not have to highlight a need for help and thus did not feel dependent on others, which in turn, preserved a positive sense of self-worth.

By examining *support members' perceptions* of support negotiations, a further contribution to knowledge and understanding was revealed when exploring the support members' perspectives of older people's negotiation tactics through a symbolic interactionist lens. The findings showed that most formal and informal support members expressed an awareness that older people used indirect negotiation tactics when highlighting unmet need. Hinting held different meanings to support members, depending on the quality of the relationship which existed between them and the older person. For both formal and informal support members who held a positive view of the older person, hinting generally elicited a favourable response, and older peoples' indirect requests were invariably fulfilled. Those who enjoyed a positive relationship tended to describe older people's hinting as 'mentioning', symbolising a neutral approach to recounting older people's hinting tactics. Support members who expressed negative feelings about older people were less tolerant of the use of hinting as a tactic for meeting unmet need, and tended to symbolise it as 'moaning'. Support members who viewed older people less favourably expressed a wish that they would be asked directly for support, because a hinting tactic made them feel annoyed or guilty.

Another contribution to knowledge was in highlighting the prevalence of ageist attitudes held by many support members, who construed older people's support needs as being of 'low priority'. Some support members suggested that older people 'overplay their inability' to carry out tasks or tended to 'exaggerate' pains or 'pretend' being unwell to gain sympathy, or because they were 'attention-seekers'. In these circumstances, older people's hinting requests were usually not fulfilled or were fulfilled reluctantly. Thus,

through examining the perspectives of support members about older people, together with older people's negotiation tactics makes a further important contribution to understanding how older people's needs may been unmet in the following two ways. In cases where support members are sceptical about the legitimacy of older people's support needs, or hold ageist attitudes towards them, support members may be less willing to provide support. In addition, older people's hinting tactics could pose additional risks in two ways. First, support members who are disinclined to provide help to them could legitimately ignore indirect requests for help, because the requests were not explicit, which could result in older people at risk of being unsupported. Second, support members who are unaware of older people's hinting tactics may not recognise that older people are making an indirect request for help and may treat the hint as a normal part of a conversation, again leaving the older person at risk. Older people whose needs remain unmet and who do not seek an alternative solution may attempt to carry out tasks themselves and put themselves at personal risk. In addition, in line with Minichiello *et al.* (2000), older people are more affected by ageist attitudes directed at them by their relatives and whose opinions matter to them, which could contribute towards older people feeling less willing to seek help from informal support members whom they sense bear negative feelings towards them or who disbelieve that they are unable to perform ADLs or IADLs.

Turning to the second main contribution to knowledge that this thesis offers, it adds to the limited but growing body of literature which examines older people's personal experiences of using PBs. The findings which extend knowledge and understanding will now be explained. First, the two older people with PBs had a limited scope to pay for activities which were aimed at promoting socialising. The PB funds and time allocation appeared insufficient to meet older people's needs, as in both cases, it became necessary for the older person to negotiate with formal carers in order to substitute one type of care activity for another, for example, to forgo a shower for a shopping trip, or a personal care task to go to the gym, which would invariably result in some form of unmet need. A second important way that the research extends knowledge is by providing insight into the challenges faced by older people of needing to renegotiate contingency support within a PB in emergency situations. This was particularly evident in Hamish's case study, when both of his PAs left his employ at the same time, and he was left unsupported. In

making contingency arrangements, Hamish engaged the same care agency that provided him with help at the weekends because he was familiar with the care staff, but in doing so, inadvertently breached the terms of his PB and was about to face official consequences from the local Council.

10.3 How is social care support negotiated by older people from different sources?

This question will be addressed by firstly examining the different sources which older people used to arrange support, in particular, examining the negotiation tactics adopted by older people. Older people's support networks were mapped using a convoy model (Antonucci *et al.* 2013) and the nature of the relationship in terms of the type of support provider and the support given was plotted. While it was helpful as an exercise to map the individuals from whom older people negotiated support with, it could only provide a snapshot of those providing support at a particular point in time, as the convoy model could not convey the complexity of characteristics within the individuals themselves and how this impacted on quality and nature of support negotiations over time.

10.3.1 Sources of support

In the present study, all participants lived alone in their own home with a diversity of support needs and arrangements. One clear message from the findings was that all older participants in the present study were active agents in managing personal care and practical tasks which characterise daily living, such as ADLs (bathing/showering, dressing, washing, cleaning, toileting) and IADLs (housework, managing finances, shopping, lifts to medical appointments, house maintenance). Carrying out as many ADLs and IADLs within their home space as practicable without needing to negotiate support from others was important not only because this symbolised independence, but also helped older people retain a sense of control over their environment. These findings are consistent with Barken (2017:8), where "*maintaining independence*" was considered a crucial goal for older people living at home. Most older people perceived themselves as self-sufficient, despite having differing levels of need (low, medium, high), and only wanted to seek help from others when they chose to. This finding accords with studies carried out elsewhere, in particular Dunér and Nordström (2010:245) where older people "…*wanted help on*

their own conditions; they wanted to have control over their everyday lives, as well as who they received help from". In particular, the two males with the highest needs level were unusually determined to carry out ADLs and IADLs, devising creative solutions to adapt to their decline in abilities to perform tasks. In line with Langford *et al.* (2018), having a tenacious disposition enables older people to find different and creative ways to navigate performing tasks in and around the home. This finding also aligns with Smith *et al*. (2007), where male identity is closely linked to independence. One argument here is that older people, and older males in particular, have internalised societal and policy messages linked to the undesirability of being seen as dependent on others for support and will search for ways to carry out tasks alone, without involving others. The findings here align with the study by Sixsmith and Sixsmith (2008), where it was important for older people to continue to live in their own home, but at the same time, the findings revealed that the home environment presented challenges which older people needed to find ways to overcome in order to manage.

In line with a recent Ipsos MORI (2017) report, the participants in the present study with medium and high support needs reported that they took longer to perform ADLs and IADLs. Older people would often devise innovative ways in which to perform ADLs and IADLs, rather than seek help with tasks, which also resonates with the findings from the Ipsos MORI (2017) report. IADL tasks involving balance were often perceived as too challenging for older people to attempt because they were fearful of falling (such as cutting branches, trimming hedges, cleaning windows, washing curtains and decorating). Contrary to Ipsos MORI (2017), who polarised older people as being either resilient or lacking confidence to perform IADLs, participants in the present study recognised the limits of their capability and weighed up the extent to which they could perform tasks safely. In cases where older people were unable to perform tasks by themselves, they tended to negotiate their own solution to meet their need. Most engaged a cleaner or gardener to assist with IADLs, and arranged for ADL needs to be met by paid carers, either through the local Council or paying using Carers Allowance. Surprisingly, there was little evidence of receipt of voluntary support by older people in their support network (as participants had been recruited from a charity). One participant reported deriving huge benefit from his weekly visits from a volunteer, who had visited him for a number of years. This accords with Lilburn *et al*'s (2018) finding that volunteers help improve older

people's wellbeing. However, when interviewed, the majority of participants reported having received visits from volunteers in the past, but services had either been withdrawn owing to austerity measures (Lloyds Bank Foundation for England & Wales 2016) or volunteers had left without warning. Withdrawal of volunteers often had a negative effect on older people's self-esteem, as older people believed they had established a meaningful relationship with their volunteer over a period of time, and consequently felt devalued when the visits ended.

In general, older people who were unable to perform IADLs had negotiated support themselves and engaged a cleaner or gardener privately. In line with older research by Phillips *et al.* (2000), who focused on support provision of older people living in three geographical areas of England in the mid-1990s, and more recent research exploring the Swedish context (Dunér and Nordström 2007), the present study found that older people tended to draw on support with IADLs from some members of their support network, but not all. This strategic approach was conceptualised by Dunér and Nordström (2007:76) as "*using what you have*". However, the findings in the present study also revealed that even when informal support members had provided assistance with IADLs before, older people were reticent about negotiating further support from them.

This finding resonates with Finch and Mason's argument relating to family obligations, specifically that "*expecting help is not acceptable*" (Finch and Mason 1993:139). Second, older people opted not to ask informal members for help with IADLs such as housework and gardening, because these tasks were considered ordinary and usual, which individuals generally perform as part of a household routine. Older people were mindful that informal members often balanced their own housework and gardening with other life commitments, such as employment and caring for children. The finding is in line with several studies (Lewinter 2003; Cahill *et al* 2009), where older people did not expect their needs to be prioritised by their adult children. The next three sub-sections will focus on the negotiation tactics used within support negotiations.

10.3.2 Indirect negotiation

No other studies were located which focused specifically on negotiation tactics adopted by older people when they arranged support with others. Rather than asking informal support members directly for support with ADLs and IADLs, the findings showed that

older people frequently adopted an indirect approach to communicate awareness of their unmet support needs to others, particularly for help with IADLs. Hinting was commonly used by older people to disguise they were making a direct request for help. Older people tended to use hinting because it was a way of preserving their sense of self by communicating their need indirectly, rather than risk being perceived as being needy or dependent. It was also a way to avoid risking the embarrassment of a direct request being rebuffed. Being independent, or giving an impression of independence, was of paramount importance for many older people, particularly for those with high support needs.

Some older people used hinting as a negotiating tactic consciously as a premeditated ploy to communicate their needs and believed that it successfully concealed an indirect request. Others seemed unaware that they used hinting, choosing language to describe unmet need in an oblique way, such as a task 'wanting doing', rather than 'needing to be done'. From the perspectives of informal support members, most tended to recognise when older people used hinting in interactions to seek support with a task. This was contrary to the general finding in a Dutch study, which found that "*relatives do not always understand or act upon subtle hints*" (Grootegoed and Dijk 2012:688). In the present study, family support members recognised hinting and some chose to act on hints while others did not. Support members who were reluctant to provide support to older people symbolised hinting as 'complaining' or 'moaning'. Support members who were amenable to acting on hints recounted them as an integral part of a conversation with an older person (for example, 'mentioning'). Thus, support members who provided support for altruistic motives were more inclined to act on the hint and meet the need that was being indirectly expressed. Hinting can potentially be a risky tactic as support members could legitimately ignore it, meaning that older people may be at risk of harm if their needs were unmet and they opted to carry out tasks which they felt unable to perform safely. The success of hinting as a negotiation tactic for older people appeared to depend on three factors: the quality of the relationship existing between the parties, the objective of the hint, or urgency. Hinting appeared to be successful in cases where the older person was viewed positively by the informal support member, or if the objective was easy to resolve, or it was time-dependent. Hints for purchasing items were often fulfilled because they were simpler to resolve than performing tasks that were time-consuming and which

involved physical effort, such as gardening or decorating. Only two studies examined hinting superficially within the context of families: Finch and Mason (1993) and a more recent Dutch study by Grootengoed and Van Dijk (2012). Both studies examined how families negotiate responsibilities in a wider context, rather than older people in particular. The essence of hinting in the present study accords with Finch and Mason's general definition of hinting as "*a process which enables someone to make their needs known while at the same time preserving the principle that you should not ask for help directly, and not show that you expect to get it*" (Finch and Mason 1993:140). The present study extends knowledge by focusing on circumstances where older people used hinting as a tactic and its success or otherwise, particularly when communicating unmet need to members of their informal support network, and also by exploring support members' reactions to hinting.

Almost all older people implied that they did not expect informal support members to provide them with support. However, if a support member chose to offer assistance with a task without being asked, then older people would accept help with it. Not needing to ask for help symbolised for older people that they were respected, and that someone was taking a genuine interest in their welfare. The findings showed that older people appreciated instances where support members had noticed that a task needed doing and had offered to help, without needing to be asked or for older people needing to resort to hinting. This finding is consistent with Stuifbergen *et al* (2012:262), where "parents valued a voluntary nature of support given to them, which confirmed their value as a person, not just as a needy person". In addition, those with medium and high needs reported needing help with personal tasks such as bathing/showering, dressing, toileting. One unsurprising finding was that older people did not want to negotiate ADL support from informal support members, which concurs with the findings of Daatland and Herlofson (2003) and Stuifenbergen *et al* (2010).

Contrary to the findings from Dunér and Nordström (2007:82), older people did not always consider informal support members inspired "*feelings of belonging, security and wellbeing*". Almost all participants were lacking in emotional support, reporting feelings of loneliness and expressing a desire to see more of their relatives. A similar conclusion was reached by Cahill *et al.* (2009) and Stuifbergen *et al*. (2010), where socialising with family was a seldom occurrence. In particular, most older males in the present study

reported feeling isolated from their respective families for a variety of reasons. Some described their interactions with adult children as difficult, owing to events which occurred earlier in the life course (such as adultery, divorce and childlessness). The impact of these past events on their current relationship adversely affected older males' willingness to openly voice their unmet needs to family members because of fears of being perceived as dependent. In addition, adult children tended to avoid visiting their father and appeared reluctant to provide support. The present study confirmed the finding in Lin's (2008) study which found that divorce negatively affected an adult child's propensity to provide support to a father in later life.

10.3.3 Direct negotiation

Direct negotiations were characterised by asking outright, or making requests explicitly (Finch and Mason 1993). The findings of this thesis revealed an unwillingness for most older people to directly ask informal support members for help with IADLs and IADLs. Not being dependent, or not being perceived as dependent, was an important consideration for all older people, especially for older people who were parents. Some older people considered their self-perception as a parent would be undermined if they asked their children for help. Independence meant not asking family for help and giving an impression that they were still able to cope with tasks in and around their home. A reason for this was because older people did not want to be seen as a burden to their children, which some framed as 'not wanting to upset them'. Yet older people reported feeling desperate and worried, not because IADLs were outstanding, but because the lack of fulfilment symbolised for them that they were finding it harder to cope with living alone. This finding accords with Breheny and Stephens (2012:445), who noted "*older people may either accept a position of dependency, or maintain their independence at great cost to their health and wellbeing*". However, the findings also revealed that older people would enter into direct negotiations with informal support members in emergency situations or as a last resort, usually from a person who was most likely to provide a solution to the immediate problem. This finding reveals that there were some situations in which older people did "expect" that others would help them and the urgency of the situation provided justification for seeking support directly. This finding builds on Finch and Mason's (1993:141) who maintained that relatives did not tend to ask for support directly because it conveyed an "expectation" that help would be provided. However, the finding

does accord with Breheny and Stephen's (2012:442) idea of family "'being there'" in a crisis situation for most case study participants.

Older people tended to feel able to enter into direct negotiations with friends with whom they had a reciprocal arrangement. Friends reported providing support such as giving lifts in the car, shopping and socialising, but were adamant that they would not be prepared to engage in ADL tasks, which aligns with the findings from Nocon and Pearson (2000). Contrary to Nocon and Pearson (2000), reciprocity was evident as a motive for providing support, which enabled older people to "*maintain a proper balance between dependence and independence*" (Finch and Mason 1993:49).

Older people more usually adopted a direct approach to ask formal support members, with whom they were engaged with on a contractual basis (such as a carer, gardener or cleaner) for assistance with tasks outside of the scope of the original agreement. Most formal support members obliged where possible, depending on the nature of the request and also whether there was flexibility in the agreement existing between them. Cleaners and gardeners were more likely to be asked, and be willing to perform, extra IADLs, such as shopping. This finding accords with Hale (2006) as cited in Barrett *et al* (2011), once a rapport has been created, formal support members are usually willing to perform additional tasks for older people. Reciprocity was also evident in contractual arrangements because older people made payment for services. Older people tended pay extra to appreciate the tasks performed, or offer 'in kind' goods such as food or alcohol, a finding mirrored in Breheny and Stephens (2009:1308) as an "equivalence of giving and receiving".

In addition, the presence of a personal alarm symbolised independence for all participants that wore them because they gave reassurance that in the event of a medical emergency, they would be able to arrange medical support. As all of the participants in this study lived alone, this finding is in line with Nyman and Victor (2014). In line also with Nyman and Victor (2014) is the finding that participants with higher support needs tended to use them, which accords with the findings, as Luke (with low level needs) did not have an alarm, and Petra only had an alarm because her daughter insisted that she wore one, and this was arranged by her daughter and paid for by her youngest son.

10.3.4 Absence of negotiation

Absence of negotiation was evidenced from the interviews with some informal support members suggesting that they felt they took away control from the older person in some situations, particularly when an older person appeared, to them, incapable of carrying out specific tasks. This finding aligns with Horton and Arber (2004:84), where support members who were seen as adopting a similar tactic were described as “protective”. However, this finding is contrary to Horton and Arber’s (2004) findings, where only sons were reported adopting this tactic with mothers. In the present study, there was evidence that both daughters and sons used this tactic with mothers, but not fathers. In the present study, daughters expressed reluctance at needing to take over control and were concerned that the approach fostered dependency, a finding which concurs with Matthews (2002), where daughters who provided higher levels of support to parents promoted a dependent response. In the present study, sons who took away control described their motivation for doing was to facilitate their mother’s independence, rather than undermine it, a view that contradicts Horton and Arber’s (2004) study which found that such actions decreased independence. It is unclear why older mothers did not report being on the receiving end of this tactic. Possible reasons could be that the behaviour has been normalised, or that it engendered embarrassment or humiliation, or that type of behaviour within the family unit has been normalised over time.

10.4 To what extent do support arrangements change over time?

This thesis also sought to uncover the extent to which support arrangements were renegotiated by older people over time to provide a better understanding of push and pull factors underpinning changes in support provision. Convoy theory (see Section 2.3.2) seeks to explain how the structure of older people’s support networks alters during their lifetime (Phillips *et al.* 2010; Antonucci *et al.* 2013). An analysis of the eight case-studies generally revealed that older people’s support arrangements had changed very little over the time under investigation (six months). In all but one of the case studies, older people’s circumstances changed very little over the time-scale and reported little change in their health conditions or in the people providing them with support.

To help address the research question, instances in the data where older people talked about historical support experience, or future plans for support were drawn upon. The research results show that older people tend to negotiate support from individuals who already form part of their support network, rather than building up new relationships with strangers, unless necessary. One important finding was when older people needed to expand their support network to fulfil an unmet need, they tended to refer to others in their support network and be guided by their opinions. “Word of mouth” was an important resource which older people used to negotiate support when it could not be fulfilled by other sources. This finding corresponds with Coleman *et al* (2016), where social networks facilitated locating trustworthy individuals to carry out house repairs. The findings indicate that older people would generally need to renegotiate support under two circumstances: in response to fluctuations in older people’s health and/or to replace or recruit support members. Uncertainty about future support needs and arrangements were evident, and older people tended to live day to day, which resonates with Clarke and Warren (2007:480)’s finding “that living in the present was more meaningful than thinking about the future”. All older people were fearful of entering residential care in the future. Residential care was perceived as a place of loss, of independence, autonomy and freedom. This finding chimes with the views of participants in Clarke and Warren (2007), who expressed similar negative views about dependency and passivity.

Barriers and facilitators which influence older people to negotiate support from different sources will now be examined.

10.5 What barriers or facilitators are available which influence older people to negotiate support from different sources?

Barriers and facilitators to negotiating which were evident in the present study will be discussed. Broadly speaking, the findings of the present study were similar to Zechner and Valokivi (2012), as support negotiation is a subjective process which is influenced by the roles and characters of the parties involved, the nature of their interactions and also how accessible and available members of the support network were to meet older people’s support needs. Barriers and facilitators to older people negotiating support from different sources will now be examined.

10.5.1 Barriers to older people negotiating support

Barriers to older people's abilities to negotiate support with informal support members which were identified in the findings were geographical and emotional proximity, lack of availability and not wanting to bother support members. Seven of the eight older people interviewed in the present research had adult children; only one was childless. In most cases, adult children lived within a 50-mile radius. Two daughters lived abroad. Contrary to the findings of Pillemer and Suitor (2013), the geographic proximity of adult family members did not mean that older people would negotiate support from them. Particularly, a daughter living nearby did not mean that she would be willing or able to provide support to her parent. Contrary to the findings of van Gaalen *et al* (2008), where children living closest to their parents tend to visit more frequently, in the present study, two of the adult daughters who lived closest to their respective parent did not visit them often. One possible explanation for the inconsistency was because one daughter had a debilitating medical condition. The other daughter had not forgiven her father for divorcing her mother many years before. Analysis of the interviews involving father-daughter dynamics revealed that relationships between daughters and fathers were less close than mother-daughter bonds. This was contrary to the findings of Horton and Arber (2004:87), where findings indicated that daughters tended to take "engaging actions" where fathers were gently encouraged to find solutions to preserve sense of self. The findings revealed that informal support members often gave an impression of being too busy to visit older people to provide support. This presented a barrier to older people in two ways. First, on a practical level, support members were not available to provide support. Second, older people felt that they could not ask support members for help in the future because they did not want to bother them or appear as dependent.

Older people therefore felt that their support needs represented a lower value than younger family members. Another linked finding was that older people tended to conceal their support needs, rather than make them known to support members. Older people would rather convey an impression of being independent than ask assistance from support members who appeared unwilling to provide help. This finding concurs with Grootegoed and van Dijk (2012:688), who also found that older people use "masking" as a ploy to hide their feelings so that family members would not become concerned, or position them as dependent.

Three of the older participants were not entitled to state support because they did not meet the eligibility criteria in force at the time of the research, which represented a barrier to them seeking formal support. All three participants were on low incomes, so engaging the same type of support privately would have proved challenging. Three important findings from the research will now be discussed. First, older people who approached social services departments for support were unclear about which options were available to them or how to negotiate the social care system. This was exemplified in Hamish's case study, where advice provided by the local Council was contradictory or non-existent. Telephone advice lines were either constantly busy or referred service users on a circular journey back to the initial number they dialled. Being tenacious was a characteristic evident in both Hamish and Lisa, which enabled them to negotiate the social care system. There was little information provided by the Council about what direct payments could be used to pay for. This finding was similar to research carried out by Newbronner *et al* (2011), who also found that there was a dearth of clear information provided to service users, particularly about what services the personal budget could be used to purchase. A surprising finding of this thesis was that local Council staff had little knowledge how to recruit and employ their own care staff. Social care staff referred service users to a local charity aimed at supporting people with disabilities for advice and support on direct payments. In addition, the Council took two years to process Hamish's personal budget and he was eventually told by Council staff to negotiate the size of his personal budget with the charity staff. Older people with low and medium support needs were unable to negotiate formal support because they did not meet the eligibility criteria in place at the time. Petra and Luke were both able to perform most ADLs and IADLs, but recognised that they were finding IADLs such as making the bed and doing the gardening challenging.

Fear of being placed in care was also an important barrier to older people seeking support from the local Council. The older participants were unanimous in expressing a dread of ending up in a care home and having to leave their home environment. Keith, in particular, refused to contact the local Council for his needs to be assessed because he believed that if he did, he would be placed in a care home against his will. This finding is broadly similar to research carried out by Phillips *et al* (2000) more than twenty years ago, which found that older people were, at best, unsure about the services which the

local Council offered, and at worst, feared a loss of autonomy. The findings tend to show that little has changed over time in terms of enhancing older people's awareness of the services which older people are offered by local Councils.

Support members tended to symbolise older people's attitudes of unwillingness to seek support or follow their suggestions as stubbornness. The thesis builds on Heid *et al's* (2014) study exploring adult childrens' perceptions of their parents' obstinate behaviour by understanding situations where older people display stubborn characteristics in two ways. Some adult family members symbolised their older relatives' behaviour as infantile, which suggested they took a stereotypical and ageist attitude to them, as they did not take their viewpoint seriously. The findings cannot be compared here, as no study was located which also explored formal support members' perspectives of older peoples' negotiating tactics.

10.5.2 Facilitators

Three main facilitators were identified which influenced older people to negotiate support from both formal and informal sources: if a good rapport existed between the parties, if support members were able to anticipate their support needs or if there was evidence of reciprocity in the relationship, whether in the past or more recently. A clear finding from the present study was the importance of building a good rapport between the older person and the support member. This was of particular importance between older people and formal carers in situations where older people might need to communicate potentially embarrassing personal issues such as incontinence. This finding concurred with Atree (2000), where it was found that developing a rapport was perceived as an important integral part of caring. Rapport building is also an important facilitator for fostering an atmosphere of trust and reflects a degree of warmth, which helps to obviate feelings of dependency (Breheny and Stephens 2012; Wiles 2002). The ability to anticipate care needs was also seen as facilitating support negotiation. The present study found that older people valued situations where support members noticed a task needed doing and were able to pre-empt unmet need. This finding is aligned with Horton and Arber (2004) and Bowers (1987) (as cited in Horton and Arber 2004:77). The latter study having identified the ability to anticipate care needs as part of a typology of care provision. Older people and support members both identified two polarised types of

person: those who could empathise and anticipate care needs and those who were incapable. The ability to anticipate support needs was described as an inherent trait and not a skill which could be learned. This finding concurs with the first step proposed by Tronto (1993) in terms of noticing that older people need some form of support (see Section 3.2.3).

Relationships based on reciprocity were perceived as facilitators to the support negotiation process because older people and support members were each acting to each other's benefit at a similar cost. In line with Finch and Mason (1993:51), parties to relationships based on reciprocity need to "[negotiate] *the balance between dependence and independence*". In the present study, a few adult children, particularly sons, felt that they were repaying their mother for bringing them up and that helping out was inevitable form of 'turn-taking'. This finding is aligned to Stuifbergen *et al (*2010:261), where "the children's view went with a long time perspective, wishing to do something in return for the things they had received in the past".

10.6 How do older people negotiate arrangements within a personal budget and what factors influence that choice?

Turning to examine how older people negotiate arrangements within a PB, three case-study participants received PBs: Hamish and Lisa via direct payments and Leslie through a managed PB. Leslie was unaware that he was in receipt of a managed personal budget and knew nothing about direct payments, which suggests this option was offered to him without him actively making an informed choice about whether or not to receive direct payments. This finding concurs with previous research which highlighted that social care staff do not always promote direct payments to older people, which suggests that older people are not always given the choice to arrange their own care and support (Baxter *et al.* 2013; Ellis-Paine *et al.* 2014; Woolham *et al.* 2017). Hamish and Lisa were both confident and articulate individuals, and might have been perceived as capable of managing their own PB, which could explain why they were offered direct payments as an option. Two key findings emerged from the present research, which build on existing knowledge of older people's experiences of negotiating within PBs. First, both PB holders reported there was no recruitment database available through the Council or guidance from staff on how to manage a PB. A surprising finding was that both participants were

referred to a local charity aimed at helping disabled people for advice and assistance with setting up accounts and recruiting PAs. Hamish used his direct payments to employ PAs and Lisa paid a family-run care company to attend her. Hamish's daughter, an accountant, managed his PB and Hamish reported that he would find administering the paperwork impossible. This finding concurs with other literature which has examined practical considerations of PBs (Slasberg and Beresford 2016; Glendinning *et al* 2014; Woolham *et al* 2018). A second surprising finding was in Hamish's case, where there was no contingency in place to meet an urgent situation which arose when both of his PAs left at short notice. Hamish was left unsupported, with no carers and no contingency fund built into his PB to help him to pay for care and support. Hamish arranged care with the same local care agency that the Council commissioned care from and unwittingly contravened the Council's rules. No study was located which examined contingency plans within PBs

10.7 Conclusion and Policy Recommendations

10.7.1 Reflection on the theoretical issues

This section will explore how the theoretical issues of the convoy model, lifecourse perspective, accumulation of advantage and disadvantage, biographical disruption and symbolic interactionism as discussed in Section 2.3 above have enriched the findings in this research.

At the outset of Stage Two of the field research, a convoy model was created for each of the eight case studies to gain a deeper understanding of which individuals older people considered belonged within their support network (Antonucci *et al.* 2013; Kemp *et al.* 2013). Exploring an older person's social convoy enriched the findings because it facilitated an understanding of who formed part of the older person's network. Three circles were drawn, each surrounding the other, and the older person was placed within the centre circle. Individuals whom older people considered were closest to them emotionally were placed in the circle nearest to the older person, and those who were more emotionally distant were placed in the outside circle (ibid.). This exercise was carried out at two different points in time over a six month period in Stage Two of the research (December/January 2014 and June/July 2015) in order to map changes in the older person's support network (ibid.). In all but one case (Hamish), the support members

of all participants remained unchanged, but nevertheless, a convoy model is particularly useful in longitudinal research over a longer time period, which maps changes in support networks (ibid.). The convoy model was also useful to understand who formed part of the older person's network and who they negotiated support from. In cases where older people felt emotionally close to a formal support member, they tended to use a direct approach to negotiating support (for example, Leslie, Hamish, Barry and Lisa). In cases where older people felt emotionally close to informal support members, older people tended to use an indirect approach such as hinting (Luke, Una, Keith and Petra). Using a convoy model added value to the research because it mapped who was potentially available to supply support to older people with unmet need. The existence of a large support network, and having adult children did not guarantee that older people would choose to negotiate support from them because the nature and quality of the relationship existing between the parties. However, one disadvantage of exploring an older person's social support network in this way is that it does not facilitate the quality of the relationship which exists between the parties (Dykstra 2015).

Reflecting on how adopting a life course perspective enriches the findings, the approach facilitates considering how older people's lives have become *linked or intertwined* with others (Elder 1994). Understanding how interactions with members of the support network were shaped over the life course helped to explain why some older people felt more able to draw on support from adult children than others (ibid.). The life course approach also helped to understand how *the timing of events* which happened in older people's past, such as having children, getting married or divorced or remarried, or becoming widowed affected changes in who formed part of their support network over time. The life course approach is key to understanding not only *who*, but also *why* certain individuals did or did not take part in negotiations to meet older people's support needs. The findings show that events earlier in the life course can have a positive effect, which is exemplified within Petra's case study, where her youngest son, Grant, willingly provided support such as gardening and decorating Petra's house. Both Petra and Grant spoke fondly of each other and enjoyed a close relationship, despite the physical distance between them. Conversely, earlier events can also have a negative effect: after Barry's extra-marital affair twenty years before, Barry's daughter still had not forgiven him for leaving her mother, and visited him infrequently. Barry described his relationship with his

daughter as 'difficult' and would not consider asking her to help him. After his diagnosis with Parkinson's disease three years beforehand, and the subsequent death of his second wife, Barry received no support from either of his children. Barry negotiated paid support from an acquaintance, Kate, who helped him with personal care and carried out household tasks. Barry also negotiated a reciprocal arrangement involving the use of his car with his friend, Gerry, in return, Gerry did his shopping and ran errands.

In addition, adopting a life course approach reveals that relationships with others are dynamic and need to be renegotiated over time (Elder 1994). This is exemplified well within Una's case study, where Una and her only son had not spoken to each other for several years. As a result of a recent intervention by Una's long-standing friend, Hannah, Sid and Una repaired their relationship and became close again. At the time the research was carried out, Sid was playing a key role in providing support to Una, taking her shopping regularly, drying her clothes and carrying out various maintenance tasks in and around her home. Hannah commented that there was a high chance that the relationship between Una and her son would not remain stable for too long and would likely follow a similar pattern owing to Una's volatile personality. Hannah attributed Una's temperament to her having a difficult life, as Una had had a difficult childhood and was subjected to physical and psychological abuse in both of her marriages.

Exploring how an accumulation of advantage and disadvantage over the course of an older person's life, the findings were enriched because it helped to form a deeper understanding of how earlier events might affect one's circumstances in later life (Dannefer 2003). A disadvantage linked to absence of family members within an older person's support network, such as childlessness, or the death of a spouse or other relative earlier in the life course could potentially accumulate so that in later life, an older person's support network is more limited (Umberson *et al.* 2010). Traumatic events occurring earlier in the life course, such as parental divorce and family rifts negatively affected the quality of the current relationship between older people and their relatives. This affected the quality of negotiations and thus the willingness of support members to provide support. In cases where support was provided, it was out of a sense of obligation or duty (Lacey to Luke). Equally, a relationship historically characterised by mutual affection positively affected the quality of the current relationship in existence, meaning that support members tended to provide support out of a sense of altruism (Barry to

Petra). Exploring the impact of how major long-term health issues resulted in an accumulation of disadvantage for some older participants. In most cases, poor health had impacted on participants' ability to work, and they were thus in a worse financial position in later life (Marmot 2010). Poor health also which resulted in many older people being increasingly unable to perform ADLs and IADLs (Marmot 2010).

Biographical disruption enriched the findings because older people tended to need to negotiate support from members of their support network as a result of a disruption to their state of health. As older people start to process their changed health status, they become aware of changes in their physical capabilities and how this impacts on their ability to perform ADLs and IADLs. This, in turn, triggers the need for a 'mobilisation of resources' (Bury 1982:170) in terms of how an older person might arrange support for themselves or how they might arrange support from others.

The sociological concept known as biographical disruption enriched the findings because it provides a framework within which to construct what long-term illnesses *mean* to an individual, how they come to terms with the changes arising from the health condition and how they choose to negotiate everyday social care support which arise from it (Bury 1982; Yuill *et al*. 2010). Biographical disruption was evident in most of the case-studies: Lisa (COPD and chronic arthritis), Petra (agoraphobia), Una (chronic arthritis), Hamish (hemiplegia resulting from a stroke), Leslie (chronic arthritis), Barry (Parkinson's Disease) and Keith (chronic arthritis and partial paralysis). Luke was the only participant who was not diagnosed with a life changing health condition. However, one commonality reported by participants was balance issues, which made them hyper-aware of their physical surroundings and the potential they held for causing injury. To participants, this meant a loss of confidence in performing any household or gardening tasks which required elevation or over-reaching, as this might risk falling and injury. Older people most often reported needing help with tasks such as cleaning curtains, painting and decorating, hedge trimming and cutting overhanging branches.

In addition to drawing out the meaning for participants of developing a long-term health condition, symbolic interactionism enriched the findings by providing a deeper appreciation of the meaning for older people of negotiating support to meet their unmet needs (Blumer 1969). The findings revealed that most older people equated the need to

negotiate support from others with a loss of independence (Sixsmith and Sixsmith 2008; Lloyd 2012). For many older people, their traditional familial role, or roles played earlier on in their life course formed an integral part of their self-perception. Often, this meant an inner struggle between how they felt and how they thought that they should feel, which led to a subjugation of their own needs. As a result, many older people were reticent about openly seeking help from others, particularly their adult children. The thematic analysis of the interview data helped to reveal common themes across the interviews, in particular, that older people would often 'disguise their unmet need' because especially for older mothers, the meaning of making unmet needs known to their children was in direct conflict with their engrained view that they should be caring for their children, and not vice versa. Again, examining what this symbolises in light of the care discourse suggests an ingrained view that females should be 'natural carers' (McKie *et al.* 2001), putting others' needs above their own. Using symbolic interactionism facilitated understanding the underlying meaning of unmet need how to meet it. Many older people, particularly older females, faced an inner dilemma between openly negotiating with their children for support and concealing their needs to convey an outward impression of independence to comply with societal norms. Thus, exploring older participants' perspectives through symbolic interactionism helped in understanding the circumstances when older people felt able, or unable, to approach members of their informal support network to negotiate for support with tasks. This depended, in part, on the meaning that acknowledging that they needed support held for them, together with the quality of the relationship which existed between them. In the same way, exploring support members' perspectives through symbolic interactionism extended knowledge by understanding not only their perceptions of older people's negotiation tactics, but also the tasks which older people indicated that they needed help with.

10.7.2 Conclusion

To conclude, the results from this thesis highlight a number of important issues arising surrounding older people and support negotiation in relation to unmet need, which are in line to some extent with previous findings. To summarise, the findings have shown that maintaining self-sufficiency is a paramount consideration for older people in light of how they perceive their sense of self and how they conduct themselves in social support negotiations. Roles assumed earlier in the life course reflect how older people perceive

themselves and how others perceive them and in turn, how these roles affect support negotiations. Older people's decline in physical and mental health can result in them becoming increasingly unable to perform ADLs and IADLs in their home environment, leading to unmet need. Correspondingly, older people's self-identity can become eroded in tandem with increasing physical limitations.

The findings show that many older people have a tendency to conceal unmet need from informal support members. One main reason that older people are reticent about making informal support members aware of their needs is because they equate asking for help with being dependent.

One coping strategy for older people is presenting a façade of independence to support members, particularly informal support members, in order not to cause them concern.

The findings also revealed a perception by older people and informal support members that older people's needs and commitments have a lower priority than younger relatives, which appears to be consolidated by casual ageism from family members. Thus, older people tend not to ask informal support members for help either because they do not want to be seen as a burden, or because they do not want to cause concern.

Generally, older people do not ask informal support members for help, particularly with IADLs such as gardening and tasks associated with housework because of their ordinariness, coupled with the perception by older people that such tasks ought to be the responsibility of the house occupier. In addition, older people tend to interpret 'busyness' as a pretext used by informal support members that they are unwilling to provide support.

The findings show that older people tend to accept support if it is offered willingly, or if support needs are anticipated, because this can indicate that the person providing support is motivated to do so by feelings of affection, rather than out of duty or obligation.

Older people in receipt of a PB reported numerous barriers to identifying information relating to PBs, how to administer PBs on a practical day-to-day basis, no formal, monitored system for recruiting new PAs and no formal review. Most importantly, the

findings showed that no contingency fund to cater for emergencies had been built into the PB at the outset.

These are two original findings identified from the results of the research, which should be of particular importance to policy-makers which will be examined further below, together with anticipated implications for policy purposes.

10.7.3 Unmet need: policy implications

As outlined in Section 10.3 above, older people tend not to ask informal support members directly, such as family, friends and neighbours, for support with ADLs and IADLs. Older people tend to use indirect negotiation tactics, such as hinting, in order to vocalise unmet need. Hinting is a risky tactic for an older person to use to communicate unmet need, for two reasons. First, if the other party interprets hinting as making a request and is disinclined to fulfil the request, they may choose to wilfully ignore the underlying meaning of the hint.

Second, there is a danger that the other party may not interpret hinting as an indirect request for support. In both cases, the older person is at risk of being unsupported. Ascertaining whether a person has unmet needs is an integral part of current social care policy (Department of Health and Social Care 2018). The Care Act 2014, which was introduced after the data in the present study were collected, introduced National Eligibility Criteria to assess whether an individual qualifies for state support (Care Act 2014). An individual is assessed as eligible if they cannot perform a minimum of two ADLs without needing help, which arise from a specific health-related disorder (Southampton City Council (undated)).

Local Councils are under a duty to develop and promote local policies for stakeholders and families to recognise unmet need, in particular, when unmet might pose a danger to vulnerable older people living in their own home (Department of Health and Social Care 2018). In addition, local Councils are tasked with implementing strategies aimed at pre-empting unmet need. There are two main ways in which the findings of this thesis can augment existing local strategies aimed at identifying and tackling unmet need. First, raising awareness of hinting as a tactic to draw attention to unmet need could potentially be beneficial for older people. Alerting health and social care professionals to the way

that older people sometimes use language to indirectly communicate unmet need could be used as part of a wider preventative strategy, so that older people at risk in the community can be identified at the earliest time. As older people are more minded to accept direct offers of help, a strategy for meeting unmet need could be discussed with them (and including others in their support network, if the older person agreed). Second, across the interviews, common areas of unmet need were identified by older people: household tasks which involved balance presented a main challenge, such as standing on a ladder or stool (cleaning windows, taking down curtains, trimming shrubbery, changing a light bulb); changing bed linen, hanging out washing and vacuuming; and lack of opportunities to socialise in a meaningful way were key areas of unmet need. Promoting awareness of these key areas locally could enable older people to be better supported in the community, both by their families and through the provision of providing subsidised services aimed at meeting these needs.

In addition, the results of the present study indicate that most older people and their support network have internalised a negative connotation of independence, namely, that asking for help equates to dependency. Much research has been carried out on the value of promoting interdependence as an alternative, positive approach to conceptualising support negotiation (Breheny and Stephens 2012) . Current social care policy is aimed at promoting independence (Department of Health and Social Care 2016). Independence as a policy concept is not clearly defined, but is generally synonymous with a functional approach, measuring what tasks a person is and is not capable of performing (Fine and Glendinning 2005; Breheny and Stephens 2009; 2012; Portacolone 2011). A policy shift towards conceptualising need in terms of interdependence may help to remove some of the stigma surrounding seeking help with unmet need, as it “includes an acknowledgement of later life decline, and constructs later life care as a stage of connectedness” (Breheny and Stephens 2012:446).

10.7.4 Personal budgets: policy implications

PBs are now enshrined in legislation within the Care Act 2014. The results of the present study revealed that for older service-users opting to receive direct payments to orchestrate their own care and support arrangements, on-going assistance with the PB was inadequate. In particular, there was a lack of information provided to service-users

about how to manage their PB from the Council. The findings of the research revealed that the two service users who were in receipt of direct payments within their PB had been directed to a local charity for assistance with managing their PB and in recruiting PAs. Consequently, Council staff had little knowledge of how to manage PBs on an on-going basis.

To better support older people with PBs, policy-makers could consider creating a database on the Council website where PB-holders and PAs can advertise vacancies free of charge and in one central place, which can be monitored and controlled by Council staff. In addition, all PBs should be reviewed as a priority to ensure that all PB-holders are able to access a contingency fund in an emergency. Clearer advice should be given to PB-holders relating to what direct payments can be used for in the event of an emergency situation arising.

Older people reported feeling unsupported with recruiting personal assistants and care staff, as there was no dedicated site for service users to advertise job vacancies or for care staff to advertise their services. Both parties to the care dyad were required to pay an advertisement fee to a national on-line employment website. Policy-makers could consider creating a bespoke Personal Budget recruitment website with a classified advertisement facility that is free to service users and to care staff/personal assistants wishing to advertise their availability in order to streamline the personal budget process, and to ensure that the site is updated on at least a daily basis.

10.7.5 Limitations and future research

The main limitation of this study was that there was not enough time to map changes in support negotiation over a six-month period. With the benefit of hindsight, richer results would have been obtained had participants been interviewed using a semi-structured interview schedule at the outset (in 2013), rather than using a structured questionnaire initially as a data-gathering instrument. Participants could have been interviewed in 2013 and followed up a year later in 2014. However, it is arguable that the data collected in the present study is rich as valuable conclusions have been made from analysing the data.

Future research could involve a larger-scale qualitative longitudinal comparative case-study approach over a longer period of time, for example, following a larger group of

older people and their support network based in different regions of England over a five-year period, in order to map changes in support and how it is negotiated with others. A multimethod design involving semi-structured interviews and adopting a participatory action research (PAR) method would add a level of richness to the research because older people would become an integral part of the research and it is well-suited for community-based studies (Baum *et al* 2006).

Further research is warranted which should examine personal budgets in more depth. In particular, a comparative (across three different local authorities) qualitative case-study approach to investigate the lived experiences of older PB-holders whose budget was in place for one year and above would help to understand practical challenges faced by older people and help to identify best practice in terms of how best to support older PB-holders.

Appendix A

1. SSEGM Ethics Form No. 6134

2. Participant Information Sheet

3. Consent Form

4. Risk Assessment Form

May 2013

1. SSEGM ETHICS SUB-COMMITTEE APPLICATION FORM: Number 6134

Please note:

- ***You must not begin your study until ethical approval has been obtained.***
- ***You must complete a risk assessment form prior to commencing your study.***
- ***It is your responsibility to follow the University of Southampton's Ethics Policy and any relevant academic or professional guidelines in the conduct of your study. This includes providing appropriate information sheets and consent forms, and ensuring confidentiality in the storage and use of data.***
- ***It is also your responsibility to provide full and accurate information in completing this form.***

1. **Name(s):** Ms Kathryn Margaret Wicks

2. **Current Position:** MPhil/PhD Gerontology student at University of Southampton.

3. **Contact Details:**

   Division/School Gerontology / Social Sciences

   Email kmw2e11@soton.ac.uk

   Phone 02380 595447 / 07984042222

4. **Is your study being conducted as part of an education qualification?**

   Yes ☒ **No** ☐

5. **If yes, please give the name of your supervisors**

   Professor Maria Evandrou and Dr Athina Vlachantoni

6. **Title of your project:**

   Negotiating social care support for older people: a study of the perspectives of older people, their families and policy stakeholders.

7. **What are the proposed start and end dates of your study?**

   October 2012 to October 2015

8. Describe the rationale, study aims and the relevant research questions of your study

This research also forms part of the Care Life Cycle project 'Responding to the Health and Social Care Needs of an Ageing Society'(http://www.southampton.ac.uk/clc/about_us/) funded by the Engineering and Physical Sciences Research Council. I plan to investigate and identify how the care of older persons is negotiated both within family settings and between families and social support services in Hampshire. A focus will be made on who makes care decisions within family and kinship groups for the benefit of older relatives and the extent to which and way in which decision-making alters over time. It is intended that recommendations will be made for policy purposes in light of the research findings.

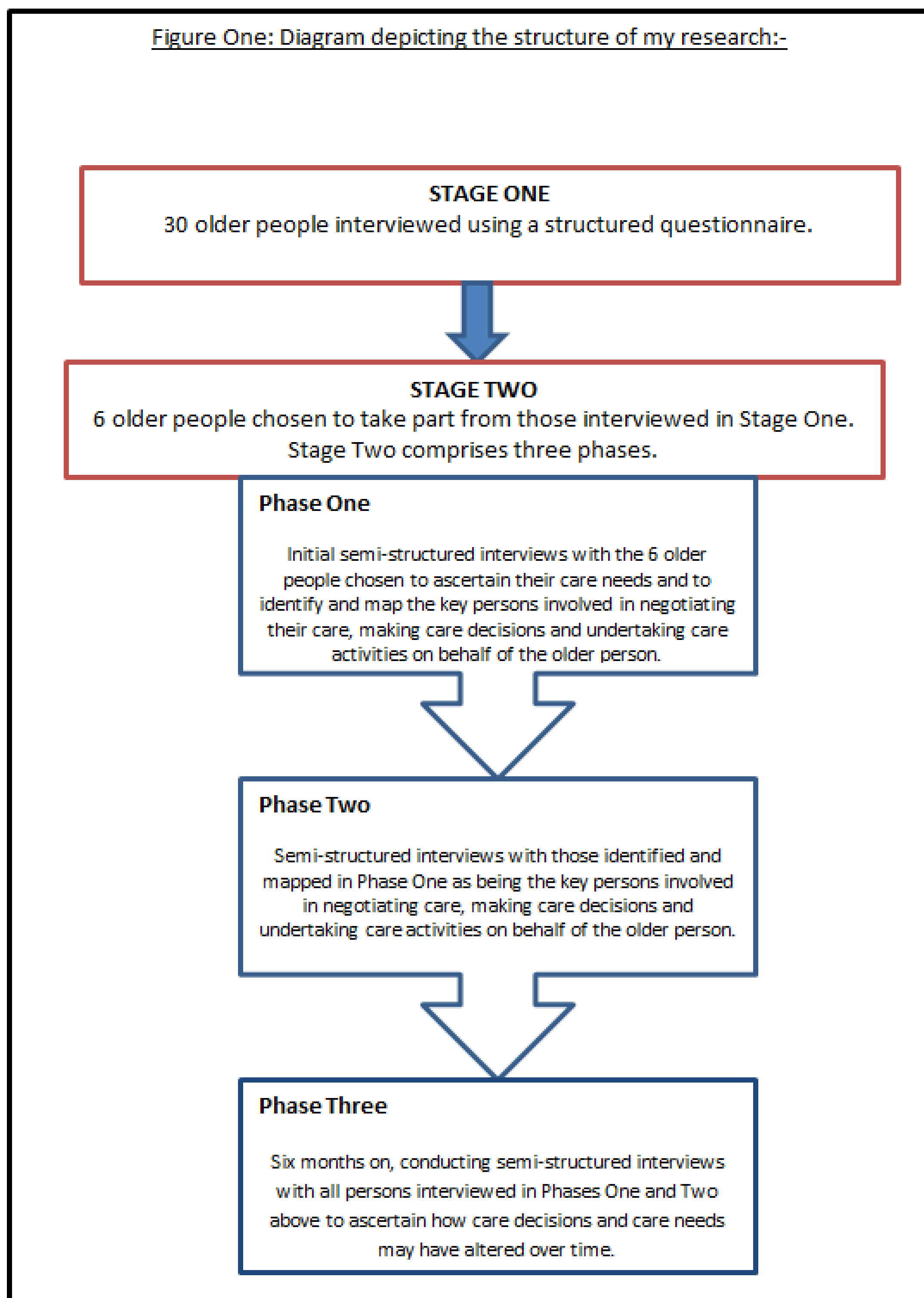
Research questions:

1. What is the nature of the negotiation that takes place between older people and their families or social circle when presented with situations requiring a decision relating to care?
2. What are the challenges and opportunities associated with examining the social and familial circle of older people and who is involved and excluded?
3. Who negotiates with local authorities regarding care decisions on behalf of older people?
4. What factors/motives are present, such as existing support networks, possibility of inheritance, social capital, sense of duty, in circumstances where family members make decisions on behalf of older relatives?
5. To what extent do particular demographic characteristics, such as gender, age or disputes between family members affect negotiations within families to decide who cares for older relatives?
6. To what extent are social care resources which are offered to older people by local authorities adequate for their needs in comparison with paid services?

9. Describe the design of your study

I plan to conduct qualitative research, using Age UK Southampton (http://www.ageuk.org.uk/southampton/our-services/) as a research setting. Age UK Southampton is happy to support this research project and I attach a letter written by Mrs Anne Carty, Chief Officer of Age UK Southampton, dated 22 March 2013, as confirmation (see Appendix A).

This research will comprise two Stages (see Figure One below), which will now be described.



Stage One

Stage One of this research will comprise interviews with thirty older people to ask them about their social networks and the types of care they receive, using a Structured Questionnaire (see Appendix B). The purpose of Stage One is to act as a filter to determine which older persons and their families will be chosen for in-depth study. Older people who are users of services provided by Age UK Southampton will be chosen using a combination of purposive sampling methods and snowballing (selecting people aged 65 or above who are able to give their full consent to take part in this study). These structured interviews will not be recorded, but contemporaneous notes will be taken of the responses given.

Stage Two

Stage Two of this research will be informed by Stage One. To clarify, from the thirty individuals approached in Stage One, six individuals will be selected, again, using purposive sampling methods (as far as possible, choosing an equal number of married/those with partners-in-life to those who are single/widowed/divorced) for further investigation, using an in-depth case study approach. Stage Two consists of three phases, which will each be described in turn.

The first phase will comprise in-depth, semi-structured interviews with the older person to establish their level of care, to map those individuals who are involved in the older person's care package (for example, family members, cohabiting partners, friends, carers, care workers, social workers or any other individual involved within their care, as the case may be) and to establish how and who is involved in the negotiation and decision-making process (see Appendix C for a copy of the Semi-structured Interview Schedule for Older Persons).

The second phase will comprise in-depth, semi-structured interviews with the individuals who are involved in the older person's care package who have been mapped in Phase One above, so that as far as possible, an holistic view of the older person's care needs and associated issues can achieved. A copy of the Semi-structured Interview Schedule appears at Appendix D. In addition, the local key policy stakeholder for the geographic area where the older person resides (social workers within Hampshire County Council) will also be approached for interview using the Semi-structured Interview Schedule appearing in Appendix D.

The third phase will take place six months later, comprising, as far as possible, a further set of semi-structured interviews with the same individuals who were interviewed in the first and second phases. Similar questions will be asked to ascertain whether any changes have taken place in the type or level of care provided to the older person and if so, to what extent (see Appendices E and F).

The purpose of Stage Two is two-fold. First, it is to ascertain a deeper understanding of the negotiation and decision-making process surrounding the care of older people. Secondly, its purpose is to identify who is involved in the negotiation and decision-making process, to identify any issues or aspects which work well or otherwise.

All semi-structured interviews taking place in Stage Two will be recorded and transcribed.

A literature review will be conducted to critically evaluate relevant policy documentation and academic publications.

10. Who are the research participants?

In the first instance, only older people aged sixty-five or above who are users of Age UK Southampton services will be approached to become research participants (see Stage One outlined in Section 9 above). From those taking part, six older people will be invited to take part in Stage Two (described in Section 9 above). It is anticipated that the research participants within Stage Two will comprise older people aged sixty-five or above, their family members, cohabiting partners, friends, carers, care workers, social workers and any other persons involved in providing assistance to the older person with activities of daily living will be approached to participate within the research. In addition, the local key policy stakeholder for the geographic area where the older person resides (social workers within Hampshire County Council) will also be approached for interview. I have chosen Age UK Southampton and Hampshire County Council within which to conduct this research because the Centre for Research on Ageing at the University of Southampton maintains strong links with both organisations. In addition, Hampshire County Council is a non-academic collaborator within the Care Life Cycle project.

11. If you are going to analyse secondary data, from where are you obtaining it?

Not applicable.

12. If you are collecting primary data, how will you identify and approach the participants to recruit them to your study?

Please attach a copy of the information sheet if you are using one – or if you are not using one please explain why.

I have created a Participant Information Sheet (see Appendix G) which has been tailored for each type of participant and provided to each participant before the interview has taken place. The participant will be asked to read the Participant Information Sheet prior to taking part in this study and to indicate their willingness to take part by signing a Consent Form (see section 14 below).

I am currently a volunteer within Age UK Southampton (formerly Age Concern Southampton) (http://www.ageuk.org.uk/southampton/) which is a charity aimed at helping older people in Southampton and the surrounding areas. At my initial interview in early February 2013, I explained to the then Volunteer Recruitment Officer, Mrs Linda Templeton, about my background and my research interests. I enquired at the time about whether it might be possible to recruit participants from users of services provided by Age UK Southampton for the purpose of this research. I was informed that this was a strong possibility.

Before being accepted as a volunteer, I was required to apply for a Criminal Records Bureau (CRB) check. The results of the CRB check revealed no adverse entries and a copy can be found in Appendix H.

At present, I am involved within the Age UK Southampton's Active Friends programme (http://www.ageuk.org.uk/southampton/how-you-can-help/volunteering/active-friend/). This programme is aimed at older people who have become isolated from the community (for example, because of health problems or bereavement). As an Active Friends volunteer, I visit older people in their homes, initially as a befriender. My role entails establishing the likes and dislikes of the older person, to get to know them in order to encourage a gradual return to participation in their local community /outdoor/outside interests (such as lunch clubs, walks, swimming or any other activities that they enjoy).

I have discussed this research with the Chief Officer at Age UK Southampton, Mrs Anne Carty. In her letter of the 22 March 2013 (see Appendix A), Mrs Carty states Age UK Southampton supports this research and is willing to assist me by identifying older people within community centres and arranging for me to meet with them to discuss this research project and to seek participants. Purposive sampling and snowballing methods will therefore be used.

In Stage One, I aim to ask approximately thirty older people about their family background and the types of care they receive using a Structured Questionnaire (see Appendix B). From those thirty older people interviewed in Stage One, six individuals will be selected, using purposive sampling methods and will be approached to ascertain whether they would be willing to take part in Stage Two.

In the first phase of Stage Two, the six older participants will be interviewed using a Semi-structured Interview Schedule (see Appendix C). As part of this first phase, other people who are actively involved in making care decisions or planning on behalf of the older person will be identified, such as family members, cohabiting partner, friends, carers, care workers, social workers and/or any other individuals, as the case may be, will also be approached to ask whether they would be willing to be interviewed. Those individuals will approached to ask them whether they would be willing to be interviewed and those participating will be interviewed in the second phase using a Semi-structured Interview Schedule (see Appendix D). The third phase is due to take place six months later on, to ascertain and understand how decision-making and negotiation relating to the care of older people alters over time. The semi-structured interview schedule to be used in the third phase for older people appears in Appendix E and for all other participants, in Appendix F.

13. Will participants be taking part in your study without their knowledge and consent at the time (e.g. covert observation of people)? If yes, please explain why this is necessary.

No, the participants will be fully informed about the study in advance and their signed consent will be obtained prior to them taking part.

14. If you answered 'no' to question 13, how will you obtain the consent of participants?

Please attach a copy of the consent form if you are using one – or if you are not using one please explain why.

After reading the Participant Information Sheet, I will then ask each participant to complete, sign and return an attached Consent Form (see Appendix I) if they wish to take part. By signing the Consent Form, participants are indicating that they wish to take part and they understand what I will be doing with their data. The Consent Form will be held on file as proof of their willingness to participate in the study. Within the Consent Form is a clause which notifies a participant that he or she is free to withdraw from the study at any time.

15. Is there any reason to believe participants may not be able to give full informed consent? If yes, what steps do you propose to take to safeguard their interests?

No respondents who are unable to give their full consent will participate in this research. Research participants may have a carer, friend or relative present, but consent to participate will be obtained from the research participant directly.

16. If participants are under the responsibility or care of others (such as parents/carers, teachers or medical staff) what plans do you have to obtain permission to approach the participants to take part in the study?

If participants are under the responsibility of, or care of others, in this case, an attorney, a carer or social worker, then I plan to approach the attorney, carer or social worker in the first instance to discuss whether or not it would be appropriate in the circumstances, to approach the potential participant for inclusion within the study. The reason for approaching the attorney, carer or social worker first is to obviate any distress to the potential participant. If, in the circumstances, the attorney, carer or social worker considered it appropriate for the potential participant to be approached, then I would explain the research aims to the participant and ask him or her to read the Participant Information Sheet (see Appendix G) and the participant directly, as well as his or her carer to sign the Consent Form (see Appendix I). I will reiterate that the participant can withdraw from the study at any time without penalty.

17. Describe what participation in your study will involve for study participants. Please attach copies of any questionnaires and/or interview schedules and/or observation topic list to be used

Participants will be users of services provided by Age UK Southampton. They will be recruited in the manner permitted by Age UK Southampton to comply with their Data Protection regulations and internal procedures, after discussion with Mrs Anne Carty and any other member of staff at Age UK Southampton that she deems appropriate.

Where possible, participants in Stage One and Stage Two will be directed to a suitable venue within premises owned or hired by Age UK Southampton, after meeting with a member of staff at Age UK to obtain his or her consent.

The Stage One interviews, using a Structured Questionnaire, will be conducted by me (see Appendix B). I will enter the responses on the questionnaire and take contemporaneous notes. This process should take no longer than an hour. The interviews will be arranged at a mutually convenient time

for the participant and me. The participants will dictate the pace of the interview. Stage One interviews will not be recorded.

Six participants from Stage One will be selected to take part in Stage Two on the basis of their circumstances. Each of the six participants will be asked whether they would be willing to take part in Stage Two. In the first phase of Stage Two, the six participants will be interviewed again, this time using a more in-depth semi-structured interview schedule (see Appendix C) to ascertain their current care requirements, care regime who is involved in making care decisions, as well as identifying those within their social circle who have been instrumental in negotiation and decision-making about care.

Those individuals who have been identified will be approached to ask whether they would also be prepared to take part in the second phase of Stage Two. This will involve being interviewed using a Semi-structured Interview Schedule (see Appendix D) to ascertain their role in the older person's care regime, which individuals were involved in negotiating care for the older person and what motivated them to be involved in care decisions.

All individuals who were interviewed in the first and second phases of Stage Two will be interviewed again six months later to ascertain whether there have been any changes in the care regime, the reason(s) for any changes, who was involved in the planning, decision-making or negotiation process and what impact this has had on the older person and their family. All participants will be interviewed using semi-structured interview schedules (see Appendix E for the schedule for older persons and Appendix F for all other participants).

Stage Two interviews should take no longer than two hours. Again, the interviews will be arranged at a convenient time for participants. The participants will dictate the pace of the interview. All those interviewed will be provided with a tailored Participant Information Sheet (see Appendix G) (for retention by the participant) and a tailored Consent Form (see Appendix I) (to be signed by the participant and retained by me).

Within the Consent Form, details will be provided of organisations where the participant can be directed if he or she is upset by or within the interview process, or if he or she has a complaint about the way research has been conducted. Participants are invited to contact Dr Martina Prude if they wish to make a complaint and her contact details have been included within the tailored Participant Information Sheet (see Appendix G), which is retained by each participant.

18. How will you make it clear to participants that they may withdraw consent to participate at any point during the research without penalty?

I will provide a Participant Information Sheet (see Appendix G) which will explain clearly to participants that they can choose to withdraw from the study at any point, with no repercussions. I will also reiterate that information verbally to all participants (and their attorney, carers or social worker if applicable) prior to the outset of each interview.

19. Detail any possible distress, discomfort, inconvenience or other adverse effects the participants may experience, including after the study and you will deal with this.

Participants will be asked about their experiences in terms of negotiation and decision-making relating to care. The topic is likely to be sensitive, as participants will be discussing matters relating to either their own social care or social care provided to a close family member or friend. This may be distressing because the care recipient may have suddenly required care and be coming to terms with a long-term disability, or has had to make difficult decisions in order to adjust their lifestyle or accommodation. If a participant should become distressed, I will change the topic of the discussion, offer to postpone the interview or stop the interview altogether. Referring the participant to relevant counselling facilities may be appropriate, as stated on the Participant Information Sheets (see Appendix G). Additionally, if appropriate, participants may be referred to organisations providing counselling which are recommended by Age UK Southampton.

20. How will you maintain participant anonymity and confidentiality in collecting, analysing and writing up your data?

Participants will be assured within the Consent Form that their details and data will remain anonymous. Anonymity of participants will be preserved by changing details such as names, locations and settings and by referring to participants' ages in age brackets (e.g. 65-69). I intend to identify each participant by applying a coded system, rather than by their names. The true identities will be stored elsewhere from the data to ensure confidentiality and will only be available to myself during the study and to my Academic Supervisors, if necessary.

21. How will you store your data securely during and after the study?

The hard copies of the responses to the structured questionnaires and the contemporaneous notes taken during the Stage One interviews will be kept in a locked drawer at the University of Southampton.

I will record all interviews taking place in Stage Two using both a laptop and an audio-recording device to ensure data is properly recorded and to minimise loss of data. After each interview, the sound file from the audio-recording device will be downloaded to a password-protected memory stick. The laptop is protected by a password entry system. The interviews will be transcribed by me and hard copies of the transcription material will be stored in a locked drawer at the University of Southampton.

22. Describe any plans you have for feeding back the findings of the study to participants.

I will ask each participant at the outset about whether they wish to receive an executive summary of this research once completed. In addition, participants will be informed in the Participant Information Sheet that once the research has been completed, a bound copy of it will be placed in the Hartley Library at the University of Southampton.

23. What are the main ethical issues raised by your research and how do you intend to manage these?

The main ethical issue raised by this research that I am aware of is to minimise any distress which is caused by the subject matter which is discussed. A system to reduce risk has been set out in Section 19 above.

Participants will receive a tailored Participant Information Sheet (see Appendix G) which clearly sets out the nature and scope of the research, what to expect if they agree to become a research participant, as well as giving their consent by signing a Consent Form (see Appendix I). Both of these documents clearly explain to participants that they have the right to withdraw from the study at any time without penalty. Participants will be advised about where they can receive further information or make a complaint, if they experience distress. I will provide details of Southampton counselling services should this become necessary (http://www.southamptoncounselling.org/index.php?page_id=2677&module_instance_id=9716).

Participants will be assured that their data will be stored confidentially and securely (see Section 20 above). Anonymity will be guaranteed within any research publication.

Older persons are classed as a vulnerable group for research purposes by the University of Southampton. The subject matter is sensitive, as it is regarding ascertaining decision-making and the negotiation process behind personal care decisions. Care will be taken to ensure participants feel comfortable discussing these matters, questions will be worded in a tactful and sensitive way,

and the topic of conversation changed within the interview or the interview terminated if participants become distressed or uncomfortable.

24. Please outline any other information you feel may be relevant to this submission.

To the best of my knowledge and belief, there is no other information which I feel may be relevant to this submission.

2. Participant Information Sheets

Participant Information Sheet (Stage One)

Study Title: Planning social care support for older people.

Researcher: Ms Kathryn Wicks **Ethics number**: 6134

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

I am a postgraduate researcher at the Centre for Research on Ageing at the University of Southampton. This research forms part of my MPhil/PhD programme, which is funded by the Engineering and Physical Sciences Research Council and is part of the Care Life Cycle project 'Responding to the Health and Social Care Needs of an Ageing Society'.

I want to find out what challenges and opportunities older people face when making decisions about their care. I am also interested in finding out who else is involved in making care decisions and the extent to which, and way in which that decision-making alters over time.

Why have I been chosen?

You have been chosen because you receive some form of care provided by, for example, a relative or a carer and you are a client of Age UK Southampton. Your involvement will help us to understand what challenges and opportunities you face when you and/or others make decisions about your care needs.

What will happen to me if I take part?

If you decide to take part, you will be invited to take part in an interview with me, which should take about an hour. I will ask you some questions about yourself, your day-to-day care needs and who provides you with support. I will take some hand-written notes during the course of the discussion.

You will then be asked whether or not you might be willing to take part in a further discussion over the coming weeks about your care. As I am interested to find out who else is involved in making care decisions on your behalf, at a later stage, I may also ask you whether I can talk to family members who provide you with support, and/or anyone else who helps out with your care.

Are there any benefits in my taking part?

There are no direct benefits to you in taking part, other than having an opportunity to talk about your living arrangements and care needs. The responses you give will help us to understand the issues faced by older people when making care decisions, which may, in turn, assist policy-makers in developing services for older people in the future.

Are there any risks involved?

There are no obvious risks to you if you take part in this research. However, if, at any time, you feel uncomfortable during our discussion, please tell me immediately. I will do my best to reassure you and you have the option of withdrawing from this study at any time.

Will my participation be confidential?

Yes, your participation will be kept confidential. The research has received ethical approval from the Ethics Committee at the University of Southampton. Please be assured that every effort will be made to ensure that your details are kept confidential and any identifiable information about you, such as your name and age, will only be accessible by myself and my Academic Supervisors. Your details will be made anonymous and the data collected will be kept within securely locked storage units and on password-protected computers.

What happens if I change my mind?

If you change your mind about taking part at any point during the research process, you are free to withdraw, and this will not affect any of the care and/or support services you receive.

What happens if something goes wrong?
If you have a complaint about the research or have any concerns, please do not hesitate to contact the following person at the University of Southampton, who is not involved in this research:

Dr Martina Prude, Head of Research Governance
Research Governance Office
George Thomas Building 37, Room 4055
University of Southampton, SO171BJ

Email: M.A.Prude@soton.ac.uk
Telephone Number: 02380 595058

Where can I see the findings of this project once it has been completed?
Once I have analysed the data and written up the project for the MPhil/PhD, you will be offered the opportunity to receive an Executive Summary of the research. Once the research has been completed, a bound copy of it will be placed in the Hartley Library at the University of Southampton.

Where can I get more information?
If you have any further questions, please contact:

Ms Kathryn Wicks (Researcher): 07984 042222; kmw2e11@soton.ac.uk

Prof. Maria Evandrou: (Academic Supervisor) 02380594808; maria.evandrou@soton.ac.uk

Dr. Athina Vlachantoni (Academic Supervisor):02380598940; A.Vlachantoni@soton.ac.uk

Alternatively, please write to me or my Academic Supervisors at:

Centre for Research on Ageing
Faculty of Social and Human Sciences
University of Southampton
Southampton, SO17 1BJ

Thank you for your time.

Participant Information Sheet (Stage Two – first phase - older person)

Study Title: Planning social care support for older people.

Researcher: Ms Kathryn Wicks **Ethics number**: 6134

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?
I am a postgraduate researcher at the Centre for Research on Ageing at the University of Southampton. This research forms part of my MPhil/PhD programme, which is funded by the Engineering and Physical Sciences Research Council and forms a part of the Care Life Cycle project 'Responding to the Health and Social Care Needs of an Ageing Society'.

I want to find out what challenges and opportunities older people face when making decisions about their care. I am also interested in finding out who else is involved in making care decisions and the extent to which, and way in which that decision-making alters over time.

Why have I been chosen?
You have been chosen because we are very interested in exploring about your care needs further. Your involvement will help us to understand what challenges and opportunities you face when you and/or others make decisions about your care needs.

What will happen to me if I take part?
If you decide to take part, you will be invited to take part in an interview with me, which should take no more than two hours. I will ask you some questions about yourself, your day-to-day care needs and who provides you with support. I will take some hand-written notes during the course of the discussion.

You will then be asked whether or not you might be willing to take part in one further discussion about your care, which is likely to take place in six months' time. As I am interested to find out who else is involved in making care decisions on your behalf, I may also ask you whether I can talk to family members who provide you with support, and/or anyone else who helps out with your care.

Are there any benefits in my taking part?
There are no direct benefits to you in taking part, other than having an opportunity to talk about your living arrangements and care needs. The responses you give will help us to understand the issues faced by older people when making care decisions, which may, in turn, assist policy-makers in developing services for older people in the future.

Are there any risks involved?
There are no obvious risks to you if you take part in the research. However, if, at any time, you feel uncomfortable during our discussion, please tell me immediately. I will do my best to reassure you and you have the option of withdrawing from this study at any time.

Will my participation be confidential?
Yes, your participation will be kept confidential. This research has received ethical approval from the Ethics Committee at the University of Southampton. Please be assured that every effort will be made to ensure that your details are kept confidential and any identifiable information about you, such as your name and age, will only be accessible by myself and my Academic Supervisors. Your details will be made anonymous and the data collected will be kept within securely locked storage units and on password-protected computers.

What happens if I change my mind?
If you change your mind about taking part at any point during the research process, you are free to withdraw, and this will not affect any of the care and/or support services you receive.

What happens if something goes wrong?

If you have a complaint about the research or have any concerns, please do not hesitate to contact the following person at the University of Southampton, who is not involved in this research:

Dr Martina Prude, Head of Research Governance
Research Governance Office
George Thomas Building 37, Room 4055
University of Southampton, SO171BJ

Email: M.A.Prude@soton.ac.uk
Telephone Number: 02380 595058

Where can I see the findings of this project once it has been completed?

Once I have analysed the data and written up the project for the MPhil/PhD, you will be offered the opportunity to receive an Executive Summary of the research. Once the research has been completed, a bound copy of it will be placed in the Hartley Library at the University of Southampton.

Where can I get more information?

If you have any further questions, please contact:

Ms Kathryn Wicks (Researcher): 07984 042222; kmw2e11@soton.ac.uk

Prof. Maria Evandrou: (Academic Supervisor) 02380594808; maria.evandrou@soton.ac.uk

Dr. Athina Vlachantoni (Academic Supervisor):02380598940; A.Vlachantoni@soton.ac.uk

Alternatively, please write to me or my Academic Supervisors at:

Centre for Research on Ageing
Faculty of Social and Human Sciences
University of Southampton
Southampton, SO17 1BJ

Thank you for your time.

Participant Information Sheet (Stage Two – carers/family – second phase)

Study Title: Planning social care support for older people.

Researcher: Ms Kathryn Wicks **Ethics number**: 6134

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

I am a postgraduate researcher at the Centre for Research on Ageing at the University of Southampton. This research forms part of my MPhil/PhD programme, which is funded by the Engineering and Physical Sciences Research Council and forms a part of the Care Life Cycle project 'Responding to the Health and Social Care Needs of an Ageing Society'.

I want to find out what challenges and opportunities older people face when making decisions about their care. I am also interested in finding out who else is involved in making care decisions and the extent to which, and way in which that decision-making alters over time.

Why have I been chosen?

You have been chosen to take part this study because you are involved in helping …………………… (name of older person) with his/her care. Your involvement will help us to understand what challenges and opportunities are faced when making decisions about an older person's care needs over time.

What will happen to me if I take part?

If you decide to take part, you will be invited to take part in an interview with me, which should not take more than an hour and a half. I will ask you some questions about ……………..'s (name of older person) care needs and provision. This interview will be recorded and I may also take some hand-written notes during the course of the discussion.

You will then be asked whether or not you might be willing to take part in one further discussion about your care, which is likely to take place in six months' time. .

Are there any benefits in my taking part?

There are no direct benefits to you in taking part, other than having an opportunity to talk about ……………………….'s (name of older person) living arrangements and care needs. The responses you give will help us to understand the issues faced by older people when making care decisions, which may, in turn, assist policy-makers in developing services for older people in the future.

Are there any risks involved?

There are no obvious risks to you if you take part in this research. However, if, at any time, you feel uncomfortable during our discussion, please tell me immediately. I will do my best to reassure you and you have the option of withdrawing from this study.

Will my participation be confidential?

Yes, your participation will be kept confidential. This research has received ethical approval from the Ethics Committee at the University of Southampton. Please be assured that every effort will be made to ensure that your details are kept confidential and any identifiable information about you, such as your name and age, will only be accessible by me and my Academic Supervisors. Your details will be made anonymous and the data collected will be kept within securely locked storage units and on password-protected computers at the University of Southampton.

What happens if I change my mind?

If you change your mind about taking part at any point during the research process, you are free to withdraw, and this will not affect any of the care and/or support services ……………………… (name of older person) receives.

What happens if something goes wrong?

If you have a complaint about the research or have any concerns, please do not hesitate to contact the following person at the University of Southampton, who is not involved in this research:

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Alternatively, please write to me or my Academic Supervisors at:

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Faculty of Social and Human Sciences
University of Southampton
Southampton, SO17 1BJ

Thank you for your time.

Appendix A

Participant Information Sheet (Stage Two – carers/family/social workers – third phase)

Study Title: Planning social care support for older people.

Researcher: Ms Kathryn Wicks **Ethics number**: 6134

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

I am a postgraduate researcher at the Centre for Research on Ageing at the University of Southampton. This research forms part of my MPhil/PhD programme, which is funded by the Engineering and Physical Sciences Research Council and forms a part of the Care Life Cycle project 'Responding to the Health and Social Care Needs of an Ageing Society'.

I want to find out what challenges and opportunities older people face when making decisions about their care. I am also interested in finding out who else is involved in making care decisions and the extent to which, and way in which that decision-making alters over time.

Why have I been chosen?

You have been chosen to take part in Stage Two of this study because you kindly agreed to take part in a discussion about ....'s (older person's care needs) approximately six months ago. I am interested in finding out whether ....'s (name of older person) have changed over the past six months or whether they have stayed the same. Your involvement will help us to understand what challenges and opportunities are faced when making decisions about an older person's care needs over time.

What will happen to me if I take part?

If you decide to take part, you will be invited to take part in a further interview with me about ....'s (name of older person) care arrangements and care need. This interview should not take more than an hour and a half. I will ask you some questions about whether ....'s (name of older person) care arrangements have changed at any time over the past six months or whether their care arrangements have stayed the same. As before, this interview will be recorded and I may also take some hand-written notes during the course of the discussion.

Are there any benefits in my taking part?

There are no direct benefits to you in taking part, other than having an opportunity to talk about ....'s (name of older person) living arrangements and care needs. The responses you give will help us to understand the issues faced by older people when making care decisions, which may, in turn, assist policy-makers in developing services for older people in the future.

Are there any risks involved?

There are no obvious risks to you if you take part in this research. However, if, at any time, you feel uncomfortable during our discussion, please tell me immediately. I will do my best to reassure you and you have the option of withdrawing from this study at any time without penalty.

Will my participation be confidential?

Yes, your participation will be kept confidential. This research has received ethical approval from the Ethics Committee at the University of Southampton. Please be assured that every effort will be made to ensure that your details are kept confidential and any identifiable information about you, such as your name and age, will only be accessible by myself and my Academic Supervisors. Your details will be made anonymous and the data collected will be kept within securely locked storage units and on password-protected computers at the University of Southampton.

What happens if I change my mind?

If you change your mind about taking part at any point during the research process, you are free to withdraw, and this will not affect any of the care and/or support services .... (name of older person) receives.

What happens if something goes wrong?
If you have a complaint about the research or have any concerns, please do not hesitate to contact the following person at the University of Southampton, who is not involved in this research:

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Research Governance Office
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Alternatively, please write to me or my Academic Supervisors at:

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Faculty of Social and Human Sciences
University of Southampton
Southampton, SO17 1BJ

Thank you for your time.

Participant Information Sheet (Stage Two – older person – third phase)

Study Title: Planning social care support for older people.

Researcher: Ms Kathryn Wicks **Ethics number**: 6134

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

I am a postgraduate researcher at the Centre for Research on Ageing at the University of Southampton. This research forms part of my MPhil/PhD programme, which is funded by the Engineering and Physical Sciences Research Council and forms a part of the Care Life Cycle project 'Responding to the Health and Social Care Needs of an Ageing Society'.

I want to find out what challenges and opportunities older people face when making decisions about their care. I am also interested in finding out who else is involved in making care decisions and the extent to which, and way in which that decision-making alters over time.

Why have I been chosen?

You have been chosen to take part in Stage Two of this study because you kindly took part in this research six months ago and I am interested in finding out what, if anything, has changed about your care arrangements since we last met. Your involvement will help us to understand what challenges and opportunities are faced when making decisions about an older person's care needs over time.

What will happen to me if I take part?

If you decide to take part, you will be invited to take part in an interview with me, which should not take more than two hours. I will ask you some questions about your care arrangements and whether or not they have changed since our last meeting. This interview will be recorded and I may also take some hand-written notes during the course of the discussion.

Are there any benefits in my taking part?

There are no direct benefits to you in taking part, other than having an opportunity to talk about your living arrangements and care needs and the ways in which they have changed over time. The responses you give will help us to understand the issues faced by older people when making care decisions, which may, in turn, assist policy-makers in developing services for older people in the future.

Are there any risks involved?

There are no obvious risks to you if you take part in this research. However, if, at any time, you feel uncomfortable during our discussion, please tell me immediately. I will do my best to reassure you and you have the option of withdrawing from this study at any time.

Will my participation be confidential?

Yes, your participation will be kept confidential. This research has received ethical approval from the Ethics Committee at the University of Southampton. Please be assured that every effort will be made to ensure that your details are kept confidential and any identifiable information about you, such as your name and age, will only be accessible by me and my Academic Supervisors. Your details will be made anonymous and the data collected will be kept within securely locked storage units and on password-protected computers at the University of Southampton.

What happens if I change my mind?

If you change your mind about taking part at any point during the research process, you are free to withdraw, and this will not affect any of the care and/or support services you receive.

What happens if something goes wrong?

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Prof. Maria Evandrou: (Academic Supervisor) 02380594808; maria.evandrou@soton.ac.uk

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Alternatively, please write to me or my Academic Supervisors at:

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Faculty of Social and Human Sciences
University of Southampton
Southampton, SO17 1BJ

Thank you for your time.

3. CONSENT FORM (Older person Stage One)

Study title: Planning social care support for older people.

Researcher name: Ms Kathryn Wicks

Ethics reference: 6134

Please provide your initials in the boxes if you agree with the following statements:

I have read and understood the information sheet (insert date /version no. of participant information sheet) and have had the opportunity to ask questions ☐

I agree to take part in this research project and agree for my data to be used ☐

I understand my participation is voluntary and I may withdraw at any time ☐

Data Protection

I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous.

Name of participant (print name)…………………………………………………

Signature of participant……………………………………………………………..

Date……………………………………………………………………………………

CONSENT FORM (Older person/all others in Stage Two)

Study title: Planning social care support for older people.

Researcher name: Ms Kathryn Wicks

Ethics reference: 6134

Please provide your initials in the boxes if you agree with the following statements:

I have read and understood the information sheet (insert date /version no. of participant information sheet) and have had the opportunity to ask questions

I agree to take part in this research project and agree for my data to be used

I understand my participation is voluntary and I may withdraw at any time

I provide my consent to the interview being audio recorded.

Data Protection

I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous.

Name of participant (print name)……………………………………………………

Signature of participant……………………………………………………………..

Date……………………………………………………………………………………

Appendix A

4. Risk Assessment Form: Ethics No.: 6134

- Please see Guidance Notes for completing the risk assessment form at the end of this document.

Researcher's name: Ms Kathryn Margaret Wicks

Part 1 – Dissertation/project activities
What do you intend to do? (Please provide a brief description of your project and details of your proposed methods.) *I intend to conduct qualitative research. My research is divided into two Stages. Stage One comprises interviews with 30 older users of services provided by Age UK. From those participants, six, willing older people will be selected to take part in Stage Two. Stage Two comprises three phases of semi-structured interviews. Phase one comprises interviews with the six older persons. The aim of these interviews is to identify individuals who either provide care for the older person or who are instrumental in assisting with arrangements for care. Phase two comprises interviews with the individuals identified in phase one. Phase three will take place six months on and will comprise follow-up interviews with all interviewees who took part in phases one and two of Stage Two.*
Will this involve collection of information from other people? (In the case of projects involving fieldwork, please provide a description of your proposed sample/case study site.) *Yes, I intend to recruit older users of services provided by Age UK Southampton (aged 65 and above) to take part in my study as outlined above. I am a volunteer for the Active Friends programme.*
If relevant, what location/s is/are involved? *I intend, where possible, to conduct the interviews at premises owned, leased or hired by Age UK Southampton. If this proves inconvenient, I will conduct the interviews at the homes of the participants.*
Will you be working alone or with others? *I intend to work alone.*
Part 2 – Potential safety issues / risk assessment.
Potential safety issues arising from proposed activity? *Age UK Southampton has granted permission for me to approach service users with a view for them to participate in my research. The arrangements for all interviews will made via a member of staff employed by Age UK Southampton and consent obtained in advance.*
Person/s likely to be affected? *Older users of services provided by Age UK Southampton, their carers, families and others involved in making care decisions or arrangements for care.*
Likelihood of risk? *The likelihood of risk is low when interviews are conducted at premises owned, leased, hired or controlled by Age UK Southampton, therefore wherever possible, interviews will be conducted at these venues. Where this is not possible, interviews will be conducted at the homes of participants.*
Part 3 – Precautions / risk reduction
Existing precautions:

The risk is higher where interviews are conducted at premises not owned or controlled by Age UK Southampton.
Proposed risk reduction strategies if existing precautions are not adequate: *The risks will be minimised by informing at least one of my supervisors about the location of the interview and my whereabouts, in addition to a member of Age UK Southampton staff. I will ensure my mobile telephone is charged and on my person during the course of the interview and that the location facility is switched to the 'on' position on my mobile telephone to track my movements.*

***CONTINUED BELOW** …*

Part 4 – International Travel
If you intend to travel overseas to carry out fieldwork then you must carry out a risk assessment for each trip you make and attach a copy of the International Travel form to this document Download the Risk Assessment for International Travel Form Guidelines on risk assessment for international travel at can be located at: www.southampton.ac.uk/socscinet/safety ("risk assessment" section). Before undertaking international travel and overseas visits all students must: • Ensure a risk assessment has been undertaken for all journeys including to conferences and visits to other Universities and organisations. This is University policy and is not optional. • Consult the University Finance/Insurance website for information on travel and insurance. Ensure that you take a copy of the University travel insurance information with you and know what to do if you should need medical assistance. • Obtain from Occupational Health Service advice on any medical requirements for travel to areas to be visited. • Ensure next of kin are aware of itinerary, contact person and telephone number at the University. • Where possible arrange to be met by your host on arrival. If you are unsure if you are covered by the University insurance scheme for the trip you are undertaking and for the country/countries you intend visiting, then you should contact the University's Insurance Office at insure@soton.ac.uk and check the Foreign and Commonwealth Office website.

Risk Assessment Form for International Travel attached	~~**YES**~~ **/ NO**	**(Delete as applicable)**

Guidance Notes for completing the risk assessment form

The purpose of assessing risks is to ensure everyone works safely. To carry out a Risk Assessment, ask yourself:

- How can the activity cause harm?
- Is it safe to carry out this activity without additional protection/support?
- If someone else is going to do the work, can they do it safely?

Activity

Give a brief outline of the activity/project including the methods to be used and the people to be involved

- Think about everything you are going to do, from start to finish.
- Ensure that you complete the assessment before you commence any work. If you are unsure if your proposed work carries any risk, go ahead and complete the form as the process could highlight some issues which otherwise may not have been aware of.

Potential Safety Issues

- Only list those hazards that you could reasonably expect to cause significant harm or injury.
- Talk to people who have experience of the activity.
- Will the activity involve lone working or potential exposure to violence? For more guidance see the Social Research Association website at www.the-sra.org.uk under Staying Safe.
- Are there any significant hazards due to where the work is to be done?

Who might be affected?

- List anyone who might be affected by the hazards.
- Remember to include yourself, co-workers, your participants and others working in or passing through the area of activity.
- Those more vulnerable or less experienced should be highlighted as they will be more at risk (e.g. children, disabled people or those with medical conditions, people unfamiliar with the area of activity).

Precautions/Risk Reduction

- List the control measures already in place for each of the significant hazards.
- Is the hazard dealt with by the School Health & Safety Policy, or a generic safety method statement?.
- Appropriate training is a control measure and should be listed.
- Is the risk a low as is reasonably practical?
- List any additional control measures/risk reduction strategies for each significant hazard (e.g. practical measures, training, improved supervision).

Risk Evaluation

- With all the existing control measures in place do any of the significant hazards still have a potential to cause significant harm? Rank as Low, Medium or High.

Remember

- Risk Assessments need to be suitable and sufficient, not perfect.
- Are the precautions reasonable?
- Is there something to show that a proper check was made?

This information is based on “An Introduction to Risk Assessment” produced by the Safety Office and the Training & Development Unit of the University of Southampton.

Stages One and Two interviews

Stage One Structured Questionnaire (Older person)

Planning social care support for older people

Thank you for agreeing to take part in this research. This study focuses on how social care is planned for people aged 65 and over, involving finding out the points of view of older people, their families and policy stakeholders. It has received approval from the University of Southampton Ethics Committee, under Ethics Number 6134.

I will be asking you some questions about your circumstances and the level and type of care you currently receive. I would like to begin by asking you a few general questions about yourself and your family and who lives in your household. I will then ask you about your health and how you rate your ability to perform some day to day activities.

The interview is likely to take about an hour and a half. I will read over each question to you and I will fill in your responses to the questions.

Please feel free to interrupt me at any time if you would like me to repeat a question or explain it to you in further detail, or if you would like to have a comfort break, or if there is any other reason.

Before I begin, do you have any questions? *[take time to answer initial questions raised by participants as appropriate]*

(Questions taken or adapted from ELSA http://www.ifs.org.uk/ELSA/documentation)

Section One: General Questions

1. Please tell me your name.

…………………………………………………………………………..

Male	Female

2. Please can you tell me your date of birth?

…………………………………………………………………………..

Section Two: About your Family/Household Demographics

I would like to ask you some questions about your family members and other people you are close to, so that I can build up a clear picture of your family tree and your household.

3. First of all, what is your marital status?

Marital status		Proceed to…
Single/Never married		Question 6
Married – first and only marriage		Question 5
Married – remarried second or later marriage		Questions 4 and 5
Cohabiting		Question 5
A Civil Partner in a legally recognised civil partnership		Question 5
Divorced		Question 4
Legally Separated		Question 4
Widowed		Question 4
Other (please specify)		Question 6
Prefer not to say		Question 6

4. How many years did your (previous, as the case may be) marriage/partnership/Civil Partnership last and what year did your partner move out/did you become a widow/widower?

Length of time of union	Year of termination	Reason for termination (divorce (Di), legal separation (LS), separation (S), death (DE))

5. Please tell me the name of your current spouse/partner/Civil Partner, how long you have been together for, his/her age (if known) and whether or not he/she lives with you.

Name of Spouse/Cohabiting Partner/Civil Partner	Length of time of union	Sex (M/F)	Age	Lives in your household Yes/No

6. Do you have any children, including natural, adopted, step and/or foster?

Yes	No	Don't know/Unsure

(if Yes, proceed to Question 7, if No or Don't know/Unsure, then proceed to Question 10)

7. Please can you tell me the name of each of your children, their age (if known)and tell me whether or not each one lives with you:

Name of Child and whether natural (N), adopted (A), step (S) or foster (F)	Sex (M/F)	Age	Lives in your household Yes/No

8. Do you have any grandchildren including any who are natural, adopted, step and/or foster?

Yes	No	Don't know/Unsure

(If Yes, proceed to Question 9, if No or Don't know/Unsure, proceed to Question 10)

9. Please give me the name of each of your grandchildren, their age (if known) and tell me whether or not they live with you:

Name of Grandchild and whether natural (N), adopted (A), step (S) or foster (F)	Sex (M/F)	Age	Lives in your household Yes/No

10. Do you have any brothers and sisters? (this includes natural, adopted, step and/or foster)

Yes	No	Don't know/Unsure

(If Yes, proceed to Question 11, if No or Don't know/Unsure, proceed to Question 12)

11. Please give me the name of each of your brothers and sisters, their age (if known) and tell me whether or not any of them lives with you:

Name of Sibling and whether natural (N), adopted (A), step (S) or foster (F)	Sex (M/F)	Age	Lives in your household Yes/No

12. Do you have surviving parents? (this includes natural, adoptive, step and/or foster)

Yes	No	Don't know/Unsure

(If Yes, proceed to Question 13, if No or Don't know/Unsure, proceed to Question 14)

13. Please give me the name of each of your parents, their age (if known) and tell me whether or not they live with you:

Name of Parent and whether natural (N), adoptive (A), step (S) or foster (F)	Sex (M/F)	Age	Lives in household Yes/No

14. Does anyone else live in the same household with you, apart from the people you've already mentioned?

Yes	No	Don't know/Unsure

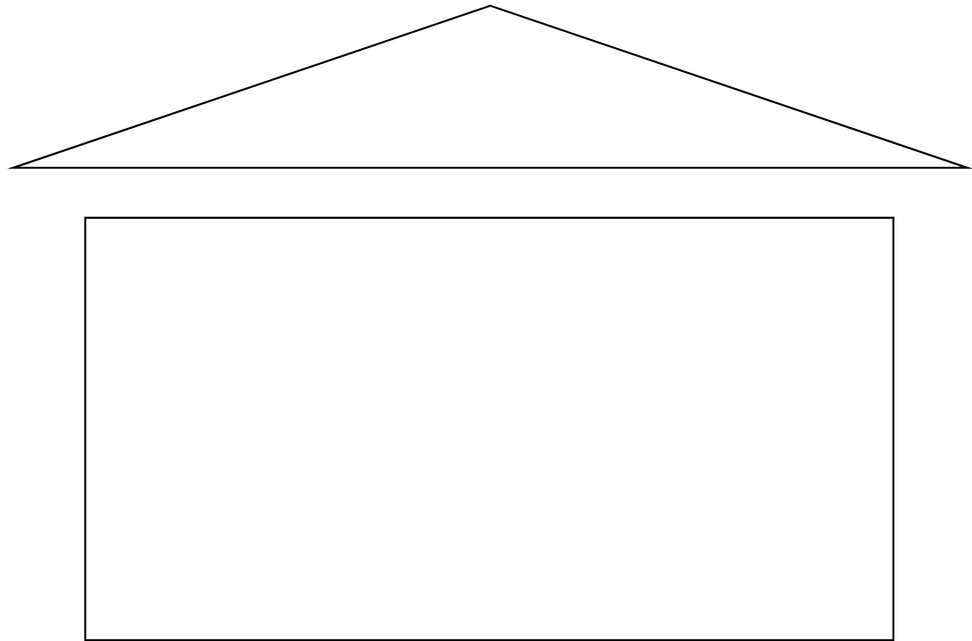
(if Yes, proceed to Question 15, if No or Don't know/Unsure, proceed to Household Checkbox)

15. Please provide me with the name(s) of the other people who live with you, their age (if known) and the relationship between you and the other people living with you.

Name of Household Member	Sex (M/F)	Age	Relationship to you

<u>Household Checkbox</u>

Enter household members in house-shaped box below and check with participant that all members are accurately recorded and also record the approximate proximity of other family members in the space below:



Section Three: About your Health

I would now like to ask you some general questions about how you would best describe your health at the moment.

16. Would you say your general health is:

Excellent	Very Good	Good	Fair	Poor

17. Would you describe your eyesight (using glasses or corrective lens as usual) as:

Excellent	Very Good	Good	Fair	Poor	Registered/ Legally Blind

18. Would you describe your hearing (using a hearing aid as usual) as:

Excellent	Very Good	Good	Fair	Poor

19. How would you rate your memory at the moment? Would you say it is:

Excellent	Very Good	Good	Fair	Poor

I would now like to ask you some specific questions about your health, if I may.

20. Have you fallen down in the last two years (for any reason)?

(If Yes, proceed to Question 21, if No or Don't know/Unsure, proceed to Question 24)

Yes	No	Don't know/Unsure

21. If Yes, how many times have you fallen down in the last two years?

……….

22. As a result of any of these falls did you injure yourself seriously enough to need medical treatment?

Yes	No	Don't know/Unsure

23. Please can you briefly tell me what injuries you received as a result of any of these falls?

……..
……..
……..

24. Have you any long-standing illness, disability or infirmity?

(long-standing in this context means anything that has affected you over a period of time or is likely to affect you over a period of time)

Yes	No	Don't know/Unsure

(If Yes, proceed to Question 25, if No or Don't know/Unsure, proceed to Question 27)

25. Do these illness(es)/disability(ies)/infirmity(ies) you have just described to me limit your activities in any way?

Yes	No	Don't know/Unsure

26. Please tell me the name or names of your long-standing illness, disability or infirmity and approximately how long you have lived with this/these condition(s) in months or years:

Name of illness/disability/infirmity	Length of time

27. Has a doctor ever told you that you have (or have had) any of the following conditions?

Condition	Please tick
Chronic lung disease, e.g. chronic bronchitis/emphysema	
Asthma	
Arthritis (including osteoarthritis and rheumatism)	
Osteoporosis	
Cancer or malignant tumour (not minor skin cancer)	
Parkinson's disease	
Any emotional, nervous or psychiatric problems	
Alzheimer's disease	
Dementia, organic brain syndrome, senility or any other serious memory impairment	
Other condition(s) (please specify)	
None of these	
Don't know/Unsure	

28. Do you currently use any of the following services? (Please tick all that apply. If any are used, proceed to Question 29, if None of these or Don't know/Unsure, proceed to Question 30)

Services used	Please tick
Occupational therapist	
Physical therapist	
Chiropodist	
Exercise classes including yoga, pilates, gym	
Other	
None of these	
Don't know/Unsure	

29. If so, who made the arrangement for you to use/attend the above services? (Please tick all that apply)

Person making the arrangement	Please tick
You	
Your Spouse/Cohabiting partner/Civil partner	
Parent(s)	
Son(s)	
Son(s)-in-law	
Daughter(s)	
Daughter(s)-in-law	
Sister(s)	
Brother(s)	
Grandson(s)	
Granddaughter(s)	
Other relative(s) (please specify)	
Friend(s) or neighbour(s)	
Unpaid volunteer(s)	
Health worker(s)	
Occupational therapist(s)	
Social worker(s)	
Privately paid care assistant(s)	
Local authority care assistant(s)	
Other person(s) (please specify)	
Don't know/Unsure	

30. Have you ever used any of the following services?

(Please tick all that apply. If any are used, proceed to Question 31, if None of these or Don't know/Unsure, proceed to Question 37)

Type of Services	**Please tick**
Lunch club	
Day care centre	
Meals on wheels	
None of these	
Don't know/Unsure	

31. If you have used a lunch club, how often do you attend?

Frequency	**Please tick**
Every day or nearly every day	
Two or three times a week	
Once a week	
Two or three times a month	
Once a month or less	
Do not currently use	
Don't know/Unsure	

32. If so, who made the arrangement for you to attend a lunch club? (Please tick all that apply)

Person making the arrangement	**Please tick**
You	
Your Spouse/Cohabiting partner/Civil partner	
Parent(s)	
Son(s)	
Son(s)-in-law	
Daughter(s)	
Daughter(s)-in-law	
Sister(s)	
Brother(s)	
Grandson(s)	
Granddaughter(s)	
Other relative(s) (please specify)	
Friend(s) or neighbour(s)	
Unpaid volunteer(s)	
Health worker(s)	
Social worker(s)	

Occupational therapist(s)	
Privately paid care assistant(s)	
Local authority care assistant(s)	
Other person(s) (please specify)	
Don't know/Unsure	

33. If you have used a day care centre, how often do you attend?

Frequency	Please tick
Every day or nearly every day	
Two or three times a week	
Once a week	
Two or three times a month	
Once a month or less	
Do not currently use	
Don't know/Unsure	

34. If so, who made the arrangement for you to use a day care centre? (Please tick all that apply)

Person making the arrangement	Please tick
You	
Your Spouse/Cohabiting partner/Civil partner	
Parent(s)	
Son(s)	
Son(s)-in-law	
Daughter(s)	
Daughter(s)-in-law	
Sister(s)	
Brother(s)	
Grandson(s)	
Granddaughter(s)	
Other relative(s) (please specify)	
Friend(s) or neighbour(s)	
Unpaid volunteer(s)	
Health worker(s)	
Social worker(s)	
Occupational therapist(s)	
Privately paid care assistant(s)	
Local authority care assistant(s)	
Other person(s) (please specify)	
Don't know/Unsure	

35. If you have used Meals on Wheels, how often would you say you eaten a meal delivered by Meals on Wheels?

Frequency	Please tick
Every day or nearly every day	
Two or three times a week	
Once a week	
Two or three times a month	
Once a month or less	
Do not currently use	
Don't know/Unsure	

36. If so, who made the arrangement for you to receive Meals on Wheels? (Please tick all that apply)

Person making the arrangement	Please tick
You	
Your Spouse/Cohabiting partner/Civil partner	
Parent(s)	
Son(s)	
Son(s)-in-law	
Daughter(s)	
Daughter(s)-in-law	
Sister(s)	
Brother(s)	
Grandson(s)	
Granddaughter(s)	
Other relative(s) (please specify)	
Friend(s) or neighbour(s)	
Unpaid volunteer(s)	
Health worker(s)	
Social worker(s)	
Occupational therapist(s)	
Privately paid care assistant(s)	
Local authority care assistant(s)	
Other person(s) (please specify)	
Don't know/Unsure	

37. Which services do you use that are co-ordinated by Age UK Southampton? (please tick all that apply)

Age UK Southampton Services	
Active Friends	
Phone Friends	
Visiting Friends	
Computer classes	
Black Asian Minority Ethnic Project	
Health and Well-being activities	
Padwell Day Centre	
Other (please specify)	
Don't know/Unsure	

38. If so, who made the arrangement for you to use/attend those services? (Please tick all that apply)

Person making the arrangement	Please tick
You	
Your Spouse/Cohabiting partner/Civil partner	
Parent(s)	
Son(s)	
Son(s)-in-law	
Daughter(s)	
Daughter(s)-in-law	
Sister(s)	
Brother(s)	
Grandson(s)	
Granddaughter(s)	
Other relative(s) (please specify)	
Friend(s) or neighbour(s)	
Unpaid volunteer(s)	
Health worker(s)	
Social worker(s)	
Occupational therapist(s)	
Privately paid care assistant(s)	
Local authority care assistant(s)	
Other person(s) (please specify)	
Don't know/Unsure	

Section Four: Activities of Daily Living and your Care Needs

I am going to ask you some questions about your daily activities and your ability to perform some usual day to day tasks. Then I will ask you whether you receive any help from anyone else with any of these tasks.

39. Did you do any of the following activities within the past month?

Activity	Please tick
Paid work	
Self-employment	
Voluntary work	
Cared for a sick or disabled adult	
Looked after home or family	
Attended a formal educational or training course	
None of these	

40. Please rate how difficult you find doing each of the following everyday activities because of a physical, mental, emotional or memory problem (excluding any difficulties you expect to last less than three months):

Activity	Easy	Fairly easy	Fairly difficult	Difficult	Depends	Cannot perform
Dressing, including putting on shoes and socks						
Walking across a room						
Bathing or showering						
Eating, such as cutting up your food						
Getting in or out of bed						
Using the toilet, including getting up or down						
Using a map to figure out how to get around in a strange place						
Preparing a hot meal						
Recognising when you are in physical danger						
Shopping for groceries						
Making telephone calls						

Taking medications						
Communicating (speech, hearing or eyesight)						
Doing work around the house or garden						
Managing money, such as paying bills and keeping track of expenses						

41. Please rate how difficult you find doing each of the following everyday activities (excluding any difficulties you expect to last less than three months):

Activity	**Easy**	**Fairly easy**	**Fairly difficult**	**Difficult**	**Depends**	**Cannot perform**
Walking 100 yards						
Sitting for about two hours						
Getting up from a chair after sitting for long periods						
Climbing several flights of stairs without resting						
Climbing one flight of stairs without resting						
Stooping, kneeling or crouching						
Reaching or extending your arms above shoulder level						
Pulling or pushing large objects such as a living room chair						
Lifting or carrying weights over 10lbs, such as a heavy bag of groceries						
Picking up a 5p coin from a table						

Section Five: Care Support

42. Thinking about the activities that you have difficulties with [provide a reminder from the answers given in Questions 40 and 41 above] does anyone ever help you with these activities (including your spouse/partner or other people living in your household)?

Yes	No	Don't know/Unsure

(if Yes, proceed to Question 43, if No or Don't know/Unsure, proceed to Question 45)

43. Who helps you with these activities? (please tick all that apply and describe task):

Person providing you with assistance	Describe task person provides assistance with
Spouse/Cohabiting partner/Civil partner	
Parent(s)	
Son(s)	
Son(s)-in-law	
Daughter(s)	
Daughter(s)-in-law	
Sister(s)	
Brother(s)	
Grandson(s)	
Granddaughter(s)	
Other relative(s) (please specify)	
Friend(s) or neighbour(s)	
Unpaid volunteer(s)	

Health worker(s)	
Social worker(s)	
Occupational therapist(s)	
Local Authority care assistant(s)	
Privately paid care assistant(s)	
Other person(s) (please specify)	
Don't know/Unsure	

44. Generally speaking, would you say that the help you have told me that you receive:

Meets your needs all the time	Usually meets your needs	Sometimes meets your needs	Hardly ever meets your needs	Don't know/Unsure

45. Do you use any of the following?

Aid	Please tick all that apply
A walking stick or cane	
A zimmer frame or walker	
A manual wheelchair	
An electric wheelchair	
A buggy or scooter	
Special eating utensils	
A personal alarm	
Other aid (please specify)	
None of these	

46. Please can you just confirm whether or not you receive help from your local Council with your care? (If Yes, proceed to Question 47, if No or Don't know/Unsure, proceed to Question 51)

Yes	No	Don't know/Unsure

47. Please can you confirm what kind of care you receive with from your local Council and how many hours of care do you receive, approximately?

Type of care received	Number of hours
Personal care tasks	
Domestic help	
Transport/Drivers	
Meals	
Companion/Social	
Gardening	
Live-in help	
Night care	
Nursing care	
Shopping	
Other type of care please specify)	
None of these	

48. Do you receive a personal budget from your local Council? (A personal budget is a sum of money allocated to you by your local Council if you are eligible to receive state support to pay for your care. The Council will draw up a support plan and you can use the money to pay for your own care and support) (If Yes, proceed to Question 49, if No proceed to Question 51)

Yes	No	Don't know/Unsure

49. How do you receive your personal budget?

Method of Payment	Please tick all that apply

Direct payment directly into your bank account	
Account managed by Council	
Account held with service provider / Individual Service Funds	
A trust managed by your carer/family/friend	
Something different	
Other method (please specify)	
Don't know/Unsure	

50. What do you spend your personal budget on?

Types of Expenditure	**Please tick all that apply**
Employing a carer or personal assistant	
Paying for meals	
Buying equipment	
Gym membership	
Joining a club or society	
Travel	
Other (please specify)	
Don't know/Unsure	

Section Six: Your Accommodation

I would like to ask you a few questions about where you currently live.

51. What type of property do you currently live in (your home)?

Type of Property	**Please tick**
Detached Bungalow or House	
Semi-detached Bungalow or House	
Terraced Bungalow or House	
Flat or Maisonette in purpose-built block	
Flat or Maisonette in house or annexed to house	
Caravan, houseboat or mobile home	

Residential home	
Other accommodation (please specify)	
Don't know/Unsure	

52. Regarding your home, do you…

Property Tenure	**Please tick**
Own it outright in your sole name	
Own it outright jointly with someone else	
Own it in your sole name subject to a mortgage or other loan	
Own it jointly with someone else subject to a mortgage or other loan?	
Rent it in your sole name	
Rent it jointly with someone else	
Live here rent free (in a relative's or a friend's house)	
Live as a squatter	
Other (please specify)	
Don't know/Unsure	

53. Does your home have any special features to assist people who have physical impairments or health problems?

Special Features	Please tick all that apply
Widened doorways or hallways	
Ramps or street level entrances	
Hand rails	
Automatic or easy open doors	
Accessible parking or drop-off site	
Bathroom modifications	
Kitchen modifications	
Lift	
Chair lift or stair glide	
Alerting devices, such as button alarms	
Any other special features (provide details)	
Other (please specify)	
Don't know/Unsure	

Section Seven: Providing care to others

54. Did you look after anyone in the past week (including your spouse or partner or any other person)? (To clarify, to 'look after' means to actively provide care to)

Yes	No	Don't know/Unsure

(If Yes, proceed to Question 55, if No or Don't know/Unsure, proceed to Question 57)

55. How many hours approximately did you spend looking after this person/these people in the past week?

……….

56. What is your relationship to this person or these people to you?

Person cared for	Please tick	Proceed to
Spouse/Cohabiting partner/civil partner		Question 55
Parent(s)		Question 55
Parent-in-law		Question 55
Son		Question 55
Son-in-law		Question 55
Daughter		Question 55
Daughter-in-law		Question 55
Sister		Question 55
Brother		Question 55
Grandson		Question 55
Granddaughter		Question 55
Other relative (please specify)		Question 55
Friend or neighbour		Question 56
Other person (please specify)		Question 56

57. I am going to read out some activities to you. Thinking back over the past 12 months, have you helped out voluntarily (that is, without receiving payment) with any of the following activities for a relative and if so, how often?

Activity	Daily	Once a week	At least once a month	Less often	One-off activity	Never
Keeping in touch with someone who has difficulty getting out and about (visiting in person, telephoning or emailing)						
Doing shopping, collecting pension or paying bills						
Cooking, cleaning, laundry, gardening or other routine household jobs						
Decorating or doing any kind of home or care repairs						
Babysitting or caring for children/grandchildren						
Sitting with or providing personal care (washing, dressing) for someone who is sick or frail						
Writing letters or filling in forms						
Representing someone (advocate at Council department or GP)						
Transporting or escorting someone (to a hospital or outing)						

58. I am going to read out some activities to you. Thinking back over the past 12 months, have you helped out voluntarily (that is, without receiving payment) with any of the following activities for someone who is not a relative and if so, how often?

Activity	Daily	Once a week	At least once a month	Less often	One-off activity	Never
Keeping in touch with someone who has difficulty getting out and about (visiting in person, telephoning or emailing)						
Doing shopping, collecting pension or paying bills						
Cooking, cleaning, laundry, gardening or other routine household jobs						
Decorating or doing any kind of home or care repairs						
Babysitting or caring for children/grandchildren						
Sitting with or providing personal care (washing, dressing) for someone who is sick or frail						
Writing letters or filling in forms						
Representing someone (advocate at Council department or GP)						
Transporting or escorting someone (to a hospital or outing)						

Section Eight: General Questions

I will be asking you some questions around how you feel about life generally.

59. I am going to read out a series of statements to you. Please can you tell me how often, if ever, you feel this way:

Statement	Hardly ever or never	Some of the time	Often
How often do you feel you lack companionship?			
How often do you feel left out?			
How often do you feel isolated from others?			
How often do you feel in tune with the people around you?			
How often do you feel lonely?			

60. I am going to read out another series of statements and am going to ask you to rate how you generally feel each one is applicable to your life at the moment:

Statement	Often	Sometimes	Not Often	Never
My age prevents me from doing the things I would like to				
I feel that what happens to me is out of my control				
I feel free to plan for the future				
I feel left out of things				
I can do the things that I want to do				
Family responsibilities prevent me from doing what I want to do				
I feel that I can please myself what I do				
My health stops me from doing things I want to do				
Shortage of money stops me from doing things I want to do				
I look forward to each day				
I feel that my life has meaning				
I enjoy the things that I do				
I enjoy being in the company of others				
On balance, I look back on my life with a sense of happiness				
I feel full of energy these days				
I choose to do things that I have never done before				
I feel satisfied with the way my life has turned out				
I feel that life is full of opportunities				
I feel that the future looks good for me				

Section Nine: Demographic Question

The interview is almost over. May I ask you…

61. What do you consider to be your ethnic background?

Ethnic Background	Please tick
White (British)	
White (Other)	
Mixed ethnic group	
Black	
Black (British)	
Asian	
Asian (British)	
Any other group (please specify)	

That was the final question. The interview is now over.

Thank you so much for giving up your time to take part in Stage One of this research. I am extremely grateful to you. Just to say, I plan to carry out further, more in-depth research about the care older persons receive and how this comes about. This will involve a further set of interviews with you and perhaps members of your family and others who are involved in your care in the coming weeks, provided you are happy for me to contact them. Would you be willing to take part in Stage Two of this research?

Yes	No

If Yes, take contact details of the participant:

Name of Participant, including title	Preferred contact method	Telephone number

I will be in contact with you over the next six months to arrange a mutually convenient time to meet with you again, but if you decide closer to the time that you would prefer not to take part in Stage Two, then you are at liberty to withdraw at any time.

Stage Two interviews

Phase One (older person)

1. How have you been since our last meeting? [ice breaker]
    a. Remind me of your health conditions
    b. How have your health conditions changed since we last met?
    c. What changes have there been in your life since we last met?
2. What support do you currently receive?
    a. Who provides you with help in and around the house and garden?
    b. Do you receive state support/private support/voluntary support/family support?
    c. Do you have a cleaner/gardener
    d. How did you arrange [any of the above]
3. If state support:
    a. Do you have a personal budget?
    b. How did you arrange your personal budget? Is it managed for you or do you receive direct payments?
    c. Tell me what you remember about the process from the start.
    d. What sorts of things did you have to do?
    e. How do you find the personal budget process?
    f. How easily were you able to find out the information you needed?
    g. How are the carers who come to see you employed? (through agency? Self-employed? Do you employ your carers directly? How do you find that?)
    h. How did you arrange the support that you received? What was the conversation like?
4. If family/friend/neighbour:
    a. Who helps you with day to day tasks? Which tasks? When did you start receiving support? How often?
    b. How did you arrange this? How did you approach them? What was the conversation like?
    c. If you think you might need additional support, how would you go about arranging this? What would you say? Who would you ask?
5. If private carer/cleaner:
    a. When did you arrange for the carer/cleaner to work for you?

   b. Tell me how the arrangement came about. (Why did you think you needed help? How did you go about arranging this support? Why did you choose that person?)
   c. What sorts of things do they do?
   d. Has the level of support they provide changed since they started? In what ways? If you needed more support, how would you go about arranging it?

6. If volunteer:
   a. When did you arrange for the volunteer to visit you? (Which organisation is he/she from? What sorts of things do you do together? How often does he/she visit?)
   b. Why did you choose that organisation?
   c. How did you arrange the support?
7. About your support needs:
   a. How far would you say that your support needs are met?
   b. What additional help do you think you might need in and around the house and garden?
   c. Who would you approach to arrange for additional support if you needed it?
   d. How do you imagine the conversation would go? Why would you say that?
8. Do you have anything else you would like to add about your support and how you have arranged it?
9. I have identified the following people that you have arranged support with. May I have your permission to approach them to take part in my research? If so, may I have their full names and a contact telephone number?

Thank you very much for your time.

Stage Two interviews

<u>Phase 2 (member of support circle)</u>

1. How long have you known [name of Phase 1 participant? [ice breaker]
    a. When did you meet?
    b. How do you know [name of Phase 1 participant]?
    c. How often do you visit [name of Phase 1 participant]?
2. What support do you currently give to [name of Phase 1 participant]?
    a. How did that support begin? Can you remember how the conversation went?
    b. What sorts of things do you do? How often do you provide support?
    c. Who else provides [name of Phase 1 participant] with help in and around the house and garden?
    d. How did [name of Phase 1 participant] arrange the support?
    e. What contact do you have with other people who provide support to [name of Phase 1 participant]?
3. If state support:
    a. What is the nature of the arrangement you have with [name of Phase 1 participant]? (through agency? Self-employed? Employed by Phase 1 participant directly? How do you find that?)
    b. If [name of Phase 1 participant] needed additional support, how would he/she arrange that do you think? Can you imagine how the conversation might go? How confident are you that he or she would ask for help? Why?
    c. Would you offer extra support or would you wait to be asked? Why?
4. If family/friend/neighbour:
    a. If [name of Phase 1 participant] needed additional support, how would he/she arrange that do you think? Can you imagine how the conversation might go? How confident are you that he or she would ask for help? Why?
    b. Would you offer extra support or would you wait to be asked? Why?
5. If private carer/cleaner:
    a. When did [name of Phase 1 participant] ask you to come to work for him/her?
    b. Tell me how the arrangement came about. (Why did you think he/she needed help? Why did he/she choose you?)
    c. What sorts of things do you do?

d. Has the level of support that you provide changed since you started? In what ways?
e. If [name of Phase 1 participant] needed additional support, how would he/she arrange that do you think? Can you imagine how the conversation might go? How confident are you that he or she would ask for help? Why?
f. Would you offer extra support or would you wait to be asked? Why?

6. If volunteer:
    a. When did [name of Phase 1 participant] arrange for you to visit him/her? (What sorts of things do you do together? How often does you visit?)
    b. Why do you think he or she chose that organisation?
    c. How did he or she arrange the support?
    d. If [name of Phase 1 participant] needed additional support, how would he/she arrange that do you think? Can you imagine how the conversation might go? How confident are you that he or she would ask for help? Why?
    e. Would you offer extra support or would you wait to be asked? Why?
7. About support needs:
    a. How far would you say that [name of Phase 1 participant's] support needs are met?
    b. What additional help do you think he or she might need in and around the house and garden?
    c. Who do you think he or she would approach to arrange for additional support if you needed it?
    d. How do you imagine the conversation would go? Why would you say that?
8. Do you have anything else you would like to add about the support you provide or [name of Phase 1 participant's support?

Thank you very much for your time.

Stage Two interviews

Phase Three (older person)

1. How have you been since our last meeting? [ice breaker]
    a. Remind me of your health conditions
    b. How have your health conditions changed since we last met?
    c. What changes have there been in your life since we last met?
2. What support do you currently receive?
    a. In what ways has your support changed since our last meeting 6 months ago?
    b. Who provides you with help in and around the house and garden?
    c. Do you receive state support/private support/voluntary support/family support?
    d. Do you have a cleaner/gardener
    e. How did you arrange [any of the above]
3. If state support:
    a. Do you have a personal budget?
    b. How did you arrange your personal budget? Is it managed for you or do you receive direct payments?
    c. Tell me what you remember about the process from the start [if new].
    d. What sorts of things did you have to do? [if new]
    e. How do you find the personal budget process?
    f. How easily were you able to find out the information you needed? [if new]
    g. How are the carers who come to see you employed? (through agency? Self-employed? Do you employ your carers directly? How do you find that?)
    h. How did you arrange the support that you received? What was the conversation like?
4. If family/friend/neighbour:
    a. Who helps you with day to day tasks? Which tasks? When did you start receiving support? How often?
    b. How did you arrange this? How did you approach them? What was the conversation like?
    c. If you think you might need additional support, how would you go about arranging this? What would you say? Who would you ask?
5. If private carer/cleaner:
    a. When did you arrange for the carer/cleaner to work for you?
    b. Tell me how the arrangement came about. (Why did you think you needed help? How did you go about arranging this support? Why did you choose that person?)
    c. What sorts of things do they do?
    d. Has the level of support they provide changed since they started? In what ways? If you needed more support, how would you go about arranging it?
6. If volunteer:
    a. When did you arrange for the volunteer to visit you? (Which organisation is he/she from? What sorts of things do you do together? How often does he/she visit?)
    b. Why did you choose that organisation?
    c. How did you arrange the support?

7. About your support needs:
    a. How far would you say that your support needs are met now?
    b. What additional help do you think you might need in and around the house and garden?
    c. Who would you approach to arrange for additional support if you needed it?
    d. How do you imagine the conversation would go? Why would you say that?
8. How do you think you will arrange your support in the future? Who might you approach? Where might you live?
9. Do you have anything else you would like to add about your support and how you have arranged it?

Thank you very much for your time

List of References

ADASS (2014) ADASS Budget Survey Report 2014: Final. Available on-line at: (accessed 28.08.2014)

Age UK (n.d.) 'About us' https://www.ageuk.org.uk/about-us/

Age UK (2012) *Personal Budgets in Social Care*: *A new way to arrange your care and support.* Available on-line at: http://www.ageuk.org.uk/documents/en-gb/information-guides/ageukig26_personal_budgets_inf.pdf?dtrk=true(accessed 28.08.2014)

Age UK (2013) *Personal Budgets in Social Care: A new way to arrange your care and support*. Available on-line at:http://www.ageuk.org.uk/documents/en-gb/information-guides/ageukig26_personal_budgets_inf.pdf?dtrk=true (accessed 26.08.2014)

Age UK (2014a) *Care in Crisis 2014; Technical Briefing.* Available on-line at: http://www.ageuk.org.uk/Documents/EN-GB/Campaigns/CIC/Care_in_Crisis_report_2014.pdf?epslanguage=en-GB?dtrk%3Dtrue (accessed 26.08.2014)

Age UK (2014b) *Older people with care needs not getting crucial help*. Available on-line at https://www.ageuk.org.uk/latest-press/archive/older-people-care-needs-not-getting-help/ (accessed 17.03.2018)

Age UK (2018a) 'Later Life in the United Kingdom'. https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/later_life_uk_factsheet.pdf

Age UK (2018b) 'Behind the Headlines: the battle to get care at home'. https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/care--support/rb_jun18_-_the_struggle_to_get_care_at_home.pdf

Age UK (2018c) 'All the Lonely People: Loneliness in Later Life'. https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/loneliness/loneliness-report.pdf (accessed 01.03.2019)

Al-Janabi, H., Coast, J. and Flynn, T.N. (2008) 'What do people value when they provide unpaid care for an older person? A meta-ethnography with interview follow-up'. *Social Science and Medicine*, 67 (1): 111-112.

Alcock, P. (2008) *Social Policy in Britain*. London: Palgrave MacMillan.

Alessie, R., Angelini, V. and Pasini, G. (2014) "Is It True Love? Altruism Versus Exchange in Time and Money Transfers". *De Economist*, 162 (2): 193-213.

Alfredson, T. and Cungu, A. (2008) *Negotiation Theory and Practice: A Review of the Literature*. EASYPol. Available on-line at: www.fao.org/easypol (accessed 28.08.2014)

Al-Janabi, H., Coast, J. and Flynn, T.N. (2008) 'What do people value when they provide unpaid care for an older person? A meta-ethnography with interview follow-up'. Social Science and Medicine, 67 (1): 111-112.

Allen, R. and Wiles, J. (2009) "A type of lady's corset? Support for older people". *Journal of Primary Health Care*. 1 (2): 156-157.

Allen, R.E.S. and Wiles, J.L. (2013) "Receiving Support When Older: What Makes It OK?". *The Gerontologist Advance Access* published May 30 2013. Available on-line at: http://gerontologist.oxfordjournals.org/content/early/2013/05/29/geront.gnt047.full.pdf+html (accessed 14.10.2014)

de Almeida Mello, J., Macq, J., Van Durme, T., Cès, S., Spruytte, N., Van Audenhove, C. and Declercq, A. (2017) The determinants of informal caregivers' burden in the care of frail older persons: a dynamic and role-related perspective, *Aging & Mental Health*, 21 (8): 838-843.

Alwin, D.F. (2012) 'Integrating Varieties of Life Course Concepts'. *The Journals of Gerontology Series B Psychological Sciences and Social Sciences*, 67 (2): 206-220. https://www.researchgate.net/publication/221686101_Integrating_Varieties_of_Life_Course_Concepts

Abramson, C.M. (2016) 'Unequal Aging: Lessons from Inequality's End Game'. *The Gerontological Society of America*, 26 (2): 68-72.

Angus, J. and Reeve, P. (2006) 'Ageism: A Threat to "Aging Well" in the 21st Century". *The Journal of Applied Gerontology*, 25 (2): 137-152.

Antonucci, T.C.; Ajrouch, K.J. and Birdett, K. S. (2013) "The Convoy Model: Explaining Social Relations from a Multidisciplinary Perspective". *The Gerontologist*, 54 (1): 82-92.

Arber, A. (2006) 'Reflexivity: A challenge for the researcher as practitioner?'. *Journal of Research in Nursing*, 11 (2): 147-157.

Arber, S. and Evandrou, M. (1993) "Mapping the Territory Ageing, Independence and the Life Course". In Arber, S. and Evandrou, M., (eds). *Ageing, independence, and the life course*. London: Jessica Kingsley Publishers.

Arber, S. and Ginn, J. (1995) 'Gender Differences in Informal Caring'. *Health and Social Care in the Community*, 3 (1): 19-31.

Aronson, J. (1992) 'Women's Sense of Responsibility for the Care of Older People: "But Who Else Is Going to Do It?". *Gender and Society*, 6 (1): 8-29.

Attree, M. (2000) "Patients' and relatives' experiences and perspectives of 'Good' and 'Not so Good' quality care". *Journal of Advanced Nursing*, 33 (4): 456-466.

Baez, S., Flichtentrei, D., Prats, M., Mastandueno, R., Garcia, A.M., Cetkovich, M. and Ibañez, A. (2017) 'Men, women. . .who cares? A population-based study on sex

differences and gender roles in empathy and moral cognition'. *PLoS ONE*, 12(6): e0179336. https://doi.org/10.1371/journal.pone.0179336

Bailey, K.A., Baker, J., Spassiani, N. and Meisner, B.A. (2012) "Gatekeepers of Gerontological Research: A Pilot Study Investigating Factors Influencing Research Compliance". Research on Aging, 34 (5): 499-506.

Bamford, C. and Bruce, E. (2000) "Defining the outcomes of community care: the perspectives of older people with dementia and their carers". *Ageing and Society*, 20 (6): 543-570.

Barbee, A.P., Cunningham, M.R., Winstead, B.A., Derlega, V.J., Gulley, M.R., Yankeelov and Druen, P.B. (1993) "Effects of Gender Role Expectations on the Social Support Process". *Journal of Social Issues*, 49 (3): 175-190.

Barken, R. (2017) "'Independence' among older people receiving support at home: the meaning of daily care practices". *Ageing and Society:* 1-23. doi:10.1017/S0144686X17001039

Barker, J.C. (2002) "Neighbors, Friends, and Other Nonkin Caregivers of Community-Living Dependent Elders". *Journal of Gerontology*, 57B (3): S158-S167.

Barrett, P., Hale, B. and Gauld, R. (2012) "Social inclusion through ageing-in-place with care?". *Ageing and Society*, 32 (3): 361-378.

Barry, A. and Yuill, C. (2012) Understanding the Sociology of Health. Third edition, London: SAGE Publications Ltd.

Barter, C. and Renold, E. (1999) "The Use of Vignettes in Qualitative Research", *Social Research Update*, Issue 25, University of Surrey. Available at: http://sru.soc.surrey.ac.uk/SRU25.html

Bartlett, J. (2009) 'At your service: navigating the future market in health and social care'. London: Demos. Available at: http://www.demos.co.uk/files/At_your_service_-_web.pdf?1256725103 (accessed 22.12.2019)

Baum, F., MacDougall, C. and Smith, D. (2006) "Participatory Action Research". *Journal of Epidemiological Community Health,* 60 (10): 854-857.

Baur, V. E., Abma, T.A. and Widdershoven, G.A.M. (2010) "Participation of marginalized groups in evaluation:Mission Impossible?". *Evaluation and Program Planning*, 33 (3): 238-245.

Baxter, K.; Rabiee, P. and Glendinning, C. (2013) "Managed personal budgets for older people: What are English local authorities doing to facilitate personalized and flexible care?". *Public Money and Management*. 33 (6): 399-406.

Beach, B. and Bamford, S. (2014) *Isolation: the emerging crisis for older men*. ILC-UK. Available on-line at: http://www.independentage.org/media/828364/isolation-the-emerging-crisis-for-older-men-report.pdf (accessed 15.10.2014)

Beach, S.R. and Schulz, R. (2016) 'Family Caregiver Factors Associated with Unmet Needs for Care of Older Adults'. *Journal of the American Geriatrics Society*, 65 (3): 560-566.

Becker, S. (2012) "Approaches and Methods". In Alcock, P., May, M. and Wright, S. (eds) *The Student's Companion to Social Policy*. Fourth Edition, Chichester: John Wiley & Sons.

Bengtson, V., Burgess, E. and Parrott, T. (1997) "Theory, Explanation, and a Third Generation of Theoretical Development in Social Gerontology". *Journal of Gerontology*, 52B (2): S72-S88.

Bengtson, V., Gans, D., Putney, N.M. and Silverstein, M. (2009) "Theories about Age and Aging". In Bengtson, V.L., Gans, D., Putney, N.M. and Silverstein, M. (eds) *Handbook of Theories on Aging* (Second Edition). New York: Springer Publishing Company LLC.: 3-23.

Bengtson, V.L. and Murray, T.M. (1993) '"Justice" Across Generations (and Cohorts): Sociological Perspectives on the Life Course and Reciprocities Over Time'. In Cohen, L.M. (ed.) 'Justice across Generations: What Does It Mean? A Publication of the Public Policy Institute': 111-138. Available at: https://eric.ed.gov/?id=ED366866

Berg, B.L. and Lune, H. (2012) *Qualitative Research Methods for the Social Sciences*. New Jersey: Pearson.

Bhamra, S., Tinker, A., Mein, G., Ashcroft, R. and Askham, J. (2008) "The retention of older people in longitudinal studies: A review of the literature". *Quality in Ageing and Older Adults*, 9 (4): 27-35.

Bland, R. (1999) 'Independence, privacy and risk: two contrasting approaches to residential care for older people'. *Ageing and Society*, 19 (5): 539-560.

Blumer, H. (1969) *Symbolic Interactionism*. London: University of California Press.

Boneham, M.A. and Sixsmith, J.A. (2006) "The voices of older women in a disadvantaged community: Issues of health and social capital". *Social Science and Medicine*, 62 (2): 269-279.

Boudiny, K. (2013) "'Active ageing': from empty rhetoric to effective policy tool". *Ageing & Society*, 33 (6): 1077-1098.

Bowers, H., Clark, A., Crosby, G., Easterbrook, L., Macadam, A., MacDonald, R., Macfarlane, A., Maclean, M., Patel, M., Runnicles, D., Oshinaike, T. and Smith, C. (2009) 'Older people's vision for long-term care'. http://www.cpa.org.uk/ltc/older-people-vision-for-care-full.pdf

Bowlby S., McKie L., Gregory S. and Macpherson I. (2010) 'Interdependency and Care Over the Life Course'. Routledge: Abingdon.

Braun, V. and Clarke, V. (2006) "Using thematic analysis in psychology". *Qualitative Research in Psychology*, 3 (2): 77-101.

Braun, V. and Clarke, V. (2013) Successful Qualitative Research: A practical guide for beginners. London: Sage.

Braun, V. and Clarke, V. (2017) "Thematic Analysis". *The Journal of Positive Psychology*, 12 (3): 297-298.

Breheny, M. and Stephens, C. (2009) "'I sort of pay back in my own little way': managing independence and social connectedness through reciprocity". *Ageing and Society*, 29 (8): 1295-1313.

Breheny, M. and Stephens, C. (2012) "Negotiating a moral identity in the context of later life care". *Journal of Aging Studies*, 26 (4): 438-447.

Brennan-Ing, M.; Seidel, L.; Larson, B. and Karpiak, S.E. (2014) "Social Care Networks and Older LGBT Adults: Challenges for the Future". *Journal of Homosexuality*, 61 (1): 21-52.

Breitholz, A., Snellman, I. and Fagerberg (2013 (a)) "Older people's dependence on caregivers' help in their own homes and their lived experiences of their opportunity to make independent decisions". International Journal of Older People Nursing, 8 (2): 139-148.

Breitholz, A., Snellman, I. and Fagerberg, I. (2013(b)) "Living with Uncertainty: Older Persons' Lived Experience of Making Independent Decisions over Time". *Nursing Research and Practice.* Available on-line at: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3606765/pdf/NRP2013-403717.pdf (accessed 27.10.2014)

Bright, L., Clarke, A. and Dalley, G. (2013) "Finding out about social care: what information seekers want". *Working with Older People,* 17 (2): 85-94.

Bryman, A. (2008) *Social Research Methods*. Third Edition. Oxford: Oxford University Press.

Bury, M. (1982) 'Chronic illness as biographical disruption'. *Sociology of Health and Illness*, 4(2): 167-182.

Cahill, E., Lewis, L.M., Barg, F.K. and Bogner, H.R. (2009) ""You Don't Want to Burden Them": Older Adults' Views on Family Involvement in Care". *Journal of Family Nursing*, 15 (3): 295-317.

Care Act (2014) c. 23. Available on-line at: http://www.legislation.gov.uk/ukpga/2014/23/contents (accessed 26.08.2014)

Care Act (2014) c. 23 *Explanatory Notes.* Available on-line at: http://www.legislation.gov.uk/ukpga/2014/23/notes/contents (accessed 26.08.2014)

Carr, S. (2011) "Enabling risk and ensuring safety: self-directed support and personal budgets". *The Journal of Adult Protection*, 13 (3): 122-136.

Carter, M.J. and Fuller, C. (2015) 'Symbolic Interactionism'. Available at: http://www.sagepub.net/isa/resources/pdf/symbolic%20interactionism.pdf

Centre for Ageing Better (2018) 'Transforming Later Lives – Strategy 2018'. https://www.ageing-better.org.uk/sites/default/files/2018-07/Ageing-Better-Transforming-Later-Lives.pdf

Chambers, P., Allan, G., Phillipson, C. and Ray, M. (2009) 'Family Practices in Later Life'. Bristol: The Policy Press.

Charon, J.M. (1995) "Symbolic Interactionism: an introduction, an interpretation, an integration". Fifth Edition. New Jersey: Prentice Hall.

Clark, H. (2006) ""It's meant that, well, I'm living a life now": Older people's experiences of direct payments". In Leece, J. and Bornat, J. (eds) *Developments in Direct Payments*. Bristol: Policy Press: 79-94.

Clarke, A. and Warren, L. (2007) "Hopes, fears and expectations about the future: what do older people's stories tell us about active ageing?". *Ageing and Society*, 27 (4): 465-488.

Clarke, V. and Braun, V. (2013) "Teaching thematic analysis: Over-coming challenges and developing strategies for effective learning". *The Psychologist*, 26 (2): 120-123.

Cobb, A. K. and Forbes, S. (2002) "Qualitative Research: What Does It Have to Offer to the Gerontologist?". *Journal of Gerontology,* 57A (4): M197-M202.

Coeling, Biordi and Theis (2003) "Negotiating Dyadic Identity Between Caregivers and Care Receivers". *Journal of Nursing Scholarship*. 35 (1): 21-25.

Coleman, T., Kearns, R.A. and Wiles, J. (2016) "Older adults' experiences of home maintenance issues and opportunities to maintain ageing in place". *Housing Studies*. 31 (8): 964-983.

Community Care (Direct Payments) Act 1996 c. 30. Available on-line at: http://www.legislation.gov.uk/ukpga/1996/30/contents (accessed 26.08.2014)

Commission on Funding of Care and Support (2011) *Fairer Care Funding: The Report of the Commission on Funding of Care and Support*. Available on-line at: http://webarchive.nationalarchives.gov.uk/20130221130239/https://www.wp.dh.gov.uk/carecommission/files/2011/07/Fairer-Care-Funding-Report.pdf (accessed 28.08.2014)

Connidis, I.A. and Kemp, C.L. (2008) "Negotiating actual and anticipated parental support: Multiple sibling voices in three-generation families". *Journal of Aging Studies.* 22 (3): 229-238.

Consultus Care and Nursing (2014) *The Care Choice Gap: Overcoming the challenges in elderly care provision* Available on-line at: http://www.consultuscare.com/_app_/resources/documents/www.consultuscare.com/care-choice-gap/care-choice-gap-report.pdf (accessed 20.10.2014)

Crystal, S., Shea, D.G., Reyes, A.M. (2017) 'Cumulative Advantage, Cumulative Disadvantage, and Evolving Patterns of Late-Life Inequality'. The Gerontologist, 57 (5): 910-920.

Daatland, S.O. and Herlofson, K. (2003) "'Lost solidarity' or 'changed solidarity': a comparative European view of normative family solidarity'. *Ageing and Society*, 23 (5): 537-560.

Dannefer, D. (2003) "Cumulative Advantage/Disadvantage and the Life Course: Cross-Fertilizing Age and Social Science Theory". *Journal of Gerontology*, 58B (6): S327-S337.

Dannefer, D. and Miklowski, C. (2006) 'Developments in the Life Course'. In Vincent, J.A., Phillipson, C. and Downs, M. (2006) 'Futures of Old Age'. London: SAGE Publications Ltd.: 30-40.

Davidson, K. (2004) '"Why Can't a Man Be More Like a Woman?" Marital Status and Social Networking of Older Men'. *The Journal of Men's Studies*, 13 (1): 25-43.

Davidson, K., Daly, T. and Arber, S. (2003) "Older Men, Social Integration and Organisational Activities". *Social Policy and Society*, 2 (2): 81-89.

Davies, M. B. (2007) Doing a Successful Research Project: Using Qualitative or Quantitative Methods. Basingstoke: Palgrave MacMillan.

Dempsey, L., Dowling, M., Larkin, P. and Murphy, K. (2016) 'Sensitive Interviewing in Qualitative Research'. *Research in Nursing and Health*, 39(6): 480-499.

Department of Health (2001) *National Service Framework for Older People*. HM Government, London. Available on-line at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/198033/ National_Service_Framework_for_Older_People.pdf (accessed 26.08.2014)

Department of Health (2005) *Independence, Well-being and Choice: Our vision for the future of social care for adults in England.* HM Government, London. Available on-line at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/272101/ 6499.pdf (accessed on 26.08.2014)

Department of Health (2007) *Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care*. HM Government, London. Available on-line at: http://ww.dh.gov.uk/en/Publicationsandstatistics/Publications (accessed 26.08.2014)

Department of Health (2010) *Putting People First: Personal Budgets for Older People – Making it Happen*. Her Majesty's Government, London. Available on-line at: http://www.ndti.org.uk/uploads/files/PSSOP.pdf (accessed 28.08.2014)

Department of Health (2013) *The Adult Social Care Outcomes Framework 2014/15*. HM Government, London. Available on-line at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/263783/ adult_social_care_framework.pdf (accessed 28.08.2014)

Department of Health and The Rt Hon Norman Lamb MP (2014) *Care Bill becomes Care Act 2014.* Available on-line at https://www.gov.uk/government/speeches/care-bill-becomes-care-act-2014 (accessed 28.08.2014)

Department of Health (2015) *Voice, Choice and Control*. Available on-line at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/474253/VCC_acc.pdf (accessed 21.02.2018)

Department of Health and Social Care (2016) *Guidance: Care Act Factsheets: Factsheet 1: General responsibilities of local authorities: prevention, information and advice, and shaping the market of care and support services*. Available at: https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets (accessed 27.03.2018)

Department of Health and Social Care (2018) *Care and Support Statutory Guidance*. Available on-line at: https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance (accessed 21.02.2018)

Department for Work and Pensions (2017) 'State Pension age review'. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/630066/print-ready-state-pension-age-review-final-report.pdf

Doyle, S. (2007) "Member Checking With Older Women: A Framework for Negotiating Meaning". *Health Care for Women International*, 28 (10): 888-908.

Dunatchik, A., Icardi, R., Roberts, C. and Blake, M. (2016) *Predicting unmet social care needs and links with well-being: Findings from the secondary analysis*. Available at: https://www.ipsos.com/sites/default/files/2017-04/SRI_Health_NIHR-unmet-need_12-12-2016.pdf.pdf (accessed 22.02.2018).

Dunér, A. and Nordström, M. (2007) "The roles and functions of the informal support networks of older people who receive formal support: a Swedish qualitative study". *Ageing and Society,* 27 (1): 67-85.

Dunér, A. and Nordström, M. (2010) "The desire for control: Negotiating the arrangement of help for older people in Sweden". *Journal of Aging Studies*, 24 (4): 241-247.

Dykstra, P. (2015) 'Aging and Social Support – Families in Context'. Blackwell Encyclopaedia of Sociology. Available at: http://www.familiesincontext.eu/wp-content/uploads/2014/04/Aging-and-social-support-Text-2014.pdf (accessed 02.03.2019)

Egdell, V., Bond, J., Brittain, K. and Jarvis, H. (2010) "Disparate routes through support: Negotiating the sites, stages and support of informal dementia care". *Health and Place,* 16 (1): 101-107.

Elder, G. (1994) "Time, Human Agency, and Social Change: Perspectives on the Life Course". *Social Psychology Quarterly*, 57 (1): 4-15.

Ellard-Gray, A., Jeffrey, N.K., Choubak, S.E. and Crann, S.E. (2015) 'Finding the Hidden Participant: Solutions for Recruiting Hidden, Hard-to-Reach, and Vulnerable

Populations'. *International Journal of Qualitative Methods*: 1-10 DOI: 10.1177/1609406915621420.

Ellis-Paine, A., Taylor, R., Needham, C., Littlechild, R. and Buckingham, H. (2014) *Maximising Older People's Personal Budget Use (MOPPU): Project Evaluation Report*. Available at: https://www.birmingham.ac.uk/generic/tsrc/documents/tsrc/reports/Age-UK-report-FINAL-23-10-14-PDF.pdf (accessed 24.03.2018)

Employment Equality (Repeal of Retirement Age Provisions) Regulations (2011) No. 1069 https://www.legislation.gov.uk/uksi/2011/1069/contents/made

Evandrou, M., Falkingham, J., Robards, J., Vlachantoni, A., and McGowan, T. (Ed.) (2015) 'Who cares? Continuity and change in the prevalence of caring, and characteristics of informal carers, in England and Wales 2001-2011'. (ESRC Centre for Population Change Working Papers; No. 68). Southampton: ESRC Centre for Population Change.

Fagan, C. (2001) 'Time, Money and the Gender Order: Work Orientations and Working Time Preferences in Britain'. *Gender, Work and Organization*, 8 (3): 239-266.

Finch, H. and Lewis, J. (2003) "Focus Groups". In Ritchie, J. and Lewis, J. (eds) *Qualitative Research Practice* London: SAGE Publications Ltd.

Finch, J. and Mason, J. (1990) "Filial Obligations and Kin Support For Elderly People". *Ageing and Society.* 10 (2): 151-175.

Finch, J. and Mason, J. (1993) *Negotiating Family Responsibilities.* London: Routledge.

Flick, U. (2007) *Designing Qualitative Research.* London: SAGE Publications Ltd.

Flick, U. (2014) *An Introduction to Qualitative Research.* Fifth Edition. London: SAGE Publications Ltd.

Flyvbjerg, B. (2006) "Five Misunderstandings About Case-Study Research". *Qualitative Inquiry*, 12 (2): 219-245.

Forder, J. E. (2008) *The Costs of Addressing Age Discrimination in Social Care* (PSSRU Discussion Paper 2538). Available on-line at: http://www.pssru.ac.uk/pdf/dp2538.pdf (accessed 14.08.2014)

Fox, G.L. and Murry, V.M. (2000) 'Gender and Families: Feminist Perspectives and Family Research'. *Journal of Marriage and the Family*, 62 (4): 1160-1172.

Francis, J., and Netten, A. (2004) "Raising the quality of home care: A study of service users' views". *Social Policy & Administration*, 38 (3): 290-305.

Gaalen van, I.R., Dykstra, P.A, and Flap, H. (2008) "Intergenerational contact beyond the dyad: the role of the sibling network". *European Journal of Ageing,* 5 (1): 19-29.

Ganong, L.H. and Coleman, M. (2006) "Obligations to Stepparents Acquired in Later Life: Relationship Quality and Acuity of Needs". *Journal of Gerontology*, 61B (2): S80-88.

Gans, D. and Silverstein, M. (2006) "Norms of Filial Responsibility for Aging Parents Across Time and Generations". *Journal of Marriage and Family,* 68 (4): 961-976.

Gheera, M. (2012) "Direct payments and personal budgets for social care". House of Commons Library. Available on-line at: http://www.parliament.uk/business/publications/research/briefing-papers/SN03735/direct-payments-and-personal-budgets-for-social-care (accessed 28.08.2014)

Giele, J.Z. and Elder, G.H. (1998) Methods of Life Course Research: Quantitative and Qualitative Approaches. London: SAGE Publications Ltd.

Glasby, J. and Littlechild, R. (2009) *Direct Payments and Personal Budgets: Putting Personalisation into Practice.* Second Edition, Bristol: Policy Press.

Glasby, J., Walshe, K. and Harvey, G. (2007) "Making evidence fit for purpose in decision making: A case study of the hospital discharge of older people". *Evidence and Policy*, 3 (3): 425-437.

Glendinning, C.; Challis, D.; Fernandez, L.F.; Jacobs, S.; Jones, K.; Knapp, M.; Manthorpe, J.; Moran, N.; Netten, A.; Stevens, M. and Wilberforce, M. (2008) *Evaluation of the Individual Budgets Pilot Programme: Final Report.* Social Policy Research Unit, University of York: York.

Glendinning, C., Mitchell, W. and Brooks, J. (2014) "Ambiguity in Practice? Carers roles in personalised social care in England". *Health and Social Care in the Community*, 23 (1): 23-32.

Gómez-León, M., Evandrou, M., Falkingham, J. and Vlachantoni, A. (2019) 'The Dynamics of Social Care and Employment in Mid-life'. Ageing and Society, 39 (2): 381-408.

Gomm, R., Hammersley, M. and Foster, P. (2000) *Case Study Method*. London: SAGE Publications Ltd.

Government Office for Science Annual (2016) 'Future of an Ageing Population'. https://www.ageing.ox.ac.uk/files/Future_of_Ageing_Report.pdf (accessed 02.03.2019)

Greenhalgh, L., and Chapman, D. I. (1995) "Joint decision making: the inseparability of relationships and negotiation". In Kramer, R.M. and Messick, D.M. (eds). *Negotiation as a Social Process.* London: SAGE Publications: 166-185.

Grootegoed, E. and van Dijk, D. (2012) "The Return of the Family? Welfare State Retrenchment and Client Autonomy in LongTerm Care" *Journal of Social Policy*, 41 (4): 677-694.

Gridley, K., Brooks, J. and Glendinning, C. (2014) "Good practice in social care: the views of people with severe and complex needs and those who support them". *Health and Social Care in the Community*. 22 (6): 588-597.

Grundy, E. (2005) "Reciprocity in relationships: socio-economic and health influences on intergenerational exchanges between Third Age parents and their adult children in Great Britain". *The British Journal of Sociology*, 56 (2): 233-255.

Grundy, E. and Henretta, J.C. (2006) "Between elderly parents and adult children: a new look at the intergenerational care provided by the 'sandwich generation'". *Ageing and Society*, 26 (5): 707-722.

Grundy, E. and Read, S. (2012) "Social Contacts and Receipt of Help Among Older People in England: Are There Benefits of Having More Children?". *Journal of Gerontology*, *Series B: Psychological Sciences and Social Sciences*, 67 (6): 742-754.

Ham, C., Dixon, A. and Brooke, B. (2012) "Transforming the delivery of health and social care: The case for change". Available on-line at: http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/transforming-the-delivery-of-health-and-social-care-the-kings-fund-sep-2012.pdf (accessed 17.03.2016)

Hampshire County Council (2014) *Individual Service Funds (ISF's)*. Available on-line at: http://www3.hants.gov.uk/adult-services/adultservices-professionals/market_development/understandingourapproach/contracting_and_procurement/isf.htm (accessed 26.08.2014)

Harrison, H., Birks, M., Franklin, R. and Mills, J. (2017) 'Case Study Research: Foundations and Methodological Orientations'. *Forum Qualitative Social Research*, 18 (1): 1-12. http://www.qualitative-research.net/index.php/fqs/article/view/2655/4079

Hastings, S.J. and Rogowski, S. (2015) 'Critical Social Work with Older People in Neo-liberal Times: Challenges and Critical Possibilities'. *Practice: Social Work in Action*, 27 (1): 21-33.

Hatton, C. and Waters, J. (2011) *Personal Budgets: Taking Stock, Moving Forward.* Available on-line at: http://www.in-control.org.uk/media/242956/national%20personal%20budget%20survey%20report%20june%202011.pdf (accessed 28.02.2018)

Health and Social Care Act (2008) c. 14 . Available on-line at: https://www.legislation.gov.uk/ukpga/2008/14/contents (accessed 17.03.2018)

Heid, A.R., Zarit, S.H, and Fingerman, K. (2016) ""My Parent is so Stubborn!" – Perception of Aging Parents' Persistence, Insistence and Resistance". *Journals of Gerontology: Series B*, 71 (4): 602-612.

Hennink, M., Hutter, I. and Bailey, A. (2011) *Qualitative Research Methods*. London: SAGE Publications Ltd.

Her Majesty's Government (2011) "Announcement: Default retirement age to end this year". Available on-line at: https://www.gov.uk/government/news/default-retirement-age-to-end-this-year (accessed 28.03.2016)

Her Majesty's Government (2012) 'Caring for our future: reforming care and support'. CM 8378
https://webarchive.nationalarchives.gov.uk/20130804123134/https://www.gov.uk/government/publications/caring-for-our-future-reforming-care-and-support

Hewitt, J. (2007) 'Ethical Components of Researcher-Researched Relationships in Qualitative Interviewing'. *Qualitative Health Research*, 17(8): 1149-1159.

Hillcoat-Nallétamby, S. (2014) 'The Meaning of "Independence" for Older People in Different Residential Settings'. *The Journals of Gerontology, Series B*, 3(1): 419-430.

Himmelweit, S. (2007) 'The prospects for caring: economic theory and policy analysis'. *Cambridge Journal of Economics*, 31 (4): 581-599.

Hockey. J. and James, A. (2003) 'Social Identities across the Life Course'. Basingstoke: Palgrave MacMillan.

Hogstel, M.O., Curry, L.C. and Walker, C. (2005) 'Caring for Older Adults: The Benefits of Informal Family Caregiving'. *Journal of Theory Construction and Testing*, 9 (2): 55-60.

Holt-Lunstad, J., Smith, T.B., Baker, M., Harris, T. and Stephenson, D. (2015) 'Loneliness and Social Isolation as Risk Factors for Mortality: A Meta-Analytic Review'. *Perspectives on Psychological Science*, 10 (2): 227-237.

Horowitz, A. (1985) 'Sons and Daughters as Caregivers to Older Parents: Differences in Role Performance and Consequences'. *The Gerontologist*, 25 (6): 612-617.

Horton, K. and Arber, S. (2004) "Gender and the negotiation between older people and their carers in the prevention of falls". *Ageing and Society*, 24 (1): 75-94.

House of Commons Library (2019) 'Adult Social Care Funding (England), Number CB07903. Available at: https://researchbriefings.files.parliament.uk/documents/CBP-7903/CBP-7903.pdf (accessed 28.02.2019)

Hurst, S.A. and Mauron, A. (2008) 'A question of method: The ethics of managing conflicts of interest'. *European Molecular Biology Organization*, 9(2): 119-123.

Hussein, S. (2011) 'Volunteers in the formal long-term care workforce'. Social Care Workforce, 13. https://core.ac.uk/download/pdf/45319364.pdf (accessed 02.03.2019)

Hussein, S. (2017) '"We don't do it for the money" ... The scale and reasons of poverty- pay among frontline long- term care workers in England'. *Health and Social Care*, 25 (6): 1817-1826.

Humphries, R. (2013) *Paying for social care: Beyond Dilnot"*. London: The King's Fund. Available on-line at:

http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_summary/social-care-funding-paper-may13.pdf (accessed 05.11.2014)

Hwang, E., Cummings, L., Sixsmith, A. and Sixsmith, J. (2011) "Impacts of home modifications on aging-in-place". *Journal of Housing For the Elderly*, 23 (3): 246-257.

Ingrisch, D. (2002) "Conforming and Resistance as Women Age". In S. Arber and J. Ginn (eds) *Connecting gender and ageing: a sociological approach*. Buckingham: Open University Press.

Ipsos MORI (2017) *Unmet Need for Care.* Available at: https://www.ipsos.com/sites/default/files/2017-07/unmet-need-for-care-full-report.pdf (accessed 22.02.2018).

Isengard, B. (2013) ""The Apple doesn't Live Far from the Tree"". *Comparative Population Studies*, 38 (2): 237-262.

Jacobs, M., Van Tilburg, T., Groenewegen, P. and Broese Van Groenou (2016) "Linkages between informal and formal care-givers in home-care networks of frail older adults". *Ageing and Society*, 36 (8): 1604-1624.

Janlöv, A., Hallberg, I.R., and Petersson, K. (2006) "Family members' experience of participation in the needs of assessment when their older next of kin becomes in need of public home help: A qualitative interview study". *International Journal of Nursing Studies*, 43 (8): 1033-1046.

Jenkins, C.L. (2000) "Care Arrangement Decisions for Frail Older Women: Quantitative and Qualitative Perspectives". *Journal of Women & Aging*, 12 (3/4): 3.20.

Jeon Y.H., (2004) "The application of grounded theory and symbolic interactionism". *Scandinavian Journal of Caring Sciences*, 18 (3): 249-256.

Jesson, J.K., Matheson, L. and Lacey, F.M. (2011) *Doing Your Literature Review* London: SAGE Publications

Jones, P., Bradbury, L. and Le Boutillier, S. (2011) *Introducing Social Theory,* Second Edition, Cambridge: Polity Press.

Kemp, C.L., Ball, M.M. and Perkins, M.M. (2013) "Convoys of care: Theorizing intersections of formal and informal care". *Journal of Aging Studies*, 27 (1): 15-29.

Kittay, E.F., Jennings, B. and Wasunna, A.A. (2005) 'Dependency, Difference and the Global Ethic of Longterm Care'. *The Journal of Political Philosophy*. 13 (4): 443-469.

Klaus, D. and Schnettler, S. (2016) 'Social networks and support for parents and childless adults in the second half of life: Convergence, divergence, or stability?'. *Advances in Life Course Research*, 29 (1): 95-105.

Lang, F.R., Wagner, J. and Neyer, F.J. (2009) 'Interpersonal functioning across the lifespan: Two principles of relationship regulation'. *Advances in Life Course Research*, 14 (1-2): 40-51.

Langford, D., Edwards, N., Gray, S.M., Fleig, L. and Ashe, M.C. (2018) ""Life Goes On." Everyday Tasks, Coping Self-Efficacy, and Independence: Exploring Older Adults' Recovery From Hip Fracture". *Qualitative Health Research*, First Published February 20, 2018 https://doi.org/10.1177%2F1049732318755675

Larsson, A.T. and Grassman, E.J. (2012) 'Bodily changes among people living with physical impairments and chronic illnesses: biographical disruption or normal illness?'. *Sociology of Health and Illness,* 34 (8): 1156-1169.

Lashewicz, B. and Keating, N. (2009) "Tensions among siblings in parent care". *European Journal of Ageing,* (2): 127-135.**Law Commission, The (2011)** *Adult Social Care*. Law Com No. 326. HC 941. London: The Stationery Office. Available on-line at: http://lawcommission.justice.gov.uk/docs/lc326_adult_social_care.pdf (accessed 28.08.2014)

Leece, J. and Peace, S. (2010) 'Developing New Understandings of Independence and Autonomy in the Personalised Relationship'. *British Journal of Social Work*, 40 (6): 1847-1865.

Leinonen, A.M. (2011) "Adult Children and parental caregiving: making sense of participation patterns among siblings". *Ageing and Society*, 31 (2): 308-327.

Leopold, T. and Raab, M. (2011) "Short-Term Reciprocity in Late Parent-Child Relationships". *Journal of Marriage and Family.* 73 (1): 105-119.

Levkoff, S., Levy, B. and Weitzman, P.F. (1999) "The role of religion and ethnicity in the help seeking of family caregivers of elders with Alzheimer's disease and related disorders". *Journal of Cross-Cultural Gerontology*, 14 (4): 335–356.

Lewinter, M. (2003) "Reciprocities in caregiving relationships in Danish elder care". *Journal of Aging Studies*. 17 (3): 357-377.

Lewis, J. (2003) "Design Issues". In Ritchie, J. and Lewis, J. (eds*). Qualitative Research Practice*. London: SAGE Publications Ltd.

Lewis, J. and West, A. (2014) "Re-Shaping Social Care Services for Older People in England: Policy Development and the Problem of Achieving 'Good Care'". *Journal of Social Policy,* 43 (1): 1-18.

Lilburn, L.E.R., Breheny, M. and Pond, R. (2018) "'You're not really a visitor, you're just a friend': how older volunteers navigate home visiting'. *Ageing and Society*, 38 (4): 817-838.

Lin, I-F. (2008) "Consequences of Parental Divorce for Adult Children's Support of Their Frail Parents". *Journal of Marriage and Family,* 70 (1): 113-128.

Livingston, G., Leavey, G., Manela, M., Livingston, D., Rait, G., Sampson, E., Bavishi, S., Shahriyarmolki, K. and Cooper, C. (2010) "Making decisions for people

with dementia who lack capacity: qualitative study of family carers in UK”. *British Medical Journal* 341.

Lowenstein, A., Katz, R., Gur-Yaish (2007) “Reciprocity in Parent-Child Exchange and Life Satisfaction among the Elderly: A Cross-National Perspective”. *Journal of Social Issues,* 63 (4): 865-883.

Lloyd, L. (2010) “The Individual in Social Care: The Ethics of Care and the ‘Personalisation Agenda’ in Services for Older People in England”. *Ethics and Social Welfare*, 4 (2): 188-200.

Lloyd, L. (2012) ‘Health and Care in Ageing Societies: A new international approach’. Bristol: The Policy Press.

Lloyd, L., Tanner, D., Milne, A., Ray, M., Richards, S., Sullivan, M.P., Beech, C. and Phillips, J. (2014) ‘Look after yourself: active ageing, individual responsibility and the decline of social work with older people in the UK’. *European Journal of Social Work*, 17 (3): 322-335.

Lloyd’s Bank Foundation England & Wales (2016) *Commissioning in Crisis: How current contracting and procurement processes threaten the survival of small charities*. Available at: https://www.lloydsbankfoundation.org.uk/Commissioning%20in%20Crisis%202016%20Full%20Report.pdf (accessed 26.03.2018)

Luborsky, M.R. and Rubinstein, R.L. (1995) “Sampling in Qualitative Research: Rationale, Issues, and Methods”. *Research Aging*, 17 (1): 89-113.

Lyttle, D.J. and Ryan, A. (2010) “Factors influencing older patients’ participation in care: a review of the literature”. *International Journal of Older People Nursing*, 5 (4): 274-282.

McGrew, K. (1998) “Daughters’ Caregiving Decisions: From an Impulse to a Balancing Point of Care”. *Journal of Women & Aging*, 10 (2): 49-65

McKie, L., Bowlby, S., Gregory, S. (2001) ‘Gender, Caring and Employment in Britain’. *Journal of Social Policy*, 30 (2): 233-258.

McNeil, C. and Hunter, J. (2014) *The Generation Strain: Collective solutions to care in an ageing society*. London: Institute for Public Policy. Available on-line at: http://www.ippr.org/assets/media/publications/pdf/generation-strain_Apr2014.pdf (accessed 26.08.2014)

Marmot, M. (2010) *Fair society, healthy lives : the Marmot Review : strategic review of health inequalities in England post-2010.* Available on-line at: http://www.instituteofhealthequity.org/projects/fair-society-healthy-lives-the-marmot-review (accessed 12.03.2016)

Mason, J. (2002) *Qualitative Researching.* Second edition. London: SAGE Publications.

Matthews, S.H. (2002) Sisters and Brothers/Daughters and Sons: Meeting the Needs of Older Parents. Indiana: Unlimited Publishing, LLC.

Marhánková, J. H. (2014) "'Women are just more active' – gender as a determining factor in involvement in senior centres". *Age and Ageing*, 34 (9): 1482-1504.

Mead, G.H. (1934) *Mind, Self and Society from the Standpoint of a Social Behaviorist* (Edited by Charles W. Morris). Chicago: University of Chicago.

Mental Capacity Act 2005 (2005) Mental Capacity Act 2005. (2005). 1st ed. [ebook] Legislation.gov.uk, p.Section 16A. Available on-line at: http://www.legislation.gov.uk/ukpga/2005/9/contents (accessed 28.02.2018)

Mental Capacity Act Code of Practice (2005) The Stationery Office https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf

Meyer, C.B. (2001) 'A Case in Case Study Methodology'. *Field Methods*, 13 (4): 329-352.

Miller, C., Bunnin, A. and Rayner, V. (2013) Older people who self fund their social care: A guide for health and wellbeing boards and commissioners. OPM. Available on-line at: http://www.opm.co.uk/wp-content/uploads/2013/10//Older-people-who-self-fund-their-care-report.pdf (accessed 28.10.2014)

Milne, A. and Larkin, M. (2015) 'Knowledge generation about care-giving in the UK: a critical review of research paradigms'. *Health and Social Care in the Community*, 23 (1): 4-13.

Minichiello, V., Browne, J. and Kendig, H. (2000) 'Perceptions and consequences of ageism: views of older people'. *Ageing and Society*, 20 (3): 253-278.

Moran, N., Glendinning, C., Stevens, M., Manthorpe, J., Jacobs, S., Wilberforce, M., Knapp, M., Challis, D., Fernández, J., Jones, K., Netten, A. (2011) "Joining Up Government by Integrating Funding Streams? The Experiences of the Individual Budget Pilot Projects for Older and Disabled People in England". *International Journal of Public Administration*, 34 (4): 232-243.

Mortimer, J. and Green, M. (2016) *Briefing: The Health and Care of Older People in England.* Available on-line at: http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/Briefing-The_Health_and_Care_of_Older_People_in_England-2015-UPDATED_JAN2016.pdf?dtrk=true (accessed 28.03.2016)

National Audit Office (NAO) (2011) 'Users of Social Care Personal Budgets. Ipsos MORI report for the National Audit Office study on the Department of Health's regulatory oversight of care markets'. Available at: https://www.ipsos.com/sites/default/files/publication/1970-01/sri-nao-users-of-social-care-personal-budgets.pdf (accessed 22.12.2018)

National Audit Office (NAO) (2014) *Adult Social Care in England: overview.* House of Commons: HC 1102

National Health and Community Care Act (1990), c. 19. Available on-line at http://www.legislation.gov.uk/ukpga/1990/19/contents (accessed 26.08.2014)

NHS Digital (2017) "Health Survey for England 2016 Social care for older adults". Available at: https://digital.nhs.uk/catalogue/PUB30169 (accessed 24.02.2018)

Netten, A., Jones, K., Knapp, M., Fernandez, J. L., Challis, D., Glendinning, C., Jacobs, S., Manthorpe, J., Moran, N., Stevens, M. and Wilberforce, M. (2011) "Personalisation through individual budgets: Does it work and for whom?". *British Journal of Social Work*, 42 (8): 1556-1573.

Neville, S. (2010) 'Delivering Personal Budgets for Adult Social Care: Reflections from Essex'. London: Office for Public Management. Available at: https://www.thinklocalactpersonal.org.uk/_assets/Personal_budgets_reflections_from_Essex.pdf (accessed 22.12.2018)

Newbronner, L.; Chamberlain, R.; Bosanquet, K., Bartlett, C. ; Sass, B. and Glendinning, C. (2011) Keeping personal budgets personal: learning from the experiences of older people, people with mental health problems and their carers. London: Social Care Institute for Excellence.

NICE (2015) 'Older people with social care needs and multiple long-term conditions'. https://www.nice.org.uk/guidance/ng22 (accessed 02.02.2019).

Nocon, A. and Pearson, M. (2000) "The roles of friends and neighbours in providing support for older people". *Ageing and Society*, 20 (3): 341-367.

Nyman, S.R. and Victor, C.R. (2014) 'Use of personal call alarms among community-dwelling older people'. *Ageing and Society*, 34 (1): 67-89.

O'Rand, A.M. (2009) 'Cumulative processes over the life course'. In Elder, G.H., Giele, J.Z. 'The craft of life course research'. New York: Guilford Press: 121-140.

Office for National Statistics (2013) "What Does the 2011 Census Tell Us About Older People?". Available on-line at: http://www.ons.gov.uk/ons/dcp171776_325486.pdf (accessed 25.01.2014)

Office for National Statistics (2014) "Estimates of the Very Old (including Centenarians) in England and Wales, and United Kingdom, 2002 to 2014". Available on-line at: http://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/bulletins/estimatesoftheveryoldincludingcentenarians/2015-09-30 [accessed 10.03.2016]

Office for National Statistics (2016) "Statistical Bulletin: Healthy life expectancy at birth and age 65 by upper tier local authority and area deprivation: England, 2012 to 2014". Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/bulletins/healthylifeexpectancyatbirthandage65byuppertierlocalauthorityandareadeprivation/england2012to2014 (accessed 17.03.2018)

Office for National Statistics (2017a) "Statistical Bulletin: National life tables, UK: 2014 to 2016". Available on-line at: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/bulletins/nationallifetablesunitedkingdom/2014to2016 [accessed 20.02.2018]

Office for National Statistics (2017b) "Overview of the UK population: July 2017". Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/overviewoftheukpopulation/july2017 [accessed 20.02.2018]

Office for National Statistics (2017c) 'Families and Households: 2017'. Statistical Bulletin. Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/bulletins/birthsummarytablesenglandandwales/2017 (accessed 03.02.2019)

Office for National Statistics (2017d) 'Marriage and divorce on the rise at 65 and over'. Available at https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/marriagecohabitationandcivilpartnerships/articles/marriageanddivorceontheriseat65andover/2017-07-18 (accessed 03.02.2019)

Office for National Statistics (2018a) 'Births in England and Wales 2017'. Statistical Bulletin. Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/families/bulletins/familiesandhouseholds/2017 (accessed 03.02.2019)

Office for National Statistics (2018b) 'National life tables, UK: 2015 to 2017'. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/bulletins/nationallifetablesunitedkingdom/2015to2017 (accessed 19.02.2019)

Olaison, A. and Cedersund, E. (2006) "Assessment for home care: Negotiating solutions for individual needs". *Journal of Aging Studies*, 20 (4): 367-380.

Olaison, A. (2009) "Negotiating needs: Processing older persons as home care recipients in gerontological social work practices". Linköping Studies in Arts and Science No 464.

Orellana, K. (2010) "Personalisation in practice: lessons from experience. Making personal budgets, support planning and brokerage work for people in later life". Available on-line at: http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Care/Personalisation_in_practice-lessons_from_experience.pdf?dtrk=true (accessed 26.08.2014)

Oudijk, D., Woittiez, I. and de Boer, A. (2011) "More family responsibility, more informal care? The effect of motivation on the giving of informal care by people aged over 50 in the Netherlands compared to other European countries". *Health Policy*, 101 (3): 228-235.

Parliament. House of Commons (2018) *Briefing Paper: Social care: the forthcoming Green Paper on older people (England)*. Available at:

http://researchbriefings.files.parliament.uk/documents/CBP-8002/CBP-8002.pdf (accessed 22.03.2018)

Pecchioni, L.L. (2001) "Implicit Decision-Making in Family Caregiving". *Journal of Social and Personal Relationships*, 18 (2): 219-237.

Perren, K., Arber, S. and Davidson, K. (2003) "Men's organisational affiliations in later life: the influence of social class and marital status on informal group membership". *Ageing and Society*, 23 (1): 69-82.

Pew Research Center (2013) 'On Pay Gap, Millennial Women Near Parity – For Now'. Chapter 5: Balancing Work and Family http://www.pewresearch.org/wp-content/uploads/sites/3/2013/12/gender-and-work_final.pdf

Phillips, J., Bernard, M., Phillipson, C. and Ogg, J. (2000) 'Social Support in Later Life: A Study of Three Areas'. *British Journal of Social Work*, 30 (6): 837-853.

Pickard, L. King, D. and Knapp, M. (2007) 'The 'visibility' of unpaid care in England'. *Journal of Social Work,* 16 (3): 263-282.

Pickard, L., Wittenberg, R., Comas-Herrera, A., King, D. and Malley, J. (2007) 'Care by Spouses, Care by Children: Projections of Informal Care Older People in England to 2031'. *Social Policy and Society*, 6 (3): 353-366.

Pillemer, K. and Suitor, J.J. (2013) "Who Provides Care? A Prospective Study of Caregiving Among Adult Siblings". *The Gerontologist,* Advance Access, doi: 10.1093/geront/gnt066.

Pohl, J.M., Boyd, C. and Given, B.A. (1997) "Mother-Daughter Relationships During the First Year of Caregiving: A Qualitative Study". *Journal of Women and Aging*, 9 (1-2) 133-149.

Portacolone, E. (2011) "The myth of independence for older Americans living alone in the Bay Area of San Francisco: a critical reflection". *Ageing and Society*. 31 (5): 803-828.

Porter, E.J. and Lanes, T. (2000) "Targeting Intermediaries to Recruit Older Women for Qualitative, Longitudinal Research". *Journal of Women and Aging*, 12 (1-2): 63-75.

Porter, E.J. (2005) "Older Widow's Experiences of Home Care". *Nursing Research*, 54 (5): 296-303.

Powell, J., Bray, J., Roberts, H., Goddard, A., and Smith, E. (2000) "Goal negotiation with older people in three day care settings". *Health & Social Care in the Community*, 8 (6): 380-389.

Pratt, C.C., Jones-Aust, L. and Pennington, D. (1993) "Decision-making Influence Strategies of Caregiving Daughters and Their Elderly Mothers". *Family Relations*. 42 (4): 376-382.

Price, D.; Bisdee, D.; Daly, T., Livsey, L. and Higgs, P. (2014) "Financial planning for social care in later life: the 'shadow' of fourth age dependency". *Ageing and Society*, 34 (3): 388-410.

Price, E. (2011) "Caring for Mum and Dad: Lesbian Women Negotiating Family and Navigating Care". *British Journal of Social Work*, 41 (7): 1288-1303.

Provis, C. (2004) "Negotiation, Persuasion and Argument". *Argumentation,* 18 (1): 95-112.

Qureshi, H. and Walker, A. (1989) *The Caring Relationship: Elderly People and their Families*. Basingstoke: Macmillan Education Ltd.

Qureshi, H. (1990) "A Research Note on the Hierarchy of Obligations among Informal Carers – A Response to Finch and Mason". *Ageing and Society,* 10 (4): 455-458.

Rabiee, P., Baxter, K. and Glendinning, C. (2016) "Supporting choice - the role of support planning in facilitating personalisation for older people using managed personal budgets". *Journal of Social Work*, 16 (4): 453-469.

Rabiee, P. (2013) "Exploring the Relationships between Choice and Independence: Experiences of Disabled and Older People". *British Journal of Social Work,* 43 (5): 872-888.

Rachlin, H. and Jones, B.A. (2008) 'Altruism Among Relatives And Non-Relatives'. *Behavioural Processes*, 79 (2): 120-123.

Rahim, N. and Arthur, S. (2012) 'Experiences of Debt and Debt Advice Services in Islington', Islington Debt Coalition.
http://www.infohub.moneyadvicetrust.org/content_files/files/finalidcreport_30_05_co_ge.pdf (accessed 17.03.2019)

Raschick, M. and Ingersoll-Dayton, B. (2004) 'The Costs and Rewards of Caregiving Among Aging Spouses and Adult Children'. Family Relations, 53 (3): 317-325.

Reeves, C.L. (2010) "A difficult negotiation: fieldwork relations with gatekeepers". *Qualitative Research,* 10 (3): 315-331.

Ritchie, J. (2003) "The Applications of Qualitative Research Methods to Social Research". In Ritchie, J. and Lewis, J. (eds) *Qualitative Research Practice*, London: SAGE Publications Ltd.

Robards, J., Vlachantoni, A., Evandrou, M., & Falkingham, J. (2015) 'Informal caring in England and Wales – Stability and transition between 2001 and 2011'. *Advances in Life Course Research*, 24, 21-33. DOI: 10.1016/j.alcr.2015.04.003

Robertson, L. and Hale, B. (2011) 'Interviewing Older People; Relationships in Qualitative Research'. *The Internet Journal of Allied Health Sciences and Practice*. 9(3): 1-8.

Robinson, O.C. (2014) 'Sampling in Interview-Based Qualitative Research: A Theoretical and Practical Guide'. *Qualitative Research in Psychology*, 11(1): 25-41.

Robson, C. (2011) *Real World Research.* Third Edition. Chichester: John Wiley & Sons Ltd.

Routledge, M. and Carr, S. (2013) *Improving Personal Budgets for Older People: Phase One Report.* Social Care Institute for Excellence and Think Local Act Personal.

Sage, J., Evandrou, M. and Falkingham, J. (2014) "The timing of parental divorce and filial obligations to care for ageing parents". *Families, Relationships and Societies*, 3 (1): 113-130.

Sammut Scerri, C., Abela, A. and Vetere, A. (2012) 'Ethical Dilemmas of a Clinician/Researcher interviewing Women who Have Grown Up in a Family Where There Was Domestic Violence'. *International Journal of Qualitative Methods*, 11(2): 102-131.

Samsi, K. and Manthorpe, J. (2011) "'I live for today': a qualitative study investigating older people's attitudes to advance planning". *Health and Social Care in the Community,* 19 (1): 52-59.

Scourfield, P. (2012) "Defenders against Threats or Enablers of Opportunities: The Screening Role Played by Gatekeepers in Researching Older People in Care Homes." *Qualitative Report*, 17 (28): 1-17.

Secker, J., Hill, R., Villeneau, L. and Parkman, S. (2003) 'Promoting independence: but promoting what and how?'. *Ageing and Society*, 23 (3): 375-391.

Seddon, D. and Harper, G. (2009) "What works well in community care: Supporting older people in their own homes and community networks". *Quality in Ageing.* 10 (4): 8-17.

Sheikh, S., Vanson, T., Comber, N., and Watts, R. (2012) *Longitudinal study of Personal Budgets for Adult Social Care in Essex Final Report.* London: Office for Public Management.

Shelton, N. and Grundy, E. (2000) "Proximity of Adult Children to their Parents in Great Britain". *International Journal of Population Geography,* 6 (3): 181-195.

Silverstein, M., Gans, D. and Yang, F.M. (2006) "Intergenerational Support to Aging Parents: The Role of Norms and Needs". *Journal of Family Issues*. 27 (8): 1068-1084.

Silverstein, M., Conroy, S.J. and Gans, D. (2012) 'Beyond solidarity, reciprocity and altruism: moral capital as a unifying concept in intergenerational support for older people'. *Ageing and Society*, 32 (7): 1246-1262. https://www.cambridge.org/core/journals/ageing-and-society/article/beyond-solidarity-reciprocity-and-altruism-moral-capital-as-a-unifying-concept-in-intergenerational-support-for-older-people/46F78FDEB80D1F78B868E2F747EEDC17

Sims-Gould, J. and Martin-Matthews, A. (2010) "We share the care: family caregivers' experiences of their older relative receiving home support services". *Health and Social Care in the Community*, 18 (4): 415-423.

Sixsmith, A. and Sixsmith, J. (2008) 'Ageing in Place in the United Kingdom'. *Ageing International* 32 (3): 219-235.

Sixsmith, J., Sixsmith, A., Callender, M. and Corr, S. (2014) Wartime experiences and their implications for the everyday lives of older people. *Ageing and Society.* 34 (9): 1457-1481.

Slasberg, C. (2010) "Can personalisation be a reality for older people?". *Working with Older People*, 14 (3): 15-22.

Slasberg, C. and Beresford, P. (2016) "The false narrative about personal budgets in England: smoke and mirrors?". *Disability and Society*, 31 (2): 1132-1137.

Smerglia, V. L., Deimling, G. T., and Barresi, C. M. (1988) "Black/White family comparisons in helping and decision-making networks of impaired elderly". *Family Relations*, 37 (3): 305-309.

Smith, J.A., Braunack-Mayer, A., Wittert, G., Warin, M. (2007) ""I've been independent for so damn long!": Independence, masculinity and aging in a help seeking context". *Journal of Aging Studies.* 21 (4): 325-335.

Smith, J. and Noble, H. (2014) 'Bias in research'. *Evidence Based Nursing*, 17 (4): 100-101.

Solé-Auró, A. and Crimmins, E.M. (2014) 'Who cares? A comparison of informal and formal care provision in Spain, England and the USA'. Ageing Society, 34 (3): 495-517.

Southampton City Council (undated) *Adult care eligibility - who can get care and support?* Available at: http://sid.southampton.gov.uk/kb5/southampton/directory/advice.page?id=tvIyXmRSxcY (accessed 27.03.2018)

Spiers, J.A.. (2002) "The Interpersonal Contexts of Negotiating Care in Home Care Nurse-Patient Interactions". *Qualitative Health Research*, 12 (8): 1033-1057.

Stenner, P., McFarquhar, T. and Bowling, A. (2011) 'Older people and 'active ageing': Subjective aspects of ageing actively'. *Journal of Health Psychology*, 16 (3): 467-477.

Stokes, T., Tarrant, C., Mainous, A. G., Schers, H., Freeman, G., & Baker, R. (2005) "Continuity of care: is the personal doctor still important? A survey of general practitioners and family physicians in England and Wales, the United States, and The Netherlands". *The Annals of Family Medicine*, 3 (4): 353-359.

Stuifbergen, M.C., Dykstra, P.A., Lanting, K.N. and van Delden, J.M.J. (2010) "Autonomy in an ascribed relationship: The case of adult children and elderly parents". *Journal of Aging Studies*, 24 (4): 257-265.

Strauss, A. (1978) Negotiations: Varieties, Contexts, Processes, and Social Order. San Francisco: Jossey-Bass.

Sutin, A.R., Stephan, Y., Luchetti, M. and Terracciano, A. (2018) 'Loneliness and Risk of Dementia'. *The Journals of Gerontology: Series B* 1-9. doi:10.1093/geronb/gby112

Sycara, K. (1990) "Persuasive Argumentation in Negotiation". *Theory and Decision*, 28 (3): 203-242.

Talbot Matthews, J., Dunbar-Jacob, J., Sereika, S., Schulz, R. and McDowell, B.J. (2004) 'Preventive Health Practices: Comparison of Family Caregivers 50 and Older'. *Journal of Gerontological Nursing*, 30 (2):46-54.

Tanner, D. (2001) 'Sustaining the self in later life: supporting older people in the community'. *Ageing and Society*, 21(3): 255-278.

Tanner (2007) 'Starting with Lives: Supporting Older People's Strategies and Ways of Coping'. *Journal of Social Work*, 7(1): 7-30.

Tanner, D., Ward, L. and Ray, M. (2017) 'Paying our own way': Application of the capability approach to explore older people's experiences of self-funding social care'. *Critical Social Policy.* 38 (2): 262-282.

Tetley, J., Grant, G. and Davies, S. (2009) "Using Narratives to Understand Older People's Decision-Making Processes". *Qualitative Health Research,* 19 (9): 1273-1283.

Tetley, J. (2013) "Using Participatory Observation to Understand Older People's Experiences: Lessons from the Field". *The Qualitative Report*, 18 (4): 1-18.

Thompson, L., Peterson, E. and Kray, L. (1995) "Social Context in Negotiation". In **Kramer, R.M. and Messick, D.M (eds)**. *Negotiation as a Social Process*. London: SAGE Publications Ltd.: 5-36.

Thornton, A. (2011) "Blurred vision: direct payments, funding cuts and the law". *Social Care and Neurodisability*, 2 (4): 218-225.

Tronto, J. (1993) 'Moral boundaries: A political argument for an ethic of vare'. Psychology Press.

Twigg, J. and Atkin, K. (1995) 'Carers and Services: Factors Mediating Service Provision'. *Journal of Social Policy*, 24 (1): 5-30.

Ullmann-Margalit, E. (1977) quoted in Badgett, M.V.L. and Folbre, N. (1999) 'Assigning care: Gender norms and economic outcomes'. International Labour Review, 138(3): 311-326.

Umberson, D., Pudrovska, T. and Reczek, C. (2010) 'Parenthood, Childlessness and Well-being: A Life Course Perspective'. Journal of Family and Marriage, 72 (3): 612-629.

University of Southampton (2012) 'Policy on the Ethical Conduct of Studies involving Human Participants'. https://www.southampton.ac.uk/about/governance/policies/ethics.page (accessed 02.08.2018)

University of Southampton (2015) *The EPSRC Care Life Cycle Programme: Final Report*. Available at: http://www.southampton.ac.uk/assets/imported/transforms/content-block/UsefulDownloads_Download/06E01744B1644A0882430F4B6C5B4FA6/Web_ready_CareLifeCycleFinalReport_V5.pdf (accessed 12.03.2016)

Victor, C.R. (2005) The Social Context of Ageing: A Textbook of Gerontology. Oxon: Routledge.

Vlachantoni, A., Shaw, R., Willis, R., Evandrou, M., Falkingham, J., and Luff, R. (2011) "Measuring unmet need for social care among older people". *Population Trends Office for National Statistics* nr 145.

Vlachantoni, A. (2017) 'Unmet need for social care among older people'. *Ageing and Society* https://doi.org/10.1017/S0144686X17001118

Walker, A. (2008) 'Active ageing in employment: Its meaning and potential'. *Asia-Pacific Review*, 13(1): 78-93.

Walker, J., Hall, S.M. and Thomas, M.C. (1995) 'The experience of labour: A perspective from those receiving care in a midwife-led unit'. *Midwifery*, 11 (3): 120-129.

Wall, J.C. and Spira, M.K. (2012) "A Conceptual Framework for Differential Use of Mediation and Family Therapy Interventions With Older Adults and Their Families". *Journal of Gerontological Social Work*, 55 (3): 282-297.

Ward, L., Barnes, M., and Gahagan, B. (2012) 'Well-being in old age: findings from participatory research'. Available at: http://eprints.brighton.ac.uk/10631/1/Well_being_in_old_age_findings_from_participatory_research_full_report.pdf (accessed 04.08.2019)

Ware, T., Matosevic, T., Hardy, B., Knapp, M., Kendall, J., and Forder, J. (2003) "Commissioning care services for older people in England: the view from care managers, users and carers". *Ageing and Society*, 23 (4): 411-428.

Walters, K., Illiffe, S. and Orrell, M. (2001) 'An exploration of help-seeking behaviour in older people with unmet needs'. *Family Practice*, 18 (3): 277-282.

Watson, N., McKie, L., Hughes, B., Hopkins, D. and Gregory, S. (2004) '(Inter)Dependence, Needs and Care: The potential for disability and feminist theorists to develop an emancipatory model'. *Sociology*, 38 (2): 331-350

Webster, S., Lewis, J. and Brown, A. (2014) 'Ethical Considerations in Qualitative Research'. In Ritchie, J., Lewis, J., McNaughton Nicholls, C. and Ormston, R. (2014)

‘Qualitative Research Practice: A Guide for Social Science Students and Researcher’. Second edition. London: SAGE Publications Ltd.: 77-110.

Wenger, G.C., Scott, A. and Patterson, N. (2000) “How important is parenthood? Childlessness and support in old age in England”. *Ageing and Society*, 20 (2): 161-182.

West, K. and Needham, C. (2017) “Making it real or sustaining a fantasy? Personal budgets for older people”. *International Journal of Social Policy*, 37 (11-12): 683-695.

Westwood, S. and Daly, M. (2016) ‘Social Care and Older People in Home and Community Contexts: A Review of Existing Research and Evidence’.

Whitehead, P.J., Drummond, A.E.R., Walker, M.F, and Parry, R.H. (2013) “Interventions to reduce dependency in personal activities of daily living in community-dwelling adults who use homecare services: protocol for a systematic review”. *Systematic Reviews*, 2 (1): 1-7.

Wiles, J. (2002) “Informal caregivers’ experiences of formal support in a changing context”. *Health and Social Care in the Community*, 11 (3): 189-207.

Wiles, J.L., Leibing, A., Guberman, N., Reeve, J. and Allen, R.E.S. (2011) ‘The Meaning of “Aging in Place” to Older People’. *The Gerontologist*, 52(3): 357-366.

Wilkins, V.M., Sirey, J.A. and Bruce, M.L. (2019) ‘Caregiver Reward and Burden: Differing Constructs in Family Members Providing Care for Medically Ill Homebound Older Adults’. Journal of Aging and Health, 1-22 https://doi.org/10.1177%2F0898264319825760 (accessed 02.03.2019)

Willyard, J., Miller, K., Shoemaker, M. and Addison, P. (2008) “Making Sense of Sibling Responsibility for Family Caregiving”. *Qualitative Health Research*, 18 (12): 1673-1686.

Wilson, S., Draper, H. and Ives, J. (2008) ‘Ethical issues regarding recruitment to research studies within the primary care consultation’. *Family Practice*, 25(6): 456-461.

Woolham, J. and Benton, C. (2013) “The Costs and Benefits of Personal Budgets for Older People: Evidence from a Single Local Authority”. *British Journal of Social Work*, 43 (8): 1472-1491.

Woolham, J., Daly, G., Sparks, T., Ritters, K. and Steils, N. (2017) “Do direct payments improve outcomes for older people who receive social care? Differences in outcome between people aged 75+ who have a managed personal budget or a direct payment”. Ageing and Society, 37 (5): 961-984.

World Health Organization (2002) ‘Active ageing: a policy framework’. https://apps.who.int/iris/bitstream/handle/10665/67215/WHO_NMH_NPH_02.8.pdf;jsessionid=42E0882613F575D19BA6CB502F1DB73F?sequence=1 (accessed 16.02.2019)

World Health Organization (2014) Definition of an older or elderly person. Available on-line at: http://www.who.int/healthinfo/survey/ageingdefnolder/en/ (accessed 25.07.2014)

World Health Organization (2015) 'World Report on Ageing and Health'. https://apps.who.int/iris/bitstream/handle/10665/186463/9789240694811_eng.pdf;jsessionid=B3599890D41B78704A83CF12C2C6A0AE?sequence=1 (accessed 18.03.2019)

World Health Organization (2017) 'Global Strategy and Action Plan on Ageing and Health'. https://www.who.int/ageing/WHO-GSAP-2017.pdf?ua=1 (accessed 18.03.2019)

Woolham, J., Steils, N., Daly, G. and Ritters, K. (2018) "The impact of personal budgets on unpaid carers of older people". *Journal of Social Work*, 18 (2): 119-141.

Xie, C.; Hughes, J.; Sutcliffe, C.; Chester, H. and Challis, D. (2012) "Promoting Personalization in Social Care Services for Older People". *Journal of Gerontological Social Work*, 55 (3): 218-232.

Yin, R. (2014) *Case Study Research: Design and Methods*. Fifth Edition. London: SAGE Publications Ltd.

Yuill, C., Crinson, I. and Duncan, E. (2010) 'Key Concepts in Health Studies'. London: SAGE Publications.

Zamfir, M. (2013) 'Personalisation through personal budgets: its effectiveness for older adults in social care services. Finding from an English-based literature review'. Research, Policy and Planning, 30 (2): 77-89.

Zechner, M. and Valokivi, H. (2012) "Negotiating care in the context of Finnish and Italian elder care policies". *European Journal of Ageing*, 9 (2): 131-140.