Transitions in health and personal relationships for older partner caregivers: A mixed methods approach

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The candidate confirms that the work submitted is his/her own, except where work which has formed part of jointly-authored publications has been included. The contribution of the candidate and the other authors to this work has been explicitly indicated below. The candidate confirms that appropriate credit has been given within the thesis where reference has been made to the work of others.

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Abstract

Increasing numbers of older adults require help with personal or practical tasks because of disease, disability or age related health limitations. Commonly it is their partner who fulfils some, or all, of this caring role. Taking on this type of caring role is associated with poorer psychological health and changes in personal relationships. What remains unclear is the nature by which personal relationships with the care recipient, other family members, and friends change when older adults take on a caring role for their partner, and how this links to health.

A mixed methods approach was used to explore changes in personal relationships and health for partner caregivers in later life. Seven older partner caregivers were interviewed about their experiences of caring for their partner, focusing on changes they experienced in their health and personal relationships when taking on the role. Waves 1 to 5 from ELSA were used to explore associations, both at one time point and changes over time, between health outcomes and personal relationship types, for older adults moving into the partner caregiver role.

Synthesising the results suggest that connections between transitions in health and personal relationships, for older adults moving into a partner caregiver role, differ for different relationships. Relationships with partners and friends before becoming a partner caregiver were found to be most associated with change in health and quality of life when moving into this role. Relationships with children and family appeared to be more stable during the transitioning into the caregiver role, while partner relationships were more likely to suffer, and friendships seemed to experience most change. Positive associations found between different personal relationship types suggest a subset of particularly vulnerable partner caregivers who are in difficult partner relationships and have little support available to them from family or friends.

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List of Abbreviations

AAH	African American Health cohort study
ACL	American Changing Lives Study
ADL	Activities of Daily Living
AHEAD	Asset and Health Dynamics among the Oldest Old
BHPS	British Household Panel Survey
BOGS	Berkeley Older Generation Study
CES-D	Centre for Epidemiologic Studies Depression Scale
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CMSSP	California Multipurpose Senior Services Project
CRD	Centre for Reviews and Dissemination
DAG	Directed acyclic graphs
ELSA	English Longitudinal Study of Ageing
EPESEP	Established Populations for the Epidemiologic Studies of the Elderly Program
ESDS	Economic and Social Data Service
GAZEL	Électricité de France-Gaz de France
ICECAP-O	Index of Capability
IFS	Institute for Fiscal Studies
GRM	Graded Response Model
HRS	Health and Retirement Study
HSE	Health Survey for England
SHARE	Survey of Health, Ageing and Retirement in Europe
SHLSET	Survey of Health and Living Status in the Elderly in Taiwan
SLIAD	Survey of the Low-Income Aged and Disabled
SOC	Selective Optimisation with Compensation
UNICLAS	University of Copenhagen Longitudinal Ageing Study
WHO	World Health Organisation

Overview

The origins of this thesis stemmed from a desire to explore how personal relationships and health change over time for older adults. The advent, in recent years, of longitudinal datasets which include a wealth of information about older adults means that now such an exploration is possible. One of these longitudinal datasets, the England Longitudinal Study of Ageing (ELSA) (ELSA, 2012), was selected as the basis for the quantitative analyses within this thesis.

The ELSA study collects data every two years from a large cohort of adults aged 50 years and over living in England. The strengths of ELSA for this thesis are in the extensive range of health and social elements which are collected about older adults living in England and, as the first wave of ELSA was collected between March 2002 and March 2003, the opportunity to use multiple ELSA waves to explore changes over time.

This thesis naturally divides into two parts. Chapters one and two form the first part of the thesis which chronicles the process by which this broad topic was narrowed down to aims which would be achievable within a doctoral project.

The aims of this doctoral project, arising from chapters one and two, were to explore transitions in personal relationships and self-rated health for older adults who have taken on a caring role for their spouse or partner (hereafter referred to as partner). Chapter’s three to nine centre on defining and addressing these aims.

In summary the chapters provide the following:

- Chapter one provides a background covering healthy ageing, defining health, social networks, connections between health and personal relationships, and changes in personal relationships based on life span models; and provides a rationale for selecting a subjective measure of health as the primary health outcome of interest.
- Chapter two presents a literature review to identify published studies which used longitudinal data to explore personal relationships and health in older adults.
- Chapter three provides an overview of caregivers in terms of prevalence, identifying with the caregiver label, and empirical evidence on the effects of caregiving on personal relationships and health in older age.

- Chapter four presents a rational for the methods used and a summary of the approaches adopted throughout this thesis.
- Chapter five presents the methods used within the qualitative study.
- Chapter six presents the findings from the qualitative study.
- Chapter seven presents the methodology used in the quantitative study.
- Chapter eight presents the findings from the qualitative study.
- Chapter nine presents the integration of the qualitative and quantitative findings and an overall discussion of the results and implications.

Chapter 1 Background

1.1 Introduction

The proportion of older adults is increasing globally WHO (2002). This has resulted in an increased interest in understanding the changes that occur as we age, in terms of what it means to remain healthy in old age, the roles older adults play within society, and changes in social forces such as employment, pensions and healthcare utilisation (Phelan and Larson, 2002).

This thesis considers how older people view their own health as they age, relating this to the personal relationships they have with partners, family, and friends. Existing research in this area is largely based on cross-section analysis, which severely limits the ability to explore directional relationships. There is also a paucity of studies which have explored how different personal relationship types influence each other. For example does the nature of the relationship an older adult has with their partner affect the relationships they have with other family and friends? This project utilises ELSA data to explore changes over time to gain a better understanding of the sequence of changes older adults experience in their perception of their own health and in their different personal relationships.

This chapter will provide a summary of the different connected themes pertinent to the study of health and personal relationships in older adults, including approaches to defining healthy ageing, models of social networks, psychosocial theories of ageing, life span models, and the use of longitudinal datasets based on observational data to infer directional associations.

This chapter will also describe the rationale behind choosing self-rated health as the primary health outcome measure, and discuss in more detail the different aspects of personal relationships which will be explored within this doctoral project.

1.2 Ageing society

People are generally living longer. The World Health Organisation (WHO, 2014) estimate that by 2020 for the first time there will be more people aged 60 years and over than children aged under 5 years worldwide. This increase is reflected in local UK figures which estimate that by the year 2024 half of the UK population will be aged over 50 years (DoH, 2010).

Increases in life expectancy are largely a result of public health initiatives and advances in medicine which have improved the control of infectious diseases and the management of chronic conditions (National Institute on Aging, 2006). As a consequence more people are living with age related health conditions (Vos et al., 2015) and people are living with health problems for a longer period of time (Westendorp and Kirkwood, 2007, Christensen et al., 2009). Global estimates for 2010 suggest that 23% of the total burden of disease can be attributable to people aged 60 years and over; increasing to 49% for high-income countries (WHO, 2008). Much of this burden is due to chronic diseases including respiratory diseases, heart disease, musculoskeletal diseases, and mental and neurological disorders (Vos et al., 2015, Prince et al., 2015).

Long-term estimates on the burden of health generally suggest that this increase will continue. For example dementia projections suggest that the number of people living with dementia worldwide will rise from 44 million to 135 million by 2050 (WHO, 2014). A recent review, however, suggested that these health projections varied considerably and are dependent on the measure of health used and the income of the country (Chatterji et al., 2015).

To reduce the health burdens associated with ageing, national and international strategies (WHO, 2002, U.S. Department of Health and Human Services, 2010, DoH, 2001) have been introduced to optimise the potential for a healthy old age. Many of these strategies recognise the importance of social engagement in maintaining good health, including “A Policy Framework on Active Ageing”(WHO, 2002) and the FUTURAGE project (FUTUREAGE, 2011), which combined expert opinions from across Europe.

1.3 Defining healthy ageing

Many different definitions and models depict what it means to remain healthy in old age. Different labels are used, such as ‘successful ageing’ (Rowe and Kahn, 1997), ‘healthy ageing’ (Hung et al., 2010), and ‘active ageing’ (Bowling, 2008), however there are similarities in the meaning behind these terms and a common thread is the need to maintain cognitive and physical functioning and remain disease free (Scheidt et al., 1999).

One prominent model is that of Rowe and Kahn (1997). They identified a combination of three components to depict successful ageing: avoiding disease and disability; high cognitive and physical functioning; and maintaining an active engagement with life. This model differentiates between three types of older adults:

those with pathologic disability or disease; those with the usual age related decline in physical, cognitive, and social functioning but with no disease or disability, defined as usual ageing; and those with no disability or disease and with little or no age related loss of physical, cognitive, and social function, defined as successful ageing. Though the model identifies three states they assert that movement between states is possible by modifying environmental and behavioural factors.

This model has however received several criticisms, including the suggestion that providing only three options to define ageing leaves little room to consider other possible patterns of ageing (Scheidt et al., 1999). Other critics assert that disease-free ageing is unrealistic for many older adults (Bowling and Dieppe, 2005), while Ouwehand et al. (2007) felt that the model was culturally and historically specific, relevant only for western societies. In addition, one study found that more older adults would view themselves as ageing successfully compared to when the parameters in this model are applied (Strawbridge et al., 2002).

One important aspect of this model to this doctoral project is that it highlighted active engagement in life as a key concept in health ageing. In this model active engagement includes two components. The first, and most relevant to this project, is that of maintaining interpersonal relationships, while the second relates to maintaining productive activities. In terms of interpersonal relationships Rowe and Kahn (1997) contend that a lack of social ties is a risk factor for poor health, and emotional and instrumental support could provide positive health benefits. They also stated that the relationship between health and interpersonal relationships was individual, based on the needs of the person and situation.

Other models of healthy ageing have also recognised the importance of social engagement, in terms of personal relationships and engaging with activities outside the home (Scheidt et al., 1999, Hung et al., 2010, Depp and Jeste, 2009). Ryff (1989) explored successful ageing in terms of overall well-being and, through her use of life span development theories, identified positive relationships with others as one of six criteria which she used to define successful ageing. Evidence suggests that health professionals also consider social engagement to be an important factor when modelling health (Chen et al., 2011), and additional studies have shown that older adults themselves also perceive personal relationships with family and friends as important features in healthy ageing (Hung et al., 2010).

The importance of personal relationships to health is also backed up by empirical evidence. Reviews assessing the connections between health and personal relationships have found significant associations between personal relationships and different aspects of health, including quality of life and well-being, when personal relationships were measured in terms of the level of social support (Uchino et al., 1996, Holt-Lunstad et al., 2010, Kruithof et al., 2013), and in terms of social networks (Pinquart and Sörensen, 2000, Smith and Christakis, 2008, Perkins et al., 2015).

1.4 Assessing health

1.4.1 Health definitions

The biomedical approach defines ill-health in terms of a failure to maintain homeostasis at the molecular, cellular, or system level resulting in disease (Weinert and Timiras, 2003). The WHO's (1946) definition of health as "*a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*", uses a broader definition, combining the biomedical approach but acknowledging the importance of good mental health and, importantly for this project, the importance of social wellbeing.

There are criticisms of the WHO definition however, in particular around the difficulty in applying the definition to measure health (Emson, 1987) and the use of the term 'complete' which, it has been argued, results in most people being deemed unhealthy most of the time (Smith, 2008). In addition Niebrój (2006) argues that the meaning of the terms 'health', 'state', and 'disease' are not necessarily universally understood and the requirement to have complete well-being is unachievable. Instead they suggest a harmonistic definition of health which encompasses the mind, body and the spirit which is unique to each individual.

Specific problems in applying the WHO definition to older adults have also been identified, as the risk of developing chronic disease increases with age resulting in a large proportion of older adults being categorised as unhealthy by the WHO definition (Westendorp and Kirkwood, 2007, Christensen et al., 2009). More recent attempts have proposed that in light of the increase in managed chronic disease globally, health should be defined in terms of the '*ability to adapt and to self-manage*' (Huber et al., 2011).

1.4.2 Measuring health

There are a profusion of approaches to measuring health. The most appropriate measure to use is dependent on the health outcome of interest. Objective measures of health include physiological biomarkers; routine data from general practitioner, hospital records, or cancer registrations; and mortality records.

Commonly within surveys, and increasingly within clinical trials, subjective, or ‘patient-based outcome measures’ are used (Fitzpatrick et al., 1998). These subjective measures can capture perceptions about general health, quality of life, and wellbeing; psychological, cognitive, functional, or disease specific health problems; and information about healthy lifestyles. Haywood et al. (2005) reported that self-assessment health instruments had an important role to play in assessing health need and health concerns in older adults.

Subjective health outcomes can be based on a single question or a composite measure made up of a number of related questions. Single item subjective health measures have advantages over multiple item health measures as they reduce the length of questionnaires and reduce the burden placed on both responders and researchers (Bowling, 2005). Single item subjective questions are commonly used to measure global health constructs, such as health in general or life satisfaction (Schimmack and Oishi, 2005), and health status such as pain (McCormack et al., 1988), limiting long-term illness, depression, and quality of life (Zimmerman et al., 2006).

1.4.3 Self-rated health

Self-rated health was chosen as the primary health outcome for this thesis because the focus is on exploring changes in health in general, and the interest is on older adults’ own perceptions of their health. The single self-rated health measure provides an opportunity to assess how older adults actually perceive their own health, capturing the elements of physical, mental and social wellbeing, as defined by WHO (1946) and enabling older adults to consider factors which are meaningful to them such as age, previous health issues, and adaptation to current chronic conditions (Simon et al., 2005). The simple nature of using a single item to capture general health also provided some benefit in terms of interpretation by, to some extent, offsetting the multiple and complex nature of the personal relationship measures which, it was anticipated, would be required within this thesis. In addition, all waves of ELSA have included a measure of self-rated health which means that an assessment of changes over time in self-rated health is feasible.

The self-rated health measure first appeared in the mid-20th century, partly as a result of the increasing recognition that health was not just about the absence of disease and disability but also incorporated mental and social dimensions (Bowling, 2005). It is now a globally accepted measure of health which is simple to administer and captures multiple dimensions of health and well-being, including past health experiences and future health expectations (Lyyra et al., 2010, Simon et al., 2005).

There are variations in the wording of the self-rated health measure, but generally the measure asks respondents to rate their own health, along a scale from positive to negative. Versions more commonly use a five point Likert scale to increase interpretability and the likelihood of picking up changes between time points (Bowling, 2005). It is used widely within gerontology as responses appear to be predictive of mortality (DeSalvo et al., 2006, Idler and Benyamini, 1997, Mavaddat et al., 2014), functional decline (Idler and Kasl, 1995, Lee, 2000), health service utilisation (Miilunpalo et al., 1997, Weinberger et al., 1986), and functional and psychological health outcomes (Ferraro, 1980, French et al., 2012).

There are many advantages of using a single item to measure self-rated health. As mentioned earlier using such a simple measure reduces the length of questionnaires, which can place a great burden on responders, especially with respect to responders who have little spare time, or who are old, ill, or frail (Bowling, 2005). In addition using multiple measures of health to capture physical, cognitive, psychological, and social aspects, as identified within the WHO (1946) definition, would be complex and may not illicit a true picture of how the respondent felt about their own health (Bowling, 2005).

The self-rated health measure is not, however, without its limitations. The subjective nature of the measure itself means that responses are not objective but are likely to be partly based on the "*norms and expectations that individuals, groups and societies have about health*" (Van Ginneken and Groenewold, 2012, Page 1) which limits the meaningfulness of the measure when comparing different groups. In addition the actual wording of the self-rated health question has been found to be important and scales using different terms are not directly comparable (Jürges et al., 2008). These limitations were not felt to be directly relevant to this thesis however as the principle comparisons will be made within individuals across time rather than between different individuals, or across different surveys.

1.5 Assessing personal relationships

1.5.1 Personal relationships and health

A wide range of measures have been used to assess personal relationships within health research.

Some studies have used measures of loneliness, isolation, or network size to capture information about personal relationships and have found evidence that feelings of loneliness, isolation and having a restrictive network were related to higher levels of depression (Fiori et al., 2006), reduced physical health (Shanker et al., 2011, Cornwell and Waite, 2009), and lower self-rated physical health (Cornwell and Waite, 2009).

Other studies have assessed subjective measures, capturing the strength of social relationships, and have found that stronger social relationships appear to have a protective effect on health and mortality risk (Gove, Choi and Marks, 2011, Ebrahim et al., 1995, Kamila et al., 2010, Penninx et al., 1997, Holt-Lunstad et al., 2010).

The frequency of contact has also been used to assess personal relationships. A meta-analysis (Pinquart and Sörensen, 2000), combining 286 studies, found that the amount of contact older adults reported having with friends had a greater influence on subjective well-being than the amount of contact with children. This is supported by a later cross-sectional study which found that lower levels of social engagement , but not lower levels of contact with family, were associated with depression and physical disability (Golden et al., 2009). This may be due to differences in positive and negative social interactions between older adults and family and friends (Larson et al., 1986). Evidence suggests that while positive social ties are positively related to well-being, negative social ties are positively related to distress (Finch et al., 1989).

Other measures which have been used to capture aspects of personal relationships include marital status (Goldstein and Hurwicz, 1989, Liang et al., 1999, Haron et al., 2010), living arrangements (Rahman et al., 2004), level of support received (Minkler et al., 1983, Okamoto and Harasawa, 2009, Ongaro and Salvini, 1995, Wang, 1998, White et al., 2009) or provided (Mui, 1995), and positive or negative interactions (Bookwala, 2011).

It appears that most studies assessing the association between personal relationships and health do not investigate if different types of relationships result in different outcomes, or explore the connection between different personal relationship types (Fiori et al., 2006). One study which has explored the association between different personal relationship types and health was that of Stafford et al. (2011). They used waves one and two of the ELSA data to explore the association between change in depressive symptoms, measured using the Centre for Epidemiologic Studies (Turvey et al., 2009), and positive and negative exchanges with partners, children, family, and friends at wave 1. The results showed that both positive and negative exchanges with partners and children, but only negative exchanges with family and friends, were significantly associated with change in depression, suggesting that the association between symptoms of depression and the quality of personal relationships may be different for different personal relationship types.

Another recent study which also used ELSA data to explore personal relationship and health was that of Rafnsson et al. (2015). They used waves two to five of the ELSA data to explore the association between change in quality of life, measured using the CASP-19 scale (Hyde et al., 2003), over six years and social network diversity (score from 0 to 3 representing whether responders had any children, immediate family, or friends), social network size, and frequency of contact at wave two. This study found that network size, frequency of contact, but not network diversity, were positively associated with quality of life.

While both of these studies used the ELSA data to explore the association between different aspects of personal relationships and health related outcomes, neither study explored the connection between both changes in personal relationships and changes in health related outcomes over time.

1.5.2 Social network types

To explore different aspects of personal relationships over time between different personal relationship types it is it is important to have some understanding of the typologies in social networks and the functions different personal relationships play for older adults.

Pahl and Spencer's (2004) work on social networks differentiated between relationships which are given and those which are chosen; and between those with high and low commitment. They asserted that given relationships were most commonly with family members but could also include honorary family members such as godparents or, for individuals requiring long term care, professional carers; while chosen relationships were most commonly with friends. The four types of relationships are presented in Table 1-1, however they recognised that there could be movement between the types and the differential between types was blurred.

Table 1-1: Pahl and Spencer's relationship types

	High commitment	**Low commitment**
Chosen relationship	Close friends or family considered friends.	Superficial friendships
Given relationship	Traditional nuclear or extended family	Distant family

(Pahl and Spencer, 2004)

They interviewed 60 participants, based on a purposive sample covering a broad age range and incorporating other demographic factors such as sex, social class and neighbourhood. Through these interviews they identified distinct networks of personal relationships, and labelled these types broadly into friend centred, family centred, partner centred, or professional centred, based on commitment level. They concluded that personal networks differed widely. While some networks demonstrated clear demarcation between the roles of given and chosen relationships, in others given and chosen relationships fulfilled similar roles. In the case of personal networks where given and chosen relationships provided different roles, family most often provided practical support while friends provided confiding and companionship roles.

Wenger (1997) identified five distinct support network typologies from qualitative interviews with older adults over a four year period (see Table1-2) and reported that network type was significantly associated with health service use and health outcomes including depression. Wenger identified different health risks associated with the five network types. Those in the locally integrated support network typology were likely to experience the lowest risk to health. Those in the local family dependent support network were likely to be the most dependent on others, while those in the private restricted support network typology were most at risk if they became ill.

Table 1-2: Wenger's support network typologies

Network typology	Description
Locally integrated support network	Most common type of network. Support from family, neighbours and friends who live close by. Involved in the local community. Larger than average network size.
Wider community focused support network	Support from friends, neighbours, but few family locally. Actively involved in the local community. Associated with migration during adulthood. Larger than average network size
Local self-contained support network	Support from neighbours and family who don't live locally. Private lifestyle. Low community involvement. More common in rural areas.
Local family dependent support network	Support from local family, especially children, and neighbours. Low levels of community involvement. Small network size.
Private restricted support network	Little local support. Distant family may provide some support. Little community involvement.

(Wenger, 1997)

Similar network typologies for older people have also been identified in other studies (Mugford and Kendig, 1986, Litwin, 2001) although one study identified two restricted network typologies; a non-family network and a non-friends network; rather than one (Fiori et al., 2006). Differences between sexes has also been identified with evidence suggesting that women generally identify more close relationships than men (Antonucci et al., 1998)

Berkman et al. (2000) drew on the contributions from Durkheim’s (1951) exploration of social integration and suicide and Bowlby’s (1969) theory of attachment to model the impact of social networks on health. They classified both upstream and downstream social network influences. While upstream influences include wider social and cultural influences which condition social network structure, downstream influences relate to the direct influences of network structure on health, through social support, social influence, social engagement, personal contact, and through access to materials and services. The model contends that these downstream factors impact health in a number of ways; through health behaviours such as smoking, diet, and help-seeking behaviours; through psychological health such as risk of depression, sense of well-being and self-efficacy; and through physiological health such as exposure to infectious diseases and fitness levels. They also acknowledged that not all social ties were supportive and the more influential impacts on health could be through acts of abuse.

1.6 Theories of ageing

1.6.1 Psychosocial theories

There are a host of theories surrounding the societal or individual processes involved in the ageing process. Although it needs to be borne in mind that many of these theories of ageing emerged decades ago, in a time that was in many respects very different for older people, they remain pertinent for this project as many focus on the role of social interactions in later life. The following will present a brief overview of some of the main psychosocial approaches to ageing.

Two psychosocial theories which focus on continuity of social function as we age are the activity theory (Havighurst, 1953, Knapp, 1977, Lemon et al., 1972) which states that life satisfaction is dependent on maintaining a level of social participation, and the continuity theory (Atchley, 1972) which contends that life satisfaction is dependent on a continuity of lifestyles, which are dictated by our fixed personality.

Other theories assert that social functioning reduces with age. The disengagement theory (Cummings and Henry, 1961) argues that a sense of psychological well-being is maintained as we age through a mutual withdrawal between the person and society. Abandonment theory (Baum and Baum, 1980) and role theory (Philips,

1957) also contend that there is a withdrawal from usual activities. Abandonment theory (Baum and Baum, 1980) sees industrial societies abandoning older people when they are no longer required, while role theory (Philips, 1957) contends that ageing is associated with a loss of usual roles associated with adulthood and an acceptance of new roles associated with old age. These theories differ from disengagement theory, however as they argue that this leads to feelings of loneliness and lower satisfaction with life rather than well-being.

Other theories include feminist approaches (Kline, 1975, Sinnott, 1977) which maintain that men and women experience the ageing process differently due to the difference roles they play through life. Finally the gerotranscendence theory (Tornstam, 1989, Tornstam, 2005) argues that as we age we move from a materialistic to a transcendent view which leads to feelings of satisfaction with life.

1.6.2 Lifespan models of ageing

Lifespan models of ageing are of particular interest for this doctoral project as they focus on the changing circumstances, values, and judgements we make as we age and relate these to changes in the dynamics of relationships. Life span models concede that development and adaptation throughout life is individual, based on experiences and personal choices (Baltes and Dickson, 2001).

One of the early lifespan models is the convoy model (Kahn and Antonucci, 1980) which views social networks as "*dynamic hierarchic structures surrounding the individual throughout life*" (Levitt et al., 1993, page 323). This model contends that each person is surrounded by an individual network of personal relationships. These personal relationships vary in their closeness, quality, and function, which are shaped over time by personal and situational factors such as age, personality, expectations, and personal values. The convoy model advanced the study of personal relationships by recognising that relationships were multidimensional, not only based on objective aspects such as size and structure, but also based on subjective perspectives including closeness and relationship quality (Antonucci et al., 2013)

Later lifespan models include the selective optimisation with compensation (SOC) lifespan model (Baltes and Dickson, 2001, Baltes and Lang, 1997) which states that as people age they renegotiate the limited time and mental, physical, and environmental resources available to maximise satisfaction with life and minimise loss. The socio-emotional selectivity model (Carstensen, 1991, Carstensen, 1992) has much overlap with the SOC lifespan model (Baltes and Dickson, 2001, Baltes and Lang, 1997) but focuses on social relationships. This model asserts that older adults become more selective with social ties as they age, reducing non intimate or peripheral ties while maintaining more intimate relationships in order to maximise their social and emotional gains while minimising their social and emotional risks.

There is evidence from cross-sectional studies showing that while the total number of social contacts reduces with age (Charles and Carstensen, 2009, Rohr and Lang, 2009, Morgan, 1988) the number (Carstensen, 1992, Yeung et al., 2008), and emotional closeness (Morgan, 1988) of close relationships remains stable, or even increases (Carstensen, 1992, Yeung et al., 2008). Evidence from a longitudinal study (Shaw et al., 2007), found similar results suggesting that older adults reduced contact with acquaintances but maintained more intimate contacts with close family and friends. This evidence supports the socio-emotional selectivity life span model, suggesting that older adults put resources into social ties which will provide the most benefit.

1.7 Assessing change over time

1.7.1 Utilising longitudinal datasets

While cross-sectional data can be used to establish an association between self-rated health and measures of personal relationships, the time dependent nature of longitudinal data can establish the sequence of change over time, help to indicate the direction of relationships, and support claims of causation (Allison, 2005, House, 2002, Schwarzer and Leppin, 1991).

As a result of the worldwide interest in trying to understand the opportunities and challenges associated with people living longer there are now several longitudinal datasets available worldwide which can be used to investigate directional associations between changes in self-rated health and personal relationships in older adults. ELSA data complements equivalent longitudinal data from the America Health and Retirement Study (HRS) and the European Survey of Health, Ageing and Retirement in Europe (SHARE).

The ELSA data was specifically chosen to be used in this thesis as both the researcher and the ELSA data are based in England. This meant that the researcher had better access to academics working on ELSA, and importantly, the legislative, governmental, and health systems in which the participants reside was familiar to the researcher.

1.7.2 Transitions over time

Exploring changes in personal relationship and general health over time is very broad as there are many reasons why personal relationships and health may change. While some changes may be gradual and may reflect, for example, gradual deteriorations in health; other changes are more rapid and represent periods of transition such as redundancy, retirement, divorce, bereavement, or moving home (Blieszner, 2000). These transitions vary considerably and are likely to have very different effects on health and personal relationships.

Studies investigating changes in personal relationships and health most commonly investigate general changes as we age. Studies which have assessed transitions following an event or change in circumstance include studies assessing the effects of bereavement (Anderson, 2000, Berg et al., 2009, d'Epinay et al., 2009), divorce or separation (Dykstra et al., 2005, Netuveli et al., 2008), initiation of a caregiver role to a family member or friend (Hash, 2006 1024, Mbanaso et al., 2006, Shawler, 2007, Ssengonzi, 2009), retirement (Bromberger and Matthews, 1994, Mein et al., 1998), relocation (Armer, 1993, Guo et al., 2009), driving cessation (Mezuk and Rebok, 2008, Pellerito, 2009), and a health crisis (Ashida et al., 2009, Esbensen et al., 2007).

The limitation of exploring gradual changes over time in health and personal relationships is that it is difficult to identify the effect of one on the other as the basic assumption when investigating directional relationships, that the cause must precede the effect, is not in place (Popper, 1959, Menard, 1991). Including an agent of change within this project, in terms of a transition due to an event or change in circumstance, will help to provide a platform from which to explore subsequent changes in personal relationship and health. In this way the sequence of change in health and personal relationships following the transition can be explored.

Thus identifying a suitable agent of change by which to carry forward this doctoral project with a more focused objective will form part of the literature review which will be discussed in the next chapter.

1.8 Chapter summary

In summary this thesis will explore transitions in personal relationships and self-rated health in older adults using data from ELSA. Research in this area has shown a strong association between different health measures, including self-rated health, and different aspects of personal relationships; however this research is commonly based on variables measured at a fixed point which means that associations between changes in self-rated health and changes in personal relationships over time cannot be explored.

This chapter has shown the range of ways personal relationships can be measured, in terms of objective and subjective measures and in terms of the different types of relationships which surround older adults. Work on social network types and lifespan models suggest that these personal relationships are individual, based on characteristics of the environment, characteristics of the individual, past experiences and current situation. Different personal relationships can fulfil different roles and the social networks surrounding older adults are associated with health behaviour and health risk.

It is hoped that exploring changes in self-rated health and personal relationships over time in older adults will help our understanding of how, and in what way, changes in personal relationships can impact on health perception, and how health deterioration can impact on relationships. This knowledge may assist in identifying older adults who require additional support to maintain their overall health and well-being when they experience changes in health or personal relationships.

Chapter 2 Literature Review

2.1 Introduction

This review will summarise the findings from published primary studies that investigated associations between personal relationships and self-rated health in older adults using longitudinal data.

The anticipated outcomes from this review were to identify gaps in the literature, ascertain the extent to which longitudinal data had been used to infer directional relationships between self-rated health and personal relationships, and identify an appropriate agent of change by which to explore transitions in personal relationships and health within a doctoral project timescale.

This chapter has previously been published (Craigs et al., 2014), however the published literature review provided a more focused aim of identifying studies which provided evidence for causal associations between personal relationships and health. Details of the authorship are included on page i.

2.2 Review aims

This review had the following three aims:

- Summarise the findings and the approaches used from published studies using longitudinal data to assess personal relationship and self-rated health in older adults.
- Assess the extent to which longitudinal data on older adults has been utilised so that directional associations between self-rated health and personal relationships can be inferred.
- Identify a suitable agent of change which would be suitable for a doctoral project and which would form the basis for the remainder of this thesis.

2.3 Methods

2.3.1 Design

Overall this review can best be described as a scoping review. The reason for defining this review as such is due to a combination of both the aims of the review and the literature of interest, which are both broad. Arksey and O'Malley (2005) suggested two common reasons for undertaking a scoping review were when the review was intended to describe the extent, range and nature of the research and to identify gaps in the current evidence base. Both of these reasons fit in with the aims for this review. In addition, applying an inclusive systematic search strategy to identify any published study that had included any personal relationship measure and self-rated health and included data which, at least in part, had been collected more than once, would have the potential of identifying many thousands of papers. The time required to assess such a volume of papers, given that this review was preliminary to defining and ultimately addressing more focused aims, made undertaking such a systematic review prohibitive.

Although the term ‘scoping review’ has been used to define this review, as far as possible a systematic approach was adopted to identify studies eligible for inclusion in this review. This is in line with the Centre for Reviews and Dissemination (CRD) (2009, page 240) recommendations that scoping reviews should be “*as extensive as possible*” and include multiple databases and hand searching.

2.3.2 Eligibility

Eligible articles were published research papers which:

- Reported on results from primary studies.
- Investigated both self-rated general health and personal relationships within the same analysis.
- Used data collected for the same participants from at least two time points.
- Included results for predominantly community based older adults.
- Included either self-rated health or personal relationships as the outcome of interest, or assessed the association between self-rated health and personal relationships.
- Included separate data for adults aged at least 45 years. This age cut-off was selected to fit in with the ELSA age criteria of 50 years and over, but provide an additional five year flexibility so that publications would not be excluded purely based on including participants who were just a few years younger.

For the purposes of this review personal relationships were defined as any relationship with another person that included an emotional bond, such that the person would be considered a family member or friend. There was no restriction on how this was assessed, whether this was based on the number of relationships, the frequency of contact, the quality of these relationships, or any other measure.

2.3.3 Data sources

MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PsycINFO were searched from inception to 12 June 2012. These three databases were chosen as they contain health related research which includes a broad range of fields, covering the biomedical, nursing, behavioural sciences and mental health literature.

The search terms are reported in Appendix A.1. The search strategy did not include any health related terms at this stage to reduce the chance of excluding studies which had used a self-rated health measure only as a subsidiary or extraneous variable. Self-rated health outcomes were identified at the screening stage.

To update and supplement the database searches additional search strategies were implemented. The reference lists of all articles selected for inclusion were assessed for eligibility. The citations of all included articles, identified through Google Scholar, were hand searched up to March 2013. The publication websites for ELSA (*www.ifs.org.uk/ELSA/publications*), SHARE (*www.share-project.org/publications.html*), and HRS (*http://hrsonline.isr.umich.edu/index.php?p=pubs*) were searched from inception to March 2013.

Finally the journals Age and Ageing, Archives of Gerontology and Geriatrics, Health & Social Care in the Community, Journal of Aging and Health, Journal of Applied Gerontology, Journal of Gerontology series B, Journal of Health and Social Behaviour, Maturitas, Research on Aging, and Social Science and Medicine were hand searched for more recent papers published between May 2012 and March 2013.

It was decided not to update these searchers during the write-up stage of this thesis because the results from this review were used as the basis to derive focused aims which were addressed throughout the remainder of this thesis, and thus represented a distinct period in time.

2.3.4 Selecting studies

The details of all articles identified through the initial searches were stored within Endnote version X6. Duplicates were removed. All articles at this stage underwent an initial appraisal for eligibility based on their titles and abstracts. Articles which were definitely not relevant were excluded. All potentially relevant articles were screened for a second time using information contained within the abstracts or, if this were not sufficient, using the full paper. Reasons for excluding articles at the second screening were documented. Additional articles identified through the references or citations from included articles, longitudinal website searches, and hand searching journals were added to Endnote.

All searches and selection of publications were completed by one person, the researcher.

2.3.5 Extracting Data

Information about the study design, characteristics of the cohort waves, characteristics of the sample, methods used to assess self-rated health, methods used to assess personal relationships, data analysis, and key relevant results were extracted and stored in an Excel spreadsheet to facilitate data synthesis. The percentages of responders at baseline who subsequently dropped-out or died were also extracted to assess the potential for bias within the analysis due to attrition.

2.3.6 Validity assessment

Although scoping reviews commonly do not include a quality assessment (Grant and Booth, 2009) quality assessments can be included within scoping reviews and it was decided to include a broad quality assessment tool devised by Dixon-Woods et al. (2006) to identify any included studies which had major problems, in terms of the research aims, design, or interpretation.

The five questions included in the quality assessment were:

- Are the aims and objectives of the research clearly stated?
- Is the research design clearly specified and appropriate for the aims and objectives?
- Do the researchers provide a clear account of the process by which their findings were reproduced?
- Do the researchers display enough data to support their interpretation and conclusions?
- Is the method of analysis appropriate and adequately explicated?

Responses to the questions were in the main either ‘Yes’ or ‘No’. ‘Partly’ was used if in general the assessment criteria were achieved but there were areas which the researcher felt could have been improved. Studies were not excluded based on study quality but any major problems identified, which it was felt directly impacted on the results presented within the synthesis, were taken into account during the data synthesis.

2.3.7 Data synthesis

A narrative synthesis was undertaken due to the heterogeneity between articles, in terms of the populations of interest, the measures used to assess self-rated health and personal relationships, and the types of analysis conducted. Results were grouped by the measures used to assess personal relationships.

Where articles identified results with a p value less than 0.05 these results were described as statistically significant within this review. Unless otherwise stated the p values used within this synthesis were based on the results after controlling for confounders.

2.4 Results

2.4.1 Literature search results

Figure 2-1 shows the literature searches and the number of articles identified at each stage.

Initial search

After de-duplication the initial search identified 1,745 articles. The first screening to remove definitely irrelevant articles, based on the title and/or abstract, reduced the number of articles to be assessed for eligibility to 418. The number of articles excluded after second screening was 404 (See Appendix A.2. for excluded studies). The reasons for exclusion were as follows:

- Not a quantitative study (n=1)
- Not a primary study (n = 14)
- Not assessing change over time (n = 99)
- Not assessing personal relationships (n = 13)
- No separate data for older adults (n = 10)
- Not assessing self-rated health (n = 248)
- Not comparing self-rated health and personal relationships (n= 19)

This left fourteen articles (Boerner and Reinhardt, 2003, Cerhan and Wallace, 1993, Cornman et al., 2003, Ferraro et al., 1984, Field et al., 1993, Holahan and Velasquez, 2011, Kohli et al., 2009, Li et al., 2009, Liang et al., 2010, Minkler and Langhauser, 1988, Mor-Barak et al., 1991, Rozario et al., 2004, van Tilburg, 1999, Wahrendorf et al., 2010) eligible for inclusion in the review.

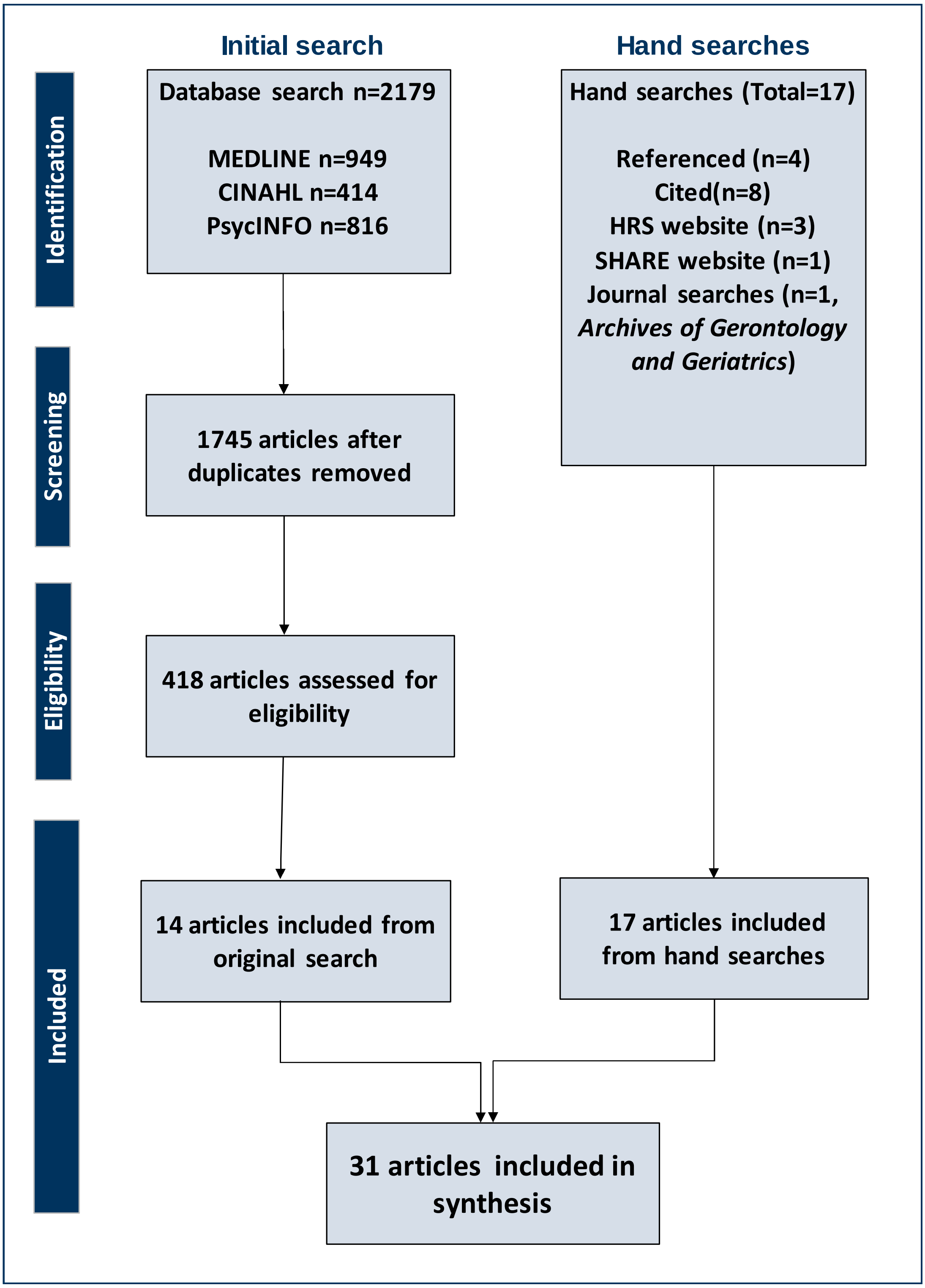
Hand searches

Hand searching the references from these fourteen articles provided four articles (Fenwick and Barresi, 1981, Yao and Robert, 2008, Liang et al., 2005a, Mor-Barak and Miller, 1991), with eight articles identified through citation searches (Ayyagari et al., 2012, Chen and Liu, 2012, Glaser et al., 2005, Greenwald and Beery, 2001, Hinterlong et al., 2007, Kim and Nesselroade, 2003, Lee et al., 2012, Lund et al., 2004). Searching ELSA, HRS, and SHARE websites revealed four additional articles: three HRS articles (Barnett, 2013, Calvo et al., 2013, Luo et al., 2012) and one SHARE article (Knudsen, 2012), while hand searching through relevant journals identified one further article (Leskinen et al., 2012).

Total number of publications

A total of thirty-one articles were included in this review.

Figure 2-1: Search results



2.4.2 Characteristics of included articles

Study characteristics

The main characteristics of the included articles are presented in Table 2-1.

Table 2-1: Study characteristics of included articles

Reference	Country	Design	Data setting	No. time points	Cohort Start year	Duration
Ayyagari et al. (2012)	USA	R	AAH	7	2000	9 yrs
Barnett (2013)	USA	R	HRS	8	1992	14 yrs
Boerner and Reinhardt (2003)	USA	P	Vision rehabilitation agency	3	NR	18 mths
Calvo et al. (2013)	USA	R	HRS	NR	1992	18 yrs
Cerhan and Wallace (1993)	USA	R	EPESEP	2	1982	3 yrs
Chen and Liu (2012)	China	R	China Health and Nutrition Survey	6	1991	15 yrs
Cornman et al. (2003)	Taiwan	R	SHLSET	4	1989	10 yrs
Fenwick and Barresi (1981)	USA	R	SLIAD	2	1973	14 mths
Ferraro et al. (1984)	USA	R	SLIAD	2	1973	14 mths
Field et al. (1993)	USA	R	BOGS	2	1969	14 yrs
Glaser et al. (2005)	UK	R	Retirement Survey	2	1988	5 yrs
Greenwald and Beery (2001)	USA	I	Seattle Housing Association	2	1993	3 yrs
Hinterlong et al. (2007)	USA	R	ACL	3	1986	8 yrs
Holahan and Velasquez (2011)	USA	R	Terman study of the Gifted	2	1996	3 yrs
Kim and Nesselroade (2003)	USA	P	Residents at Cornwall Manor	25	NR	27 wks
Knudsen (2012)	Europe	R	SHARE	2	2004/5	2 yrs
Kohli et al. (2009)	Europe	R	SHARE	2	2004/5	2 yrs
Lee et al. (2012)	Taiwan	R	SHLSET	5	1989	14 yrs
Leskinen et al. (2012)	Finland	R	War veterans	2	1992	12 yrs
Li et al. (2009)	China	R	Well-being of Elderly Survey	3	2001	5 yrs
Liang et al. (2005a)	USA	R	AHEAD	3	1993	5 yrs
Liang et al. (2010)	USA	R	HRS	5-6	1995	11 yrs
Lund et al. (2004)	Denmark	R	UNICLAS	3	1986	8 yrs
Luo et al. (2012)	USA	R	HRS	2	2006	2 yrs
Minkler and Langhauser (1988)	USA	P	Department of Ageing Alameda County	2	1980	5 yrs
Mor-Barak and Miller (1991)	USA	R	CMSSP	2-4	1982	18 mths
(Mor-Barak et al., 1991)	USA	R	CMSSP	2-4	1982	2 yrs
Rozario et al. (2004)	USA	R	ACL	3	1986	8 yrs
van Tilburg (1999)	Nether-lands	P	Population registries of Netherland municipalities	3	1992	4 yrs
Wahrendorf et al. (2010)	France	R	GAZEL	2	2005	2 yrs
Yao and Robert (2008)	USA	R	ACL	4	1986	16 yrs

Data/setting: AAH (African American Health cohort study), ACL (American Changing Lives Study), AHEAD (Asset and Health Dynamics among the Oldest Old), BOGS (Berkeley Older Generation Study), CMSSP (California Multipurpose Senior Services Project), EPESEP (Established Populations for the Epidemiologic Studies of the Elderly Program), GAZEL (Électricité de France-Gaz de France), HRS (Health and Retirement Study), SHARE (Survey of Health, Ageing and Retirement in Europe), SHLSET (Survey of Health and Living Status in the Elderly in Taiwan), SLIAD (Survey of the Low-Income Aged and Disabled), UNICLAS (University of Copenhagen Longitudinal Ageing Study); Design: P (prospective), R (retrospective), I (intervention); yrs (years); mths (months); wks (weeks); NR (not reported)

Baseline data collection years were from 1969 to 2006. Duration of follow-up varied widely, ranging from 27 weeks to 18 years. Over forty per cent of the included articles used only two time points. At least three time points are recommended to assess change over time (George, 2009), though two time points may help infer directional relationships when change is rapid, occurs between time points, and the circumstances suggest the association is unidirectional (Gerring, 2005), for example investigating the effect of accidental death of a partner or child.

One article used an intervention design, four articles were prospective studies, and the remaining twenty-six articles used existing retrospective longitudinal cohort data.

Data from twenty-two different cohorts were used. Data from the following longitudinal cohorts were used in more than one article: American Changing Lives Study, California Multipurpose Senior Services Project (CMSSP), HRS, SHARE, the Survey of the Low-Income Aged and Disabled (SLIAD), and the Survey of Health and Living Status in the Elderly in Taiwan (SHLSET). Three studies were each reported in two articles [(Mor-Barak and Miller, 1991) and (Mor-Barak et al., 1991)]; [(Hinterlong et al., 2007) and (Rozario et al., 2004)]; [(Fenwick and Barresi, 1981) and (Ferraro et al., 1984)].

In summary the thirty-one articles were reporting on the results from twenty-eight studies and used data from twenty-two cohorts.

Samples characteristics

The samples sizes varied between articles, from 57 participants to 27,284 (see Table 2-2). Where reported, most articles included more females within the sample. Mean reported age ranged from 55 to 83 years. All articles which did not provide a mean age reported that responders were aged at least 60 years.

Table 2-2: Sample characteristics within included articles

Reference	Age	Sample size	% Female
Ayyagari et al. (2012)	56.8 (4.4)	998	58%
Barnett (2013)	Median 55 (Range: 50-61)	1,300	79%
Boerner and Reinhardt (2003)	79.8 (6.9)	449	52%
Calvo et al. (2013)	55.67 (3.1)	6,624	46%
Cerhan and Wallace (1993)	All 65+ years	2,576	65%
Chen and Liu (2012)	65.2 (7.7)	1,990	53%
Cornman et al. (2003)	All 60+ years	2,904	NR
Fenwick and Barresi (1981)	73.5 (6.2)	7,696	61%
Ferraro et al. (1984)	All defined as elderly	4,366	67%
Field et al. (1993)	83.0 (NR)	60	68%
Glaser et al. (2005)	Range:55-64 years	1,136	35%
Greenwald and Beery (2001)	All 62+ years	87	73%
Hinterlong et al. (2007)	70.4 (7.4)	1,644	66%
Holahan and Velasquez (2011)	83.8 (3.8)	119	NR
Kim and Nesselroade (2003)	77 (7.2)	57	68%
Knudsen (2012)	69.0 (6.2)	5,449	54%
Kohli et al. (2009)	All 50+ years	27,284	NR
Lee et al. (2012)	All 60+ years	3,937	43%
Leskinen et al. (2012)	Range: 70.5-71.5	4,999	13%
Li et al. (2009)	All 60+ years	1,018	55%
Liang et al. (2005a)	77.2 (7.0)	5,081	70%
Liang et al. (2010)	64.0 (10.0)	18,486	59%
Lund et al. (2004)	Range: 70-95 years	823	NR
Luo et al. (2012)	65.5 (9.5)	6,377	55%
Minkler and Langhauser (1988)	All 60+ years)	280	74%
Mor-Barak and Miller (1991)	78.4 (7.7)	3,559	73%
Mor-Barak et al. (1991)	78.4 (7.7)	3,559	73%
Rozario et al. (2004)	Mean 69.1(caregivers), 70.7 (Non caregivers)	1,669	67%
van Tilburg (1999)	Range:55-84 years	2,903	NR
Wahrendorf et al. (2010)	60.4 (Range: 52-66)	11,421	24%
Yao and Robert (2008)	70.0 (7.4)	1,631	67%

Age: Mean (Standard Deviation) unless otherwise stated; NR: Not reported.

Response rates

Baseline response rates were not reported in 15 articles (Barnett, 2013, Calvo et al., 2013, Cerhan and Wallace, 1993, Chen and Liu, 2012, Ferraro et al., 1984, Field et al., 1993, Hinterlong et al., 2007, Kim and Nesselroade, 2003, Knudsen, 2012, Kohli et al., 2009, Leskinen et al., 2012, Liang et al., 2010, Mor-Barak and Miller, 1991, Mor-Barak et al., 1991, Rozario et al., 2004). Where reported, response rates ranged from 56% (Boerner and Reinhardt, 2003) to 95% (Li et al., 2009).

Sixteen articles did not provide details of the number of responders who died between baseline and final data collection (Ayyagari et al., 2012, Barnett, 2013, Calvo et al., 2013, Fenwick and Barresi, 1981, Ferraro et al., 1984, Glaser et al., 2005, Knudsen, 2012, Kohli et al., 2009, Leskinen et al., 2012, Liang et al., 2010, Luo et al., 2012, Mor-Barak and Miller, 1991, Mor-Barak et al., 1991, Rozario et al., 2004, Wahrendorf et al., 2010, Yao and Robert, 2008). Where reported, death rates ranged from 1.7% for data collected over 27 weeks (Kim and Nesselroade, 2003) to 48% for data collected over 14 years (Field et al., 1993). Death rates were generally reported in studies with longer follow-time periods and reflected the mean baseline age of responders.

The method used to report on responder retention rates also varied between articles. Some articles calculated retention rates only for responders who remained alive at follow-up waves, while other articles also included deaths. Nine articles did not provide enough information to calculate retention rates with or without the inclusion of deaths (Barnett, 2013, Calvo et al., 2013, Fenwick and Barresi, 1981, Ferraro et al., 1984, Liang et al., 2010, Mor-Barak and Miller, 1991, Mor-Barak et al., 1991, Wahrendorf et al., 2010, Yao and Robert, 2008). Retention rates for survivors only were reported in sixteen articles and ranged from 60% (Greenwald and Beery, 2001) to 99% (Minkler and Langhauser, 1988). Retention rates including deaths ranged from 43% (Lund et al., 2004) to 95% (Kim and Nesselroade, 2003). Retention rates tended to be higher in articles reporting on studies with short follow-up periods.

2.4.3 Measures used

Self-rated health

Table 2-3 provides a summary of the self-rated health measures used.

Where reported, most articles asked responders to rate their overall or general health status and did not provide a time frame for this response, or a comparison group. Articles which included additional specifications were as follows: one article specified physical health only (Luo et al., 2012), one article included a self-rated health component reflecting how much responders activities were limited by their health (Kim and Nesselroade, 2003), five articles specified present health status (Ferraro et al., 1984, Field et al., 1993, Liang et al., 2010, Rozario et al., 2004, Yao and Robert, 2008), one article specified self-rated health during the previous twelve months (Glaser et al., 2005), and two articles (Chen and Liu, 2012, Leskinen et al., 2012) asked responders to compare their health with people of a similar age. The actual self-rated health question which was presented to responders was provided in only twelve articles (Ayyagari et al., 2012, Calvo et al., 2013, Chen and Liu, 2012, Ferraro et al., 1984, Field et al., 1993, Kim and Nesselroade, 2003, Lee et al., 2012, Li et al., 2009, Lund et al., 2004, Rozario et al., 2004, van Tilburg, 1999, Wahrendorf et al., 2010), while a further thirteen articles described the nature of the question but not the actual question used (Barnett, 2013, Fenwick and Barresi, 1981, Glaser et al., 2005, Greenwald and Beery, 2001, Hinterlong et al., 2007, Holahan and Velasquez, 2011, Leskinen et al., 2012, Liang et al., 2010, Luo et al., 2012, Minkler and Langhauser, 1988, Mor-Barak and Miller, 1991, Mor-Barak et al., 1991, Yao and Robert, 2008).

The self-rated health measure was obtained using one question in all but one article. A variety of scales were used to represent self-rated health. The most common scale was a 5-point scale, predominantly ranging from excellent to poor. Of the remaining articles, one article used a 6-point scale by including death as an additional point. Four articles used a 4-point scale ranging from excellent to poor. Seven articles used a binary scale, using different cut-offs to represent two self-rated health groups.

Of the articles which used an ordinal, rather than a binary, scale six articles treated the self-rated health measure as an ordinal measure (Ayyagari et al., 2012, Holahan and Velasquez, 2011, Lee et al., 2012, Leskinen et al., 2012, Minkler and Langhauser, 1988, Wahrendorf et al., 2010), while the remaining articles treated self-rated health as an integer, in the analysis. Although this is common practice within social sciences (Wu, 2007) assuming that the ordinal self-rated health measure has interval properties presupposes that responses to the scale are normally distributed and the distance between each measure on the self-rated health scale is equal; that is for example the difference between poor and fair health is the same as the distance between good and excellent health. Evidence shows that these properties do not hold for responses to a self-rated health question. Responses are not normally distributed and are dependent on the wording of the question and scales (Jürges et al., 2008), the position of the question within the questionnaire (Bowling and Windsor, 2008), and the characteristics of the responders (Finnäs et al., 2008).

Most of the articles included self-rated health over multiple time points within the analysis.

Table 2-3: Measures of self-rated health used within included articles

Reference	Self-rated health	Multiple time points?
Ayyagari et al. (2012)	6-point scale: Excellent/Very good/Good/Fair/Poor/Death	Yes
Barnett (2013)	5-point scale: Excellent/Very good/Good/Fair/Poor	No
Boerner and Reinhardt (2003)	5-point scale: Excellent/Very good/Good/Fair/Poor	No
Calvo et al. (2013)	5-point scale: Excellent/Very good/Good/Fair/Poor	Yes
Cerhan and Wallace (1993)	Binary: Excellent or good/Fair or poor or very poor	No
Chen and Liu (2012)	4-point scale: Excellent to Poor (all responses not specified)	Yes
Cornman et al. (2003)	Binary: Excellent or good or average/Fair or poor	Yes
Fenwick and Barresi (1981)	4-point scale: Excellent/Good/Fair/Poor	Yes
Ferraro et al. (1984)	4-point scale: Excellent/Good/Fair/Poor	Yes
Field et al. (1993)	5-point scale: Excellent, no handicap to Severe handicap (all responses not specified)	Yes
Glaser et al. (2005)	Binary: Good or fairly good/Not good	Yes
Greenwald and Beery (2001)	5-point scale: Excellent to Poor (all responses not specified)	No
Hinterlong et al. (2007)	5-point scale: Excellent to Poor (all responses not specified)	Yes
Holahan and Velasquez (2011)	5-pont scale: Very good/Good/Fair/Poor/Very poor	Yes
Kim and Nesselroade (2003)	Three questions all 5-point scale: How satisfied? Not at all to Very; Health has been? Excellent to Poor; Activities limited by health? A great deal to Not at all (full details provided within article)	Yes
Knudsen (2012)	5-point scale: Excellent to Poor (all responses not specified)	No
Kohli et al. (2009)	Binary: Very good or better/Less than very good	Yes
Lee et al. (2012)	5-point scale: Excellent/Good/Average/Not so good/Very poor	No
Leskinen et al. (2012)	5-pont scale: Very good/Good/Moderate/Rather poor/ Poor	Yes
Li et al. (2009)	Binary: Very good or good/Poor or average or not so good	Yes
Liang et al. (2005a)	5-point scale: Excellent/Very good/Good/Fair/Poor	No
Liang et al. (2010)	5-point scale: Excellent/Very good/Good/Fair/Poor	Yes
Lund et al. (2004)	Binary: Excellent or good/Fair or poor	Yes
Luo et al. (2012)	5-point scale: Excellent/Very good/Good/Fair/Poor	Yes
Minkler and Langhauser (1988)	4-point scale: Excellent/Good/Fair/Poor	Yes
Mor-Barak and Miller (1991)	5-point scale: Excellent to Poor (all responses not specified)	Yes
Mor-Barak et al. (1991)	5-point scale: Excellent to Poor (all responses not specified)	Yes
Rozario et al. (2004)	5-point scale: Excellent to Poor (all responses not specified)	Yes
van Tilburg (1999)	5-point scale: Excellent to Poor (all responses not specified)	Yes
Wahrendorf et al. (2010)	Binary: Poor/Not poor	Yes
Yao and Robert (2008)	5-point scale: Excellent/Very good/Good/Fair/Poor.	Yes

Personal relationships

The following measures of personal relationships were assessed: marital status (fifteen articles), caring for family or friends (six articles), providing support for family or friends (four articles), receiving support from family of friends (five articles), frequency of contact (five articles), number of family or friends (five articles), living arrangements (five articles), satisfaction with relationships (four articles), or other measures of personal relationships (five articles). Descriptions of the actual measures used are presented within the synthesis of results.

Other variables

Table 2-4 details the most common additional variables, included either as confounders, dependent or independent variables, or as part of the selection process. For example Ayyagari et al. (2012) included only participants who were African American.

Other health variables included were functional health, psychological health and health risk factors such as smoking and alcohol consumption. Additional variables which were used less commonly included variables related to the neighbourhood in which participants lived, religion, life satisfaction, and other activities.

Table 2-4: Other variables commonly included

Reference	Age	Sex	Education	Race	Work	Income	Socio-economic	Other health
Ayyagari et al. (2012)	Yes	Yes	Yes	Yes		Yes	Yes	Yes
Barnett (2013)	Yes	Yes	Yes	Yes		Yes		Yes
Boerner and Reinhardt (2003)	Yes	Yes	Yes					Yes
Calvo et al. (2013)	Yes	Yes	Yes	Yes	Yes	Yes		Yes
Cerhan and Wallace (1993)	Yes	Yes	Yes					Yes
Chen and Liu (2012)	Yes	Yes	Yes		Yes	Yes	Yes	Yes
Cornman et al. (2003)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Fenwick and Barresi (1981)	Yes	Yes	Yes	Yes				
Ferraro et al. (1984)	Yes	Yes	Yes	Yes		Yes		
Field et al. (1993)	Yes	Yes	Yes		Yes			Yes
Glaser et al. (2005)	Yes	Yes	Yes				Yes	
Greenwald and Beery (2001)	Yes	Yes	Yes	Yes		Yes		
Hinterlong et al. (2007)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Holahan and Velasquez (2011)	Yes	Yes						Yes
Kim and Nesselroade (2003)								Yes
Knudsen (2012)	Yes	Yes	Yes		Yes			
Kohli et al. (2009)	Yes	Yes	Yes		Yes			
Lee et al. (2012)	Yes	Yes	Yes	Yes			Yes	Yes
Leskinen et al. (2012)	Yes	Yes						
Li et al. (2009)	Yes	Yes	Yes		Yes	Yes		Yes
Liang et al. (2005a)	Yes	Yes	Yes	Yes		Yes	Yes	Yes
Liang et al. (2010)	Yes	Yes	Yes			Yes		Yes
Lund et al. (2004)	Yes	Yes						Yes
Luo et al. (2012)	Yes	Yes	Yes		Yes	Yes	Yes	
Minkler and Langhauser (1988)	Yes	Yes	Yes				Yes	
Mor-Barak and Miller (1991)	Yes	Yes	Yes	Yes				Yes
Mor-Barak et al. (1991)	Yes	Yes						Yes
Rozario et al. (2004)	Yes	Yes	Yes	Yes		Yes		Yes
van Tilburg (1999)								Yes
Wahrendorf et al. (2010)	Yes	Yes	Yes		Yes	Yes		
Yao and Robert (2008)	Yes	Yes	Yes	Yes		Yes		Yes

2.4.4 Methods of analysis

Most articles used regression methods to compare self-rated health and personal relationships. Nineteen of these articles included self-rated health as the dependent variable (Ayyagari et al., 2012, Calvo et al., 2013, Chen and Liu, 2012, Cornman et al., 2003, Fenwick and Barresi, 1981, Glaser et al., 2005, Lee et al., 2012, Leskinen et al., 2012, Hinterlong et al., 2007, Liang et al., 2010, Li et al., 2009, Lund et al., 2004, Luo et al., 2012, Mor-Barak et al., 1991, Minkler and Langhauser, 1988, Rozario et al., 2004, Wahrendorf et al., 2010, Yao and Robert, 2008), eight articles included personal relationships as the dependent variable (Barnett, 2013, Cerhan and Wallace, 1993, Boerner and Reinhardt, 2003, Greenwald and Beery, 2001, Kohli et al., 2009, Knudsen, 2012, van Tilburg, 1999, Liang et al., 2005a), and one article conducted separate analyses with the dependent variable represented by self-rated health and personal relationships in turn (Mor-Barak and Miller, 1991). The remaining three articles investigated correlations between the two factors (Field et al., 1993, Ferraro et al., 1984, Kim and Nesselroade, 2003).

Changes over time were assessed by the inclusion of latent trajectories (Barnett, 2013, Ayyagari et al., 2012, Lee et al., 2012), by conducting hierarchical modelling (Boerner and Reinhardt, 2003, Chen and Liu, 2012, Liang et al., 2005a, Liang et al., 2010, van Tilburg, 1999, Yao and Robert, 2008) or structural equation modelling (Field et al., 1993, Kim and Nesselroade, 2003, Rozario et al., 2004), by including previous time points for self-rated health and/or personal relationship as covariates (Calvo et al., 2013, Cornman et al., 2003, Hinterlong et al., 2007, Greenwald and Beery, 2001, Li et al., 2009, Lund et al., 2004, Luo et al., 2012, Mor-Barak et al., 1991, Mor-Barak and Miller, 1991, Wahrendorf et al., 2010), or by investigating change between two time points (Cerhan and Wallace, 1993, Fenwick and Barresi, 1981, Kohli et al., 2009).

2.4.5 Validity Assessment

The results from the quality assessment are presented in Table 2-5. Twenty-one articles performed well in all aspects of the quality assessment, four articles performed well in most assessment criteria but were coded as only partly meeting one or more criteria, while the remaining six articles were assessed as not meeting at least one of the criteria.

The aims and objectives (Q1) were reasonably well described in the majority of studies. In the two articles which were assessed as not providing clear aims the aims could be interpreted from the introduction or abstract but were not clearly specified as a question, aim, or hypothesis.

In five articles it was felt that the research design was not clearly specified or appropriate given the objectives specified (Q2). In two cases (Greenwald and Beery, 2001, Holahan and Velasquez, 2011) it was felt the research design was not clear enough, while in the remaining three articles it was felt that there was disparity between the objective and the design. In these articles the specified aim was to investigate a directional association between personal relationships and health, but the analysis was equipped only to infer an association. In all cases the analysis was based on a change between two time points, either between a simultaneous change in personal relationships and health over time or between a change in one item against the value of another item at a fixed point in time. Thus it was felt there was not enough evidence presented within these articles to show that the cause preceded the effect, an essential element when trying to infer causal associations (Popper, 1959, Menard, 1991).

All studies were thought to provide a clear account of the process by which findings could be reproduced (Q3).

The interpretation of the results appeared reasonable in most articles, however the researcher felt that five articles did not provide quite enough baseline or descriptive information to be confident in the interpretation of the results (Q4), while a further two articles (Li et al., 2009, Wahrendorf et al., 2010) concluded a directional relationship based on only two time points.

The method of analysis (Q5) was deemed to be appropriate in twenty-seven studies, partly appropriate in three studies and not appropriate in one study. The three studies which were partly appropriate used reasonable approaches but reduced the meaningfulness of the data by reducing Likert scales to dichotomous scales or assessed time-varying independent or dependent variables as time-invariant. The one article assessed as using inappropriate methods of analysis was assessing change in self-rated health over two time points but transformed the self-rated health Likert scale values at each time point into dichotomous values before then creating a new variable which denoted change in self-rated health, thus reducing the meaningfulness of the self-rated health outcome.

Table 2-5: Validity assessment of included articles

Reference	Q1	Q2	Q3	Q4	Q5
Ayyagari et al. (2012)	Yes	Yes	Yes	Yes	Yes
Barnett (2013)	Yes	Yes	Yes	Yes	Yes
Boerner and Reinhardt (2003)	Yes	Yes	Yes	Yes	Yes
Calvo et al. (2013)	Yes	Yes	Yes	Yes	Yes
Cerhan and Wallace (1993)	Yes	Yes	Yes	Yes	Partly
Chen and Liu (2012)	Yes	Yes	Yes	Yes	Yes
Cornman et al. (2003)	Yes	Yes	Yes	Partly	Partly
Fenwick and Barresi (1981)	Yes	Yes	Yes	Yes	Yes
Ferraro et al. (1984)	Yes	Yes	Yes	Yes	Yes
Field et al. (1993)	Yes	Yes	Yes	Yes	Yes
Glaser et al. (2005)	Yes	Yes	Yes	Yes	Yes
Greenwald and Beery (2001)	No	No	Yes	Yes	Yes
Hinterlong et al. (2007)	Yes	Yes	Yes	Yes	Yes
Holahan and Velasquez (2011)	Yes	No	Yes	Partly	Yes
Kim and Nesselroade (2003)	Yes	Yes	Yes	Partly	Yes
Knudsen (2012)	No	Yes	Yes	Yes	Yes
Kohli et al. (2009)	Yes	Yes	Yes	Yes	Yes
Lee et al. (2012)	Yes	Yes	Yes	Yes	Yes
Leskinen et al. (2012)	Yes	Yes	Yes	Yes	Yes
Li et al. (2009)	Yes	No	Yes	No	No
Liang et al. (2005a)	Yes	Yes	Yes	Yes	Yes
Liang et al. (2010)	Yes	Yes	Yes	Yes	Yes
Lund et al. (2004)	Yes	Yes	Yes	Yes	Yes
Luo et al. (2012)	Yes	Yes	Yes	Yes	Yes
Minkler and Langhauser (1988)	Yes	No	Yes	Partly	Yes
Mor-Barak and Miller (1991)	Yes	Yes	Yes	Partly	Yes
Mor-Barak et al. (1991)	Yes	Yes	Yes	Yes	Yes
Rozario et al. (2004)	Yes	Yes	Yes	Yes	Yes
van Tilburg (1999)	Yes	Yes	Yes	Yes	Yes
Wahrendorf et al. (2010)	Yes	No	Yes	No	Partly
Yao and Robert (2008)	Yes	Yes	Yes	Yes	Yes

Q1: Are the aims and objectives of the research clearly stated? Q2: Is the research design clearly specified and appropriate for the aims and objectives of the research? Q3: Do the researchers provide a clear account of the process by which their findings were reproduced? Q4: Do the researchers display enough data to support their interpretation and conclusions? Q5: Is the method of analysis appropriate and adequately explicated?

2.4.6 Synthesis of results

Marital status

Fifteen articles, reporting on thirteen studies, using data from twelve cohorts, investigated the association between self-rated health and marital status (see Table 2-6).

Three articles from two studies (Fenwick and Barresi, 1981, Ferraro et al., 1984, Liang et al., 2010) assessed the connection between change in marital status and change in self-rated health.

Two of these articles (Fenwick and Barresi, 1981, Ferraro et al., 1984) from one study investigated the effect of widowhood on self-rated health. Both articles suggest that losing a spouse results in poorer self-rated health within the short-term but not in the long-term. Both articles include only two waves of data, collected fourteen months apart and the information about the death of a spouse before baseline was collected retrospectively, though it would seem fair to suppose that responders would be able to recall with some accuracy when their spouse died. The authors assume a unidirectional association between self-rated health and death of a spouse, that is, they assume that while losing a spouse could influence someone's self-rated health, someone's self-rated health should not directly influence the likelihood of their spouse dying. While this seems reasonable there is some evidence that people caring for a partner in poor health are at an increased risk of dying (Schulz and Beach, 1999), although these results were not replicated in most studies (Roth et al., 2015). Thus the association between self-rated health and death of a spouse could be bidirectional. The implications of these results are also limited as the results were based on data collected between 1973 and 1975, which may represent a time when support for widows and widowers was very different to the support provided today.

The remaining study (Liang et al., 2010) concluded that responders who married between waves were significantly more likely to report worse self-rated health in the subsequent wave. These results do not, however, provide evidence of a directional association, that is you can't infer from these results that getting married reduces self-rated health, as getting married is an active act which may have been influenced by a change in self-rated health between waves. Thus results from this study only suggest that that there is a relationship between change in marital status and change in self-rated health and do not provide evidence of a unidirectional association.

Four studies (Calvo et al., 2013, Chen and Liu, 2012, Cornman et al., 2003, Hinterlong et al., 2007) assessed the association between marital status and self-rated health over time but did not investigate the sequence of changes in marital status and self-rated health. Two studies (Calvo et al., 2013, Hinterlong et al., 2007) found evidence that non married responders experienced better self-rated health over time, while (Chen and Liu, 2012) and (Cornman et al., 2003) found no signficant difference.

Seven studies assessed the association between marital status at a fixed point and self-rated health over time (Ayyagari et al., 2012, Leskinen et al., 2012, Li et al., 2009, Luo et al., 2012, Minkler and Langhauser, 1988, Rozario et al., 2004, Yao and Robert, 2008). In most of these cases marital status was used within the analysis as a control variable. The results from these studies were mixed, with three studies (Leskinen et al., 2012, Minkler and Langhauser, 1988, Rozario et al., 2004) finding no significant difference, two studies (Ayyagari et al., 2012, Luo et al., 2012) finding a marital status of divorced or separated was associated with reduced self-rated health, one study (Yao and Robert, 2008) finding married responders had significantly better self-rated health, and one study (Li et al., 2009) finding married women, but not men, had significantly worse self-rated health compared to unmarried responders. Lee et al. (2012) compared only marital status and self-rated health at wave one and found no significant difference. The mixed results coming from these studies is likely to, at least in part, reflect the heterogeneity between the studies, in terms of the country in which the study was based, the measure used to define marital status, and the period of follow-up.

Table 2-6: Measures of marital status used within included articles

Reference	Marital status	Multiple time points?
Ayyagari et al. (2012)	4-point scale: Married, Divorced or separated, Widowed, Never married	No
Calvo et al. (2013)	3-point scale: Employed spouse, No spouse, Spouse not employed	Yes
Chen and Liu (2012)	Binary: Married Yes/No	Yes
Cornman et al. (2003)	Binary: Married Yes/No	Yes
Fenwick and Barresi (1981)	5-point scale: Married, Divorced, Separated, Widowed, Not married	Yes
Ferraro et al. (1984)	3-point scale: Widowed between waves, Widowed between 1-4 years before wave two, Widowed over 4 years before wave two	Yes
Hinterlong et al. (2007)	Binary: Married Yes/No	Yes
Lee et al. (2012)	Binary: Married Yes/No	No
Leskinen et al. (2012)	Binary: Widowed or divorced Yes/No	No
Li et al. (2009)	Binary: Married yes/no	No
Liang et al. (2010)	3-point scale: Becoming married, No change, Becoming unmarried	Yes
Luo et al. (2012)	4-point scale: Married/partner, Separated/divorced, Widowed, Never married	No
Minkler and Langhauser (1988)	Marital status (no other information)	No
Rozario et al. (2004)	Binary: Married Yes/No	No
Yao and Robert (2008)	Binary: Married Yes/No	No

Overall these results provide reasonable evidence of an association between marital status and self-rated health, however the direction this association may take is not clear.

Caring for family or friends

Six studies, using data from five cohorts, assessed self-rated health and caring for others (see Table 2-7). A wide range of caring roles were assessed, from caring for a relative or friend (Glaser et al., 2005, Hinterlong et al., 2007), caring for a parent or step-parent (Barnett, 2013), caring for grandchildren (Chen and Liu, 2012, Knudsen, 2012), and caring in any capacity (Rozario et al., 2004).

Only one study (Glaser et al., 2005) compared transitions into or out of a caring role and changes in self-rated health. Glaser et al. (2005) found no significant difference between self-rated health and caring for a family member for males. For females, those who reported poor self-rated health at follow-up were significantly less likely to be caring for a friend or relative at follow-up but significantly more likely to be caring for a family member or friend in the previous wave. This suggests either a deterioration in perceived health increased the likelihood of stopping caring at follow-up, or stopping caring for a family member or friend was detrimental to perceived health. The results from Hinterlong et al. (2007) using a different cohort also suggested that responders who were caring for a friend or relative were more likely to report better self-rated health than those who were not caring.

Barnett (2013) selected older caregivers who reported caring for a parent or step-parent in at least one of eight waves, spanning 14 years. Distinct latent classes of older caregivers; based on marital status, working status, and whether co-residing with children; were compared with self-rated health at base-line. No significant difference in self-rated health between the latent classes was identified.

Chen and Liu (2012) found grandfathers caring for grandchildren experienced a significantly steeper deterioration in self-rated health compared to grandmothers. The results from Knudsen (2012) however seem to contradict this. They compared grandfathers and grandmothers who were looking after a grandchild and found that grandfathers had significantly better self-rated health compared to grandmothers; however this is based on cross-sectional analysis and may reflect decisions as to whether to take on a caring role for a grandchild, rather than the effect of caring for a grandchild on self-rated health.

Rozario et al. (2004) compared caring status in the final wave with change in self-rated health over time and found that caregivers who also undertook voluntary or paid work reported significantly better self-rated health over time than caregivers only.

These results provide evidence of a connection between caring and self-rated health, however the diversity in the types of caring role assessed, the differences in the approaches taken, and the lack of studies assessing transitions into or out of the caring role, make it difficult to form any strong conclusions.

Table 2-7: Measures of caring for family or friends used within included articles

Reference	Caring for family and friends	Multiple time points?
Barnett (2013)	4 latent class pathways: 1(not married, early transition to not working, caregivers for parents/step-parents); 2(married, not working, caregivers for parents/step-parents); 3(married, late transition to not working, caregivers for parents/step-parents); 4(married, not working, caregivers for parents/step parents with co-residing Child).	Yes
Chen and Liu (2012)	3-point scale: Number of hours caring for grandchildren aged 0-6 years. High intensity (15+ hours per week), Low intensity (1-14 hours per week), No-care.	Yes
Glaser et al. (2005)	Binary: Looked after relative, friend or anyone living with you who are sick, elderly or handicapped. Yes/No.	Yes
Hinterlong et al. (2007)	Binary: Provide care to a friend or relative who has trouble taking care of themselves. Yes/No.	Yes
Knudsen (2012)	5-point scale: Looking after grandchild without their parent. 0(never) to 4(almost daily)	No
Rozario et al. (2004)	Binary: Caregiver, Caregiver plus voluntary or paid work. Integer: Number of hours caring	No

Providing support for family or friends

Four studies assessed self-rated health and providing support, in terms of financial support to children; informal support such as running errands; instrumental support, such as helping with chores; or affective support, measured by intimate interactions, giving advice, and giving positive feedback.

Two studies (Li et al., 2009, van Tilburg, 1999) assessed change in providing support and changes in self-rated health. While the results for Li et al. (2009) were predominantly non-significant they found that financial support provided by older fathers to children was a significant positive predictor of an improvement in their self-rated health in the next wave, while an increase in instrumental support to children between waves for older mothers was significantly associated with an improvement in their self-rated health between waves. The results for van Tilburg (1999) were also predominantly none significant, however they found that self-rated health measured at baseline was significantly positively associated with instrumental support given to family or friends at each wave.

Hinterlong et al. (2007) also found a significant positive association between self-rated health and providing support at each wave, though they assessed informal social assistance to family and friends. Boerner and Reinhardt (2003) found no association between self-rated health measured at baseline and change in affective or instrumental support provided to family or friends however their study was based on data covering only 18 months which may have been too short a period to observe any significant change.

Overall the different types of measures used to assess support varied widely. These studies provide limited evidence of an association between providing support and self-rated health and little evidence for an association between transitions in providing support and self-rated health over time.

Table 2-8: Measures of providing support to family or friends

Reference	Providing support to family or friends	Multiple time points?
Boerner and Reinhardt (2003)	Integer: Affective support (number of network members participants are providing intimate interaction, advice, and positive feedback). Total score 0-45 Integer: Instrumental support (number of network members participants are providing material aid, physical assistance, and watching the home). Total score 0-45	No
Hinterlong et al. (2007)	Binary: Informal assistance (provide transportation, run errands, help with housework, provide childcare) to a friend or relative. Yes/No	Yes
Li et al. (2009)	Integer: Financial support to children. Integer: Instrumental support (household chores, personal care) to children. Total 0-15.	Yes
van Tilburg (1999)	Integer: Mean instrumental support (help with daily chores) to network members. Range 0-3	Yes

Receiving support from family of friends

Five studies assessed self-rated health and receiving support (see Table 2-9). All studies found significant associations, though receiving support was measured in a number of ways, including social support, emotional support, and financial support.

Three studies (Kim and Nesselroade, 2003, Li et al., 2009, van Tilburg, 1999) assessed change in support received and change in self-rated health. Kim and Nesselroade (2003) used concurrent and time lagged data to investigate the connection between positive and negative social support and health. They measured social support based on nine items covering positive and negative emotional support from children, family, and friends. Although they found no direct association between social support and self-rated health they did identify indirect associations between negative social support and self-rated health, which was mediated by self-concept. This study only assessed short term changes based on changes occurring over one to two weeks. The results from this study shed some light on short-term changes in social support and self-rated health.

van Tilburg (1999) found worse self-rated health at baseline was associated with more help with daily chores at all three time points, and an increase in help with daily chores over time was associated with a deterioration in self-rated health over time. The results from Li et al. (2009) support this outcome for fathers. They found an increase in instrumental support from children, such as help with chores or personal care, was significantly associated with worse self-rated health over time. This result was not significant for mothers however, and it seemed for mothers emotional support was important, with an increase in emotional support received from children over time significantly associated with better self-rated health over time.

One study (Cornman et al., 2003) assessed self-rated health and perceived social support received across survey waves, which were spaced three to four years apart. They found a positive association between the amount of social support received and participants' assessment of their self-rated health in the following wave but no significant association between received social support and change in self-rated health between waves. The ability to detect change over time in self-rated health was limited in this study as they transformed the self-rated health responses into dichotomous outcomes representing either fair to poor, or excellent to average.

In terms of seeking advice Minkler and Langhauser (1988) found a positive association between seeking advice and self-rated health at baseline, but no significant association when comparing across waves.

These results suggest that there is an association between receiving support and self-rated health, however the relationship between support received and self-rated health appears very much dependent on the type of support received.

Table 2-9: Measures of receiving support from family or friends

Reference	Receiving support from family or friends	Multiple time points?
Cornman et al. (2003)	Integer: Social support (3 items). Total score 0-6	Yes
Kim and Nesselroade (2003)	Latent construct made up of nine items reflecting positive and negative emotional support from family and friends	Yes
Li et al. (2009)	Integer: Financial support to children. Integer: Instrumental support (household chores, personal care) to children. Total 0-15. Integer: Emotional support Mean 0-3.	Yes
Minkler and Langhauser (1988)	Seeking advice (no additional information provided)	No
van Tilburg (1999)	Integer: Mean instrumental support (help with daily chores) by network members. Range 0-3	Yes

Frequency of contact with family or friends

Six studies, using data from five cohorts, assessed frequency of contact with family or friends and self-rated health (See Table 2-10).

None of the studies investigated changes in frequency of contact and changes in self-rated health, however two studies (Lund et al., 2004, Rozario et al., 2004) investigated changes in self-rated health over time.

Three articles found significant associations. Field et al. (1993) found a positive association between an unobserved (latent) construct which incorporated contact with children, contact with grandchildren, being married, and contact with siblings; and self-rated health, suggesting that more contact was associated with better self-rated health. Lund et al. (2004) found that responders with sustained poor self-rated health over time were significantly more likely to report low contact frequency at first and second follow-up compared to responders who reported sustained good self-rated health. While Minkler and Langhauser (1988) found a significant association between the number of family and friends responders spoke to in the previous week, reported in 1980, and self-rated health five years later.

The remaining articles found no significant association between the number of friends who responders see or speak to regularly and self-rated health over time (Cornman et al., 2003), frequency of contact and self-rated health over time (Hinterlong et al., 2007), or frequency of contact and change in self-rated health over time (Rozario et al., 2004).

Overall the articles provide some evidence that more frequent contact with family and friends may be associated with better self-rated health; however there is no evidence of connections between changes in family or friend contact frequency and change in self-rated health.

Table 2-10: Measures for frequency of contact with family or friends

Reference	Frequency of contact with family or friends	Multiple time points?
Cornman et al. (2003)	Binary: Number of friend's respondent sees or speaks to regularly. 0-1, 2 or more.	Yes
Field et al. (1993)	Latent construct made up of frequency of contact with children, grandchildren, marital status, and contact with siblings.	Yes
Hinterlong et al. (2007)	Integer: Frequency of contact with friends , neighbours, or relatives	Yes
Lund et al. (2004)	Integer: contact with children, grandchildren, siblings, other relatives, friends. Total range 0-16.	Yes
Minkler and Langhauser (1988)	5-point scale: Number of friends or relatives talked to in the last week. 0, 1-2, 3-5, 6-9, 10+.	Yes
Rozario et al. (2004)	Integer: Standardized number of times contact with neighbours or relatives. Range -3.07 to 1.35, higher scores reflect more contact	No

Number of family and friends

Five studies assessed connections between self-rated health and number of family, friends, or contacts (See Table 2-11).

Only one study (van Tilburg, 1999) assessed change in self-rated health and change in network size over time and found no significant association.

Of the remaining studies, only one study found a significant association. Minkler and Langhauser (1988) assessed both self-rated health and number of close contacts at two time points but did not assess change over time in either measure. They found that more family and friends at time one was associated with better self-rated health at time two, however no other analyses between the self-rated health and number of close contacts were significant.

Cornman et al. (2003) found no significant association between number of living children and self-rated health over time. Finally Cerhan and Wallace (1993) and Greenwald and Beery (2001) included only baseline data for self-rated health and both found no association between self-rated health at baseline and number of close family and friends over time.

These results provide little evidence of an association between the number of family and friends and self-rated health.

Table 2-11: Measures for number of family or friends

Reference	Number of family or friends	Multiple time points?
Cerhan and Wallace (1993)	Binary: Number of close friends and relatives. Less than three, three or more.	Yes
Cornman et al. (2003)	3-point scale: Number of living children. 0 or 1-2 or 3+.	Yes
Greenwald and Beery (2001)	3-point scale: Number of friends and relatives with whom they talk to freely about personal matters.	Yes
Minkler and Langhauser (1988)	4-point scale: Number of close contacts. 0-2, 3-9, 10-15, 16+.	Yes
van Tilburg (1999)	Integer: Count of network members with regular important contact	Yes

Living arrangements

Five studies assessed the connection between self-rated health and living arrangements (See Table 2-12). In all cases living arrangements referred to living with children and/or grandchildren.

Cornman et al. (2003) and Chen and Liu (2012) both assessed change in self-rated health and living arrangements at each wave. Cornman et al. (2003) found that responders who co-resided with children in the previous wave were significantly more likely to report excellent, good, or average health in the following wave, however there was no significant association between co-residing with children in the previous wave and change in self-rated health. Chen and Liu (2012) found that maternal grandparents living in three generation households experienced the steepest health decline, while paternal grandparents living with grandchildren but not children had the slowest rate of health decline.

Two studies (Li et al., 2009, Glaser et al., 2005) included living arrangements at only one time point. Li et al. (2009) found that men were significantly more likely to report better self-rated health if living with grandchildren, but not children, at wave one. There was no significant difference between living arrangements and self-rated health for women. Glaser et al. (2005) found no significant association between living with children and the likelihood of reporting poor self-rated health at either time point.

Liang et al. (2005a) found no significant association between self-rated health and living with children, living with others, or change in living arrangements.

Although Chen and Liu (2012) and Li et al. (2009) both found evidence of a positive association between paternal grandparents living with grandchildren and self-rated health as both of these articles were based in China cultural differences in the experiences and expectations of cross-generation living arrangements mean these results may not be applicable to western societies.

Table 2-12: Measures for living arrangements

Reference	Living arrangements	Multiple time points?
Chen and Liu (2012)	Binary: Living with children and grandchildren. Yes or No. Binary: Living with grand-children but not children. Yes or No.	Yes
Cornman et al. (2003)	Binary: Living with children. Yes or No.	Yes
Glaser et al. (2005)	Binary: Living with children of any age. Yes or No.	No
Li et al. (2009)	Binary: Living with children. Yes or No Binary: Living with grand-children. Yes or No.	No
Liang et al. (2005a)	Binary: Living with children. Yes or No. Binary: Living with others. Yes or No.	Yes

Satisfaction with relationships

Four studies assessed satisfaction with relationships, assessed in terms of satisfaction with emotional care, different family members, or social relationships.

No studies assessed changes in satisfaction with personal relationships and self-rated health over time and only one study (Lund et al., 2004) assessed changes in self-rated health. Lund et al. (2004) compared change in self-rated health over two and three time points and satisfaction with social relationships at follow-up. The results showed that compared to participants who experienced sustained excellent self-rated health, participants who experienced sustained fair to poor self-rated health over two and three time points were significantly more likely to report they were not very satisfied with social relationships at follow-up. They also found however that participants who experienced a deterioration in their self-rated health over two time points were significantly more likely to report that were very satisfied with their social relationships at follow-up. This result is difficult to interpret without knowing if the participant’s assessment of their social relationships improved over the same period or if they remained very satisfied despite the perceived deterioration in their health.

Other significant results were Field et al. (1993) who found a positive association between self-rated health and satisfaction with children and grandchildren at both time points, and Wahrendorf et al. (2010) who assessed satisfaction with partner and trust in relationships and found both variables were positively associated with self-rated health at both time points. In contrast Cornman et al. (2003) compared self-rated satisfaction with emotional care in each survey wave with self-rated health in the following wave and found no significant association.

Overall these results suggest some evidence for a positive association between satisfaction with relationship and self-rated health, although the negative association between change in self-rated health and satisfaction with relationships

(Lund et al., 2004) suggests that interpreting changes in these variables over time is complex.

Table 2-13: Measures for satisfaction with relationships

Reference	Satisfaction with relationships	Multiple time points?
Cornman et al. (2003)	5-point-scale: Satisfaction with emotional care. Very satisfied to Very unsatisfied	Yes
Field et al. (1993)	4-point scale: Satisfaction with children and grand-children: Very satisfied to Not at all satisfied.	Yes
Lund et al. (2004)	Binary: Satisfaction with social relationships. Very satisfied vs. Some satisfied to Very dissatisfied.	Yes
Wahrendorf et al. (2010)	Binary: Satisfaction with partner. Yes or No. Binary: Trust in relationships. Yes or No.	No

Other measures of personal relationships

Four studies reported in five articles, used general or composite variables to define personal relationships in broad terms (see Table 2-14).

Ferraro et al. (1984) compared personal relationship and self-rated health between married and recently widowed participants over two time points. They generated a latent construct score called friendship support and found a significant association between friendship support and self-rated health at both time points. They also found that while there was a significant association between friendship support at time one and self-rated health at time two, there was no significant association between self-rated health at time one and friendship support at time two, suggesting that friendships support may influence future self-rated health.

Mor-Barak et al. (1991) and Mor-Barak and Miller (1991) generated a composite measure of social networks, using the Lubben Social Network Scale (Lubben, 1988) to compare social networks and self-rated health outcomes over four time points. The results showed a significant relationship between social networks at base line and self-rated health six months later but no significant association between social networks at baseline and self-rated health 12 and 18 months later, or between self-rated health at baseline and social networks at 6, 12 and 18 months later. Suggesting that social networks may influence self-rated health in the short-term, but not in the long-term.

Kohli et al. (2009) included a two binary variables to represent informal support, either provided or received from family and friends respectively, and compared responses at both time points with a change in self-rated health over the two time points. They found no significant association between informal support from family or friends and change in self-rated health.

Holahan and Velasquez (2011) used an undefined measure of social relationships and only assessed associations between social relationship and self-rated health within the same time point. The results seem to suggest a significant positive relationship between social relationships and better self-rated health in the first wave but no significant relationships in the second wave, however as they use different terminology within the tables and narrative it difficult to infer if the results are for social relationships or social activities.

Three of these four studies lend some support to the assertion of an association between personal relationships and self-rated health, with two studies providing some evidence that personal relationships may influence future self-rated health.

Table 2-14: Other composite measures used

Reference	Other composite measures	Multiple time points?
Ferraro et al. (1984)	Latent construct called friendship support based on two binary variables: intimacy, friendship network size; and one 9-point-scale: frequency of interaction	Yes
Holahan and Velasquez (2011)	Binary: Mentioned social relationships. Yes or No.	Yes
Kohli et al. (2009)	Binary: Providing or receiving practical help from friends, neighbours or colleagues. Yes or No. Binary: Providing or receiving practical help from family outside the home or child cohabiting. Yes or No.	Yes
Mor-Barak and Miller (1991), Mor-Barak et al. (1991)	Lubben Social Network Scale (Lubben, 1988)	Yes

2.5 Chapter discussion

2.5.1 Summary of findings and approaches used

Overall these studies provide reasonable evidence of an association between self-rated health and personal relationships, in terms of marital status, caring for family or friends, receiving support from family or friends, frequency of contact with family or friends, living arrangements, and satisfaction with relationships. There was limited evidence for an association between self-rated health and participants providing support and number of family and friends.

In terms of quality most included studies were reasonably well described within the articles and used methods which were appropriate given the objectives of the study.

Despite all of these studies including an assessment of personal relationships and health in older adults, and using longitudinal data, all aspects of the studies selected were heterogeneous; in terms of the study objectives; the cohort sample setting, duration, and time points used; the measures used for both self-rated health and personal relationships; the methods of analysis; and the additional variables included within the analysis.

The measures used to assess personal relationships covered a wide spectrum. Even within measures assessing a particular aspect of personal relationships, such as marital status or caring, there was great variability. Despite the wide range of personal relationship measures assessed few of these studies investigated the relationship between different aspects of personal relationships within the same analysis and no studies explored the connection between personal relationship measures for different personal relationship types, in terms of family members and friends, either at one time point or over time.

The measure used to assess self-rated health also varied between studies in terms of the wording of the question, the response categories, and the number of response categories within a scale. The populations represented in the studies varied in terms of participant age, study year, and country of origin; which have also been shown to influence self-rated health responses (Jürges et al., 2008, Finnäs et al., 2008). Thus while all the studies were assessing self-rated health it would be incorrect to assume they were all measuring the same thing, or that the results were comparable.

In summary the studies included in this review varied widely. The absence of restrictions in terms of the populations of interest also resulted in studies assessing personal relationships from a diverse range of cultures. As there are well established (Adams and Plaut, 2003) cultural differences with regards to personal relationships a narrative synthesis was appropriate for this review.

2.5.2 Utilisation of longitudinal data

Despite using longitudinal data most studies assessed the connection between personal relationships and self-rated health only in terms of an association, and did not investigate the relationship between changes in either or both measures over time. Studies which did investigate changes generally did not assess changes in personal relationship and self-rated health due to an event or change in circumstance but only assessed changes in personal relationships to reflect general changes over time. Of the few studies which did investigate changes due to an event or circumstance, such as one study (Fenwick and Barresi, 1981, Ferraro et al., 1984) that looked at the effect of spousal bereavement, without exception these changes were the only measure of personal relationship assessed within the analysis; that is they did not investigate the effect of this change on other aspects of their personal relationships.

While including personal relationships and/or self-rated health for only one fixed point in time was often appropriate given the objectives of the study, restricting time-variant variables to time-invariant reduced the meaningfulness of the results for this review. We also know from studies exploring self-rated health trajectories in older adults (Lee et al., 2012, Liang et al., 2005b, Sacker et al., 2007) and from studies investigating changes in relationships over time using a life span perspective (Carstensen, 1992, Charles and Carstensen, 2009, Morgan, 1988, Rohr and Lang, 2009, Shaw et al., 2007, Yeung et al., 2008) that assuming self-rated health or personal relationships are time-invariant is not a valid assumption, and it is recommended when using longitudinal data that changes in time-varying independent variables are included in the analysis (Allison, 2012).

These studies provide little evidence for directional associations between changes in personal relationships and changes in self-rated health, as only three studies, reported in five articles (Fenwick and Barresi, 1981, Ferraro et al., 1984, Kim and Nesselroade, 2003, Mor-Barak et al., 1991, Mor-Barak and Miller, 1991), investigated directional associations over time. All of these studies found evidence that a change in personal relationships resulted in a change in self-rated health and none of these studies found evidence that a change in self-rated health was affecting personal relationships.

2.5.3 Identifying an agent of change

One of the aims from this literature review was to identify a suitable agent of change by which to explore transitions in personal relationships and self-rated health within a doctoral project timescale. This literature review shows that few of the studies explored changes due to a change in event or circumstance and there are many gaps in our understanding of transitions in personal relationship and self-rated health in older adults.

Based on the focus of the studies included within this review, the change in event or circumstance which this doctoral project could focus on include spousal bereavement, divorce or separation, or initiation into a caregiver role for a family member or friend. Other possible change agents which were not picked up within these studies include retirement, relocation, driving cessation, or a health crisis. All of these different agents of change could be explored using ELSA data.

The initiation of caring for a partner (which includes spouse) was selected as the focus for this thesis. Taking on a caring role for a partner was chosen for a number of reasons including:

- The UK Government’s recent Care Act (2014) now recognises the importance of protecting the health and well-being of not only the cared for but also the caregiver.
- The number of adults who are taking on a caring role in later life has increased substantially over the last ten years (Carers UK and AgeUK, 2015).
- In contrast to spousal bereavement and divorce or separation, changes in the relationship older adults have with their partner after taking on a caring role for their partner can be explored using ELSA data.
- ELSA also collects data from partners of ELSA responders meaning that the partner’s health status can also be included within the analysis.

Thus this doctoral project will explore transitions in personal relationships and self-rated health in older adults after they have taken on a caring role for their partner.

2.5.4 Strengths and limitations of the literature review

To maximise the likelihood of identifying relevant articles, and to allow for detailed methodological assessment to take place, few methodological restrictions were imposed within the study inclusion criteria. Multiple search strategies were also included to minimise the risk of missing relevant articles and the methodology used to select studies has been described in detail to increase transparency in the review process.

Two weaknesses have been identified in the review methodology. Firstly only one researcher, the PhD candidate, selected studies for inclusion, extracted data and synthesised the results; and secondly only articles written in English were included. These limitations increase the likelihood of bias in the selection of studies. As the inclusion criteria was broad and the review was a scoping review intended only to summarise findings, approaches used, and identify gaps in the literature, it is unlikely that these weaknesses would result in such a volume of articles missed that a different conclusion would be necessary.

2.6 Chapter conclusion

The results from this review provide good evidence of an association between personal relationships and self-rated health in older adults. Despite the increased interest in investigating the mechanisms supporting health in older adults, and the large numbers of longitudinal datasets available to support ageing research, few studies investigated directional associations between self-rated health and personal relationship in older adults. The limited evidence which was available from these studies on directional associations between self-rated health and personal relationships suggests that personal relationships may influence future self-rated health.

More research is required to investigate the directional relationship between changes in different personal relationship types and self-rated health in older adults.

Chapter 3 Review of the caregiving role

3.1 Introduction

The previous chapter identified taking on a caring role for a partner as the focus for this thesis by which to explore transitions in health and personal relationships in older adults.

This chapter will provide a brief overview of informal caring: what the term informal caregiver means, the prevalence of informal caring, and who is fulfilling this role. This chapter will also discuss the empirical evidence for how taking on a caring role may affect health and personal relationships, and the connection between health and personal relationships for informal caregivers.

3.2 Defining an informal caregiver

3.2.1 Definition

Informal caregivers are commonly considered to be anyone who provides unpaid care, assistance, or support on a regular basis to family or friends who have physical, behavioural, psychological, or intellectual impairments, or any other health problem, which results in them requiring assistance (O'Connor, 2007, Molyneaux et al., 2011, Carerstrust, 2012). Differences between definitions are mainly in terms of the level of care, the inclusion or exclusion of emotional support, and the continuation of the label once the person requiring care moves into a care home (O'Connor, 2007).

For this thesis identifying older adults who are informal caregivers for their partner will be based on the self-perceptions of the caregiver. Any older adults who consider themselves to be providing care to their partner, irrespective of the reason, were recognised as an informal caregiver for this thesis and will be termed caregiver throughout the rest of this thesis.

3.2.2 Accepting the label

One of the problems with identifying people who are providing informal care is that they may not recognise themselves as caregivers. This is partly because many aspects of the caring role could also describe the normal or usual role individuals expect to have with family or friends. This is demonstrated in several studies including Harding and Higginson (2001) who found that many informal caregivers looking after loved ones with terminal cancer did not identify with the caring label as they saw their role as part of the relationship and did not view the care they provided as an activity requiring an additional label. Not identifying with the caregiver label has also been demonstrated in other qualitative studies that have investigated the label applied to partners of people with bipolar disorder (Henderson, 2001), partners looking after memory-impaired spouses (O'Connor, 1999) and family or friends looking after older people (Netto, 1998).

A later study by O'Connor (2007) included qualitative interviews with 47 caregivers of family members. Again she found that caregivers commonly did not recognise that the care they were providing fell outside that of their usual relationship, even when becoming a caregiver had resulted from a sudden deterioration in health for the person requiring care. This study found that typically there was a time lag between when a person could be considered to be a caregiver and when they actually acknowledged to themselves that they were performing this role. For a few, this delay lasted years rather than months. This study found other reasons for not adopting the label were a reluctance to recognise that the balance of caring in the relationship had changed, feeling overwhelmed, and a feeling that to take on the label was an admission that things were failing. For some, accepting the label was based on a need to access additional support services and to feel part of a community group

Molyneaux et al. (2011) made a more general criticism about the use of the caregiver label arguing that the term implies a burden and dependency which are terms the caregiver and cared for are reluctant to accept.

It is clear that taking ownership of the term caregiver is not straightforward. It seems to require an acceptance of the label, some insight into the changing roles within the relationship, and recognition of what the label may imply about the change in relationship. Certainly it seems that for some the caregiver role may not be acknowledged or realised until such a time that additional support such as respite care or financial assistance is required (Corden and Hirst, 2011). This delay in accepting the caregiver label has implications for this project as it is likely that some participants within the ELSA study, who were identified as transitioning into a caregiver role within this thess, may have been fulfilling this role for some time previously. This issue will be discussed further within chapter eight.

3.3 The position of caregivers within the UK

3.3.1 Demographic characteristics

The latest 2011 Census figures show that approximately 5.8 million people in England and Wales reported providing unpaid care at the time of the last Census. This equates to approximately 10 percent of the population, with nearly one quarter (24%) of these providing 50 hours or more of unpaid care per week (ONS, 2013b). The percentage of caregivers in the population has grown in the last ten years (ONS, 2013b) and this increase is particularly apparent in those aged 85 years and over, who saw a percentage increase of 128 percent between 2001 and 2011 compared with a much smaller 35 percent increase overall for people aged 65 and over (Carers UK and AgeUK, 2015).

People aged 50 years and over are far more likely to be providing unpaid care compared to younger age groups. While it is adults aged 50 to 64 years who are most likely to be providing care (ONS, 2013a) the percentage of older people aged 65 years and over who describe providing unpaid care is substantial. A recent report by Carers UK and AgeUK (2015) stated that approximately 1.2 million people in England aged 65 and over reported caring for someone at the time of the 2011 Census.

The people caregivers are looking after appear to be dependent on age. A report using Wave 3 of the ELSA data (Vlachantoni, 2010) found that adults aged 50 to 59 years were most likely to be caring for a parent or parent-in-law, while those aged 60 to 69, 70 to 79, and 80 and over were most likely to report looking after their partner. This likelihood increased with age, with over 60 percent of caregivers aged 80 and over reporting caring for their partner. The figures from a report by Carers UK and AgeUK (2015) were even higher. They found that for those aged 75 and over just over four out of five caregivers (81%) reported that they were looking after their partner. The latest Health Survey for England (HSCIC, 2014) also found that people aged 65 and over who required help with at least one activity of daily living (ADL) (Katz et al., 1963) most frequently reported receiving help from their partner. This was particularly true for older males requiring assistance however it is likely this reflected, at least in part, the greater percentage of older women who were widowed.

Gender differences in the likelihood of caring seemed to be related to age (Vlachantoni, 2010, Carers UK and AgeUK, 2015). Up to the age of 70 it seems women are more likely to report being a caregiver than men; however after 70 there is a shift. Between 70 and 79 years the ratio between males and females appears roughly equivalent but for those aged 80 years and over more males report being a caregiver than females. In addition, males who report being caregivers are more likely to report that they are looking after their partner. This again is likely to reflect the longer life expectancy for women, with a greater likelihood that older men are still in relationships while older women are more likely to be widowed.

3.3.2 Government initiatives

It is clear the provision of care for older adults is reliant on help provided by family or friends. While informal caregivers undoubtedly help to reduce NHS and social services expenditure the true costs and savings of informal caring are difficult to establish due to the impact on potential lost earning and long-term pension contributions, and the potential effect of caring on health (Beesley, 2006). A recent cross-sectional survey by Carers UK (2014) found that many caregivers face financial pressures not only due to having to give up or reduce their working hours but also due to the increased financial demands of caring for someone with an illness or disability, such as increased heating bills, the provision of special equipment, and the costs of attending appointments.

To help support those requiring care, and their caregivers, the Government have recently introduced the Care Act (2014). This new act sets out to provide a clearer picture of the universal duties and responsibilities that caregivers and those requiring care should expect from local authorities within England. The act includes a national eligibility threshold at which the needs of those requiring care, as well as their caregivers, are entitled to funded services; which replaces the previous local authority led approach (CarersUK, 2014). The underlying principle behind the act is in the promotion of physical, mental, and emotional well-being for both caregivers and cared for. Under the act caregivers and those requiring care are entitled to an assessment of their support needs; a financial assessment, with a cap on care costs to be introduced by April 2016; and assistance with deciding on how best to address these support needs. The act also places an obligation on local authorities to work towards an integration of social care provision and health care provision.

As most of the changes only came into effect from April 2015, with some changes not coming into effect until April 2016, the impact of this act on caregivers cannot yet be assessed.

3.4 Effects of taking on a caring role

Chapter one explained how increased life expectancy has resulted in an increase in older adults requiring help with personal or practical tasks because of disability or age related health problems. This chapter has, to this point, described how this help is frequently provided by family or friends and commonly, in older age groups, by partners, who may themselves have age-related health problems.

Following on from this, this section will now consider the empirical evidence for the connections between taking on a caring role and changes to health and personal relationships. Where possible this evidence has come from studies assessing older partner caregivers, however when this was limited, studies investigating other informal caring roles were considered.

3.4.1 Caregiver burden

Caregiver burden is a common term used to describe the overall effects of caring on the caregiver. While Chou (2000, page 399) suggested that a collective definition of caregiver burden could be "*the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for a chronically ill or impaired family member*", Adelman et al. (2014) suggested a broader definition which has advantages over Chou's definition as it does not limit caregivers to family members, but includes anyone who is providing unpaid care including friends or neighbours, and includes spiritual functioning which may help to capture deterioration in overall well-being.

There is a plethora of studies which have assessed the factors associated with caregiver burden. Adelman et al. (2014) recently published a review of caregiver burden and concluded that being female, having low educational attainment, living with the cared for person, spending more hours caring, depression, social isolation, financial stress, and having no choice in taking on the caregiver role increased the risk of caregiver burden. This review has been included here as it provides a clear summary of risk factors for caregiver burden. It is difficult to determine the accuracy or completeness of this list however as, although these conclusions were based on a review of cohort studies, the review does not provide any details about the methodologies used or the studies included in the review of risk factors. Other publications do appear to provide some support for this list however (Young and Kahana, 1989, Pinquart and Sörensen, 2003, Bakas and Burgener, 2002, Brazil et al., 2009, Guerriere et al., 2015). In addition other studies have also found that more support from family or friends can help reduce the risk of caregiver burden

(Goldstein et al., 2004, Francis et al., 2010, Burton et al., 2012, Yoon and Kim, 2014).

To compare the experiences of caregiving between spouses and children Pinquart and Sörensen (2011) conducted a meta-analysis of 168 empirical studies. They found that people caring for their partner seemed to experience more physical and financial burden, report more depressive symptoms, and report lower levels of well-being compared to caregivers looking after their parents or parents-in-law. They also found that these differences could be explained, to a large extent, by differences in the amount of care provided and the socio-demographic characteristics of the groups. Although this review was generally well conducted; with searches of multiple databases and hand searches, clear and appropriate inclusion criteria, and comparisons between spousal and children caregivers based on a large number of demographic factors, health outcomes, and caregiver role differences; a narrative approach may have been more appropriate as there were large heterogeneity detected between studies. In addition, this review did not provide any information regarding the health of the care recipient. As there were large differences between the hours of caregiving provided each week and the likelihood of co-residing with care recipients, between spouses and children, understanding the nature of the health problems care recipients were experiencing may have provided a greater insight into the reason why spouse caregivers experienced higher levels of caregiver burden than children.

It seems therefore that there are many factors associated with the risk of experiencing caregiver burden, which include the nature of the caring role, the social support available, symptoms of depression in the caregiver, and the caregiver’s financial situation.

3.4.2 Health effects

Self-rated health

None of the six studies (Rozario et al., 2004, Glaser et al., 2005, Hinterlong et al., 2007, Chen and Liu, 2012, Knudsen, 2012, Barnett, 2013) presented in Chapter two, which assessed the association between self-rated health and providing a caring role, investigated the effect of taking on a caring role for a partner. Two of the studies (Chen and Liu, 2012, Knudsen, 2012) investigated the effects of caring for a grandchild which is a very different role to the help required when looking after someone who requires assistance due to health limitations. Two studies assessed caring for a friend or relative (Glaser et al., 2005, Hinterlong et al., 2007) and found evidence of a positive association between caring and self-rated health, however as both studies only explored associations between caring and self-rated health these results do not provide any insight into whether the act of caring was beneficial to health, or if the health of individuals dictated their ability to take on a caring role. Barnett (2013) focused on caregivers looking after parents or step-parents and found that marital status, employment status and whether caregivers were living with children were not significantly related to self-rated health. While Rozario et al. (2004) found that caregivers who also undertook voluntary or paid work reported significantly better self-rated health over time. Subsequent to the review in Chapter two, two additional studies were identified which used longitudinal data to assess the association between caregiver involvement and self-rated health.

Beach et al. (2000) included 680 responders from waves one and two of the Caregiver Health Effects Study to explore the caring role and changes in health over one year. Caregivers were identified as responders aged at least 65 years who reported in wave one that their spouse had difficulty with at least one ADL. Controls reported that their spouse had no difficulty with ADL in wave one, and were matched with caregivers by age and gender. By attributing caring status based on their spouses difficulty with ADL this study assumed that any care which spouses may require due to difficulties in ADL would be provided by their spouse, rather than spouses managing themselves or receiving care through other means. This study also failed to take into account caregivers who provide other forms of support, such as emotional support, or support with communication difficulties. Thus it is possible that caregivers and controls may not have differed in the amount of care they actually provided to their spouse. The analysis did however also control for other measures of caring, including caregiver strain, defined as the level of emotional and physical strain experienced through providing help. The results showed that change in self-rated health was not significantly different between caregivers and controls, and there were no significant associations between change in self-rated health and the quality of the spousal relationship or the amount of help provided , either at wave one or change over time. Caregiver strain at wave one, and increase in caregiver strain over time, were however associated with a decrease in self-rated health over time. Problems with functional ability at wave one, for caregivers and controls, measured using ADL, were also related to a reduction in self-rated health, which may suggest that the amount of caregiver strain experienced may at least in part be a reflection of the functional ability of the caregiver to care for their spouse.

Ross et al. (2008) used cross-sectional and longitudinal data to explore the experiences of older caregivers using waves two and three from ELSA. They found that there was no difference between caregivers and non-caregivers in the likelihood of reporting good or excellent health; however responders who were caring in both waves were significantly less likely to report poor self-rated health compared with responders who reported not caring in both waves. As self-rated health was fairly stable for both caregivers and non-caregivers over the two waves, and there were no transitions into or out of the caring role for these groups, it is difficult to interpret whether this indicates that caring is beneficial to perceived health, or perceived health influences the likelihood to taking on a caring role. Though not assessed statistically self-rated health appeared stable for most groups apart from caregivers who moved out of the caregiving role in wave 3, who seemed to experience an increase in the likelihood reporting poor health, perhaps suggesting that deteriorations in health may be guiding their ability to continue to provide care.

The UK census also includes a measure of self-rated health. The recent report by Carers UK and AgeUK (2015) compared self-rated health and hours of informal caring provided by older adults using census 2011 data. They found that compared to older adults who did not report caring for family or friends, older adults providing 1 to 19 hours of care per week were less likely to consider their health to be ‘not good’, while older adults providing 20 or more hours of care each week were more likely to rate their health as ‘not good’, although the differential was less clear for the oldest caregivers.

Overall, evidence for the connection between self-rated health and caring for a partner is limited. The few studies which were identified predominantly only investigated associations between caring and self-rated health and provided little evidence of the effect of becoming identified as a caregiver on self-rated health. Beach et al. (2000) and AgeUK (2015) both provide some evidence that caregiver strain may be detrimental to self-rated health but it is clear from this section that further work in this area is required.

While the focus of this thesis is on the effect of caring for a partner on self-rated health, it is also worth considering the effects on other health outcomes as any other health effects will influence how individuals perceive their overall own health to be (Bowling, 2005).

Depression

The study by Beach et al. (2000), discussed in the previous section, also assessed change in anxiety and depression, based on self-reports using the Diagnostic Interview Schedule (DIS-III-R). They found that caregiver strain, increase in caregiver strain, and increase in help provided were all associated with an increase in anxiety and depression. Other studies have also found an association between caring and depression. Dunkle et al. (2014) included 5,837 married heterosexual couples aged at least 50 years, from the 2000 to 2006 HRS, and found that spouses who moved into a caring role for their spouse experienced more depressive symptoms, measured using CES-D (Radloff, 1977), than spouses who did not move into a spousal caregiving role. This result is also consistent with that of Kramer and Lambert (1999) who included 288 married males aged 55 and older from waves one and two of the National Survey of Families and Households. Though the sample size was small, with only 26 males reporting starting caring for a spouse at wave two, these males reported significantly higher depression scores, measured using CES-D, than those who did not report caring for their spouse in either wave. There is evidence from a recent study that the association between caring and depression may be different between male and female caregivers however. McGarrigle et al. (2014) assessed the association between caring for a spouse and depression, again measured using CES-D, based on 5,220 respondents who reported being married or partnered in two waves of the Irish Longitudinal Study of Ageing, 123 of whom reported starting caring in the second wave. They found, even after adjusting for various demographic and health factors, that starting to care for a partner was associated with increased depression for women, but not for men, while receiving respite care, home help and personal care attendants reduced this effect.

An earlier study by Goode et al. (1998) recruited 122 informal caregivers looking after a family member with Alzheimer’s, of which nearly half were caring for their partner. They found that mental health, measured using CES-D (Radloff, 1977), and physical health did not significantly change over one year even though the number of functional, mental and behaviour problems experienced by the person receiving care significantly increased and the number of people identified as supportive in their social network decreased. As all of the participants were caregivers at the start of the study this study provides little evidence of the effect of transitioning into the caregiver role, however may suggest that the mental health of established caregivers does not significantly change in the short term even if the health of the care recipient is deteriorating and there is less support available.

Although this study did not identify a relationship between social support and mental health, two later cross-sectional studies (Grant et al., 2006, Butterworth et al., 2010) did find a statistically significant association between social support and depression for caregivers, suggesting that more social support may be associated with fewer symptoms of depression.

Pinquart and Sörensen (2003) undertook a large systematic review of 228 studies to assess the association between depressive mood and informal caregiving. They found increased symptoms of depression in caregivers was associated with providing more hours of care, completing more caring tasks, length of time in the caring role, and physical, cognitive, and behavioural problems in care recipients;. They also found perceived positive caregiver affects, such as "*feeling useful, appreciating closeness … and experiencing pride in one's own abilities*" (Pinquart and Sörensen, 2003, page P114) were associated with fewer symptoms of depression. They stress, however, that these associations varied by the health problems experienced by the care receiver and the nature of the relationship between the care provider and care receiver.

The studies included here are generally consistent in their findings of an association between caregiving and symptoms of depression. As the evidence presented include a large well-conducted review, and several studies utilising data from national longitudinal studies, overall it appears that there exists good evidence that caregiving increases the risk of experiencing depressive symptoms. The results also suggests that some caregivers; particularly those who are experiencing caregiver strain, have poor health, or who are not coping well with the caring role; are at a greater risk of depression than others. There is also some evidence of an association between social support and depression.

Physical health

Salter et al. (2010) reviewed the evidence from longitudinal studies assessing the impact of caring for a stroke survivor on physical health. Multiple databases and reviewing the reference lists of all included studies, resulted in the identification of sixteen studies for inclusion. It is unclear how many researchers were involved in the selection of studies, though the review did provide a clear breakdown on the number of hits identified within the databases and the reasons for exclusion. Good descriptions of the participants, outcomes of interest and results for each included study were also provided. In all of the included studies, most of the participants were partner caregivers. Importantly this review did not compare physical health of caregivers before and after taking on the caregiver role, but rather investigated changes in physical health over time, post-stroke. Overall the review concluded that caregiver's physical health remained stable over time. This review provides little evidence of the long-term effects of caring however, as the periods of follow-up were short, ranging from only one month to two years; with studies most commonly including six and twelve month follow-ups. Results from this review provide some evidence that poorer psychological health and caregiver strain may increase the risk of a deterioration in physical health over time.

A large meta-analysis (Pinquart and Sörensen, 2007) investigated factors associated with physical health in informal caregivers. In total 176 studies were included in the meta-analysis, of which approximately half focused on spousal caregivers but only 12 studies included a longitudinal design. They found worse physical health was associated with increasing age; caring for a spouse; providing more hours caring or undertaking more caring tasks; caring for someone with more physical, cognitive or behavioural problems; and reporting more caregiver burden or depressive symptoms. Caregivers with more education, income, and more informal support from others experienced significantly better physical health. Unfortunately as this review only assessed associations it is difficult to establish the nature of these connections, though it is likely that many of these associations describe the likelihood to taking on a caring role, rather than highlighting an effect of caring.

These reviews suggest that for most caregivers physical health is not significantly affected in the short-term however the physical health of some caregivers may be more vulnerable, particularly in those experiencing psychological health problems or who experience an increased burden through the caring role. These reviews also provide evidence of a positive association between social support and physical health.

Mortality

The effect of caregiving on mortality risk was first explored by Schulz and Beach (1999), who included 819 participants aged between 66 and 93 years from the Cardiovascular Health Study to examine the association between caring for a spouse and mortality risk. They found that four year mortality risk was 63 percent higher in caregivers who were also experiencing caregiver strain compared to non-caregivers; however they found no significant difference in mortality risk between caregivers and non-caregivers when caregivers did not report caregiver strain.

In response to the findings by Schulz and Beach (1999), Roth et al. (2015) reviewed the evidence from six studies, including the Schulz and Beach (1999) study, assessing mortality risk and caregiving. Unfortunately the review does not clearly describe how these studies were identified or selected. The studies included within this review contained between 568 and 1,137,334 participants, with two studies using population data. Mortality was based on between four and eight years follow-up. In contrast to Schulz and Beach (1999) this review found that the remaining five studies all obtained statistically significant results suggesting that caregivers had a reduced risk of dying compared to non-caregivers. Though the strength of the findings from this review are reduced due to the uncertainties surrounding how studies were selected, the consistency in the findings, with the exclusion of Schulz and Beach (1999), and the inclusion of population level data make the overall findings from this review quite compelling.

These studies suggest that caregivers may be at a reduced risk of dying overall compared to non-caregivers. The reason for this association is unclear however and may only reflect the factors which influence the decision to move into a caregiver role, such as being physically able to care for another person. The study by Schulz and Beach (1999) does highlight that there may be a subgroup of caregivers experiencing caregiver strain who are at a greater mortality risk.

Summary

As most of the studies only explored associations, either within one time point or associations between changes over time, it is difficult to draw strong conclusions about the effect of caring on health; however there is good evidence that taking on a caring role for a partner may increase the risk of depression.

What has emerged from these studies is that it appears caregivers who experience caregiver strain or are overly burdened by the caring role may be more susceptible to experiencing deteriorations in their health due to caring. Social support also seems to be positively associated with health.

3.4.3 Personal relationship effects of caring for a partner

As reported above evidence suggests that social support may be important to health for older caregivers. This section will explore the evidence for changes in the personal relationships the caregiver has with their partner and other family and friends.

Partner relationship

Studies which have explored relationship changes between partners when one partner takes on a caring role for the other consistently highlight that the caregivers take on more roles and responsibilities within the relationship (Murray and

Livingston, 1998, Ussher et al., 2011, Quinn et al., 2014, Evans and Lee, 2014). This seems logical given that the definition of a caregiver is to provide care and support to another person who requires assistance. Thus by a person identifying themselves as having moved into a caregiver role implies that they perceive themselves to be providing additional care and support which they weren’t previously required to do. This section will instead focus on evidence for changes in the quality and meaning of the relationship to the caregiver.

Studies most commonly use qualitative methods, which provide a richer understanding of the changing relationship dynamics, however a study by Kramer and Lambert (1999) used longitudinal quantitative data to explore the changes in the quality of the spousal relationship for older men who had started caring for their spouse over a five year period. They found that older men who had started to care for their wife reported significantly lower marital happiness and were significantly more likely to perceive their marriage to be in trouble at follow-up, compared to males who did not report caring for their spouse over the two time points.

In contrast, qualitative studies generally suggest that taking on a caring role can result in both positive and negative changes (Fitting et al., 1986). This was demonstrated by a recent meta-synthesis (Seal et al., 2015) exploring the experiences of informal caregivers looking after a friend or family member with cancer. This review included seventeen qualitative studies covering a wide age range, from 19 to 85 years, and included caregivers looking after other family and friends, although the majority of participants were looking after a partner. The number of participants in the qualitative studies ranges from 4 to 63, resulting in 380 participants included in the meta-synthesis. The findings do however provide important evidence of the changes experienced by caregivers and hint at shared experiences which cut across ages and the nature of the relationship with the care recipient. They found positive changes included caregivers experiencing a sense of increased togetherness and closeness because of the increased time and shared activities, a sense of being united together, and a shift in their priorities from financial pursuits to appreciating the importance of their relationships. Some caregivers caring for their partner also expressed a realisation of the depth of their love for their partner. Not all experiences however were positive. The results suggested that friction in the relationship could occur when the caregiver and the care recipient had different ways of coping with the situation or when the relationship had been difficult before the care recipient required additional care. Some caregivers also reported feeling guilty or frustrated about their changing role.

In addition the evidence suggested that caring could be more challenging when there were changes in the care recipient’s personality due to brain metastases.

Shim et al. (2012) also found positive and negative experiences in their secondary analysis of interviews from 21 partner caregivers looking after a partner with a diagnosis of dementia, taken over a twelve month period. They identified three distinct caregiver groups split into positive, ambivalent, and negative. The positive group described a positive relationship with their partner, both currently and before the diagnosis. These participants focused on the needs of their partner rather than their own needs, got satisfaction out of the caregiver role, and valued what remained of their relationship. The ambivalent group were mostly positive about their past relationship but described a conflicted current relationship. They had mixed emotions about their caring role; they tried to focus on the needs of their partner but struggled to overcome the changes which had occurred, and they reported feeling powerless at times. Finally the negative group described a difficult relationship with their partner both before the diagnosis and currently. This group attributed their partner’s negative or difficult behaviour to how their partner treated them before the diagnosis, while the other two groups attributed their partner’s behaviour to the illness. This group focused on their own needs and did not describe any satisfaction with being a caregiver.

Both these studies suggest that the quality of the relationship before taking on the caregiver role plays a big part in how the relationship develops once one partner needs additional care. Caregivers in previously difficult relationships appear to have more difficulty accepting the caregiving role. It also appears that caregivers may find it more difficult when their partner experiences changes in their behaviour or personality. Results from other qualitative studies (Murray and Livingston, 1998) also suggest that partner caregivers in relationships which were previously difficult may struggle more with taking on the caregiver role.

Several qualitative studies also identify changes in the intimacy caregivers experience with their partners. Sanders and Power (2009) interviewed 17 husbands who were looking after their wives who had a range of conditions. They found that loss of intimacy was common but some caregivers reported that this had been replaced by closeness built around ‘respect and thoughtfulness’. Ussher et al. (2011) also found that a reduction or loss of intimacy was common in partner caregivers looking after a partner with cancer. Reasons for the reduction in intimacy given by caregivers included changes in how they viewed their partner’s body and the changing role of caregiver resulting in viewing their partner in a more clinical, asexual way.

Family and friends

Fewer studies have explored the changing relationships with family and friends after taking on a caregiver role for a partner; however studies which have assessed this commonly show that family and friends are important to caregivers. Quinn et al. (2014) reviewed qualitative studies of caregivers looking after their spouses following a stroke and found that caregivers felt social support from family and friends was important to help them adapt and cope with their new role. Many of the studies included in this review placed particular emphasis on the support provided by family. An earlier study my Fitting et al. (1986) found that caregivers with children commonly classified at least one of their children as a confidante, suggesting that for caregivers the '*Given relationships'* defined by Pahl and Spencer (2004) can incorporate companionship roles more commonly associated with *'Chosen relationships'.*

A previous review also found that caregivers recognise the importance of family and friends to their own health and wellbeing (Cecil et al., 2011). This is backed up by a cross-sectional study (Burton et al., 2012) which assessed psychosocial outcomes related to well-being in 139 caregivers and found that the desire for more assistance from family and friends was the only significant factor associated with an increased risk of caregiver burden. Another study found that caregivers also recognised the importance of maintaining social contacts, not only for their own health but also to help their partner's mental health (Sanders and Power, 2009).

While Fitting et al. (1986) found that all of the 54 spousal caregivers they interviewed had at least one person they could discuss their problems with and all spoke to a friend or family member at least once per week, there is evidence that friendships might decrease over time. Adriaansen et al. (2011) followed up 180 partner caregivers, looking after a spouse who had had a stroke, for three years. They found that social support, in terms of both social and emotional support and support during difficult situations, decreased significantly over this time. Possible reasons for this might include limitations on the time available, as found by Ussher et al. (2011) who interviewed 62 informal caregivers for people with cancer. They found that many caregivers reported that the demands of fulfilling the caregiver role had resulted in a focus on the person requiring care, to the detriment of other personal relationships. Or as Cecil et al. (2011) concluded, caregivers distinguish between friends who are ‘there for you’ and friends who don’t know how to cope with their spouses disability.

Summary

Qualitative studies play an important role in understanding the changing dynamics in personal relationships when taking on a caregiver role. While many studies have focused on the changing relationship between the caregiver and cared for it seems fewer studies have explored the changes which occur in the wider social network which surround the caregiver.

The relationship caregivers have with their partner appears to be directly related to the quality of the relationship before becoming a caregiver. It also appears that some caregivers struggle more with the changing role when their partner’s condition results in a change in behaviour or personality. Though a loss of intimacy was common it seems there are positive relationship changes for some, with caregiving providing an opportunity to share more time together and an increased feeling of togetherness.

Caregivers seem to appreciate the social support offered by family and friends and recognise that tapping into this support is beneficial to their health. Evidence suggests that the number of friendships reduces over time when taking on the caregiver role; however it is unclear whether this reduction in friendships equates to a reduction in the support provided by friends, of if caregivers are selecting the friends who provide the most support.

3.5 Chapter summary

The percentage of older adults providing informal care has increased in recent years, with many older caregivers providing care for their partner, which is likely to be a reflection of the increasing number of older adults living with age related health conditions (Vos et al., 2015). While some caregivers appear to cope well with the transition into a caring role others do not and report symptoms of caregiver burden and mental health problems associated with depression. Factors which appear to be associated with how well caregivers cope relate not only to the nature and demands of the caring role but also to the amount of social support available to them. It also appears that the characteristics of the relationships caregivers had with their partner before taking on a caring role impact on their ability to adapt, with previously difficult relationships presenting the greatest challenge for caregivers.

To date most of the evidence on the association between caring for a partner in later life and changes in health and relationships stem from cross-sectional or qualitative studies and the evidence for the effect of taking on a caregiver role on self-rated health is limited. There are also gaps in knowledge in terms of the roles family and friends play in supporting caregivers, the changes in these relationships over time as older adults transition into a caregiver role for their partner, the connection between these changes and the relationship older adults have with their partner, and how these changes may influence, or be influenced by the health of the caregiver.

Chapter 4 Methodology

4.1 Introduction

This chapter presents the overall aims of the project and the methods used, in terms of the philosophical stance of the researcher and reasons for adopting a mixed methods approach. Justifications for the methods used in the qualitative and quantitative studies, within the mixed methods approach, are also provided.

Full details of the qualitative and quantitative methods are described in chapters five and seven respectively.

4.1.1 Gaps in knowledge

Evidence on the association between personal relationships and health in older populations is predominantly based on cross-sectional analyses. While Chapter three highlighted that personal relationship characteristics and health are related to the caregiving experience, evidence on how becoming a partner caregiver may effect health perception and personal relationships is scant, particular with regards to the effect on family relationship and friendships.

Importantly there is a lack of evidence regarding how different personal relationships types may affect, or be affected by, health over time; and how different personal relationships types may affect, or be affected by other personal relationships over time; in partner caregivers.

4.1.2 Overall aim

The overall aim of this project is to enhance our understanding in this area by exploring transitions in health and personal relationships with partners, family and friends for older adults taking on a caring role for their partner.

4.1.3 Expected benefits

It was anticipated that the results would contribute to knowledge in two ways; firstly by providing a better insight into how changes in one facet of an older adult’s life, that of a change in the level of support required by their partner, could affect change in their personal relationships and their perception of their health over time; and secondly by increasing understanding of the connections between transitions in relationships and health in older adults, which will contribute to the existing knowledgebase on social relationships and health in older age groups.

4.2 Research paradigm

As the perspectives, experiences, and beliefs of the researcher invariably shape the research it is important to place the researcher and the research aim within the context of the distinct methodological perspectives which exist. In this project the research paradigm post-positivist, as described by Wahyuni (2012), most closely matched the researcher’s beliefs about the social world and how knowledge is acquired.

This section includes a brief introduction to four common paradigms, a reflection of the life experiences of the researcher and how these have shaped her beliefs, and a summary of the philosophical stance taken by the researcher, which has guided the focus and methodologies used within this project.

4.2.1 Metatheory

The terms metatheory and paradigms are often used interchangeably and relate to a set of theoretical or world view assumptions which guide our understanding about the social world, in terms of the nature of the social world (ontology), and how knowledge is acquired (epistemology) (Wahyuni, 2012). Within research, paradigms not only guide the nature of the questions to be addressed, but also the research methods used, and the frameworks in which to interpret the outcomes (Bowling, 2002).

Morgan and Smircich (1980) were amongst the first scholars to acknowledge the importance for researchers to recognise their own ontological and epistemological assumptions before embarking on research. They used the terms subjectivist and objectivist at either end of a continuum and described different assumptions or beliefs along this continuum. Broadly they discerned that researchers at the subjectivist end of the continuum believe that the social world is personal, based on individual experiences and consciousness; while researchers at the objectivist end of the continuum believe that the social world is external, determines behaviour, and knowledge is universal and observable (Morgan and Smircich, 1980, Cunliffe, 2011). While researchers with subjectivist beliefs predominantly use qualitative methods, researchers at the objectivist end predominantly use quantitative methods.

Developments in theoretical perspectives and qualitative methods have resulted in a broader, richer range of paradigms (Cunliffe, 2011). Three common paradigms are positivism, post-positivism, and interpretivism (Wahyuni, 2012) (see Table 4-1).

Table 4-1: Summary of three research paradigms

Characteristics	Positivism	Postpositivism	Interpretivism
Ontology	There is a single reality which is external and independent of the players	Reality is external but is influenced by the players within this reality	There are multiple realities which exist only within the social and time bound constructs in which they were created
Epistemology	The world is independent, observable, and unaffected by the players.	The world is observable but is influenced by the cultural and social experiences of the players.	Observations are the result of, and are bound within, the interactions between players
Methodology	Quantitative	Quantitative and Qualitative	Qualitative

Adapted from Wahyuni (2012)

Based on Wahyuni's (2012) definitions, both positivists and post-positivists hold objectivist beliefs and contend that the world is deterministic and reality can be observed and measured. While positivists aim to uncover the truth, post-positivists recognise that observations and measurements are imperfect, biased by cultural issues, social environment, and beliefs. Thus for post-positivists the truth is unobtainable and the aim is to get as near as possible to the truth. While both positivist and post-positivist approaches investigate measurable outcomes, post-positivists take into account the context in which observations are measured. In terms of research methods positivists favour quantitative methodologies, such as randomised controlled trials, while post-positivists favour more observational methods which can encompass both qualitative and quantitative methods.

In contrast to the positivist and post-positivist paradigms, interpretivists' hold subjectivist beliefs and assert that there is no single truth; reality is socially constructed, based in individual perspectives and experiences. Interpretivists are interested in individual experiences and the meanings that are ascribed to them, and employ predominantly qualitative methods.

A fourth paradigm is that of pragmatism (Morgan, 2007, Wahyuni, 2012). Pragmatism is set apart from positivism, post-positivism, and interpretivism as scholars favouring this approach maintain that it is the research question, rather than ontology and epistemology, which determines the research methodologies. Thus pragmatists accept all ontology and epistemology perspectives and embrace all research methodologies, as the focus is on using the most appropriate approach in order to answer the research question.

Most scholars generally agree that before a researcher starts any research they should have a clear understanding of the paradigm which most strongly fits in with their beliefs and understanding. In the case of positivist, post-positivist, and interpretivists these beliefs will guide the purpose of the research and the methodologies used (Snape and Spencer, 2010, Cunliffe, 2011, Bowling, 2002), and for a pragmatic approach considering the ontological and epistemological beliefs of the researchers will highlight any conflicts between the methodological approaches and the beliefs of the researchers.

4.2.2 Role of reflexivity

Reflexivity within research

Reflection is an important tool which is used widely within social science research (Mauthner and Doucet, 2003, Ryan and Golden, 2006). It not only provides an opportunity for the researcher to be open and honest about their values, beliefs, and assumptions before starting the research, it also enables the researcher to reflect on their position during the research process, acknowledging themselves as having an active role, and placing themselves within the context of their own experiences and social circumstances (Willig, 2001). While reflexivity is not traditionally used within quantitative research recent years have seen a shift with researchers arguing that both qualitative and quantitative analysis are influenced by the values, beliefs, and experiences of the researcher and, irrespective of the methods used, the key to good quality research is in reflexivity (Ryan and Golden, 2006, Chamberlain et al., 2011).

Reflexivity has been used in this project within both the qualitative and quantitative studies to help provide a transparent picture of the choices and decisions which the researcher made, which may have impacted on the observations and findings coming out of the analyses.

Below is a reflection, written in first person, of the researcher’s experiences to date, how these experiences have moulded her beliefs about the social world and the acquisition of knowledge, and how these beliefs have influenced the direction of the research.

Reflections from the researcher

My early career was spent working as a statistician within the NHS. I predominantly analysed observational data and much of my analyses focused on exploring inequalities in health and describing differences in health outcomes between groups. During this time I gained an appreciation that while aspects of reality could be measured, errors were built into these measurements and realities varied by the individual circumstances in which people live. I later moved into a nursing career which further established for me that social and cultural influences and life experiences affect our social reality.

I believe that many aspects of social reality can be observed and described, but outcomes derived from these observations can only ever be an approximation of the truth. I also believe that the experiences we have throughout our lives, as well as social and cultural factors, influence this social reality.

While I agree with the pragmatic principle that the research aims should guide the research methods used I feel the types of research questions I am interested in and the research aims I naturally gravitate towards are guided by my beliefs and experiences.

Thus I place myself within Wahyuni’s conceptualisation of post-positivism.

Possessing this philosophical stance has resulted in this exploratory project focusing on describing aspects of personal relationships and health perception in older caregivers, in terms of similarities and differences between groups; using measurable outcomes where possible; and taking into account social and cultural influences within the analyses.

4.3 Mixed methods methodology

This project uses a sequential, exploratory mixed methods approach, incorporating a qualitative study initially to get a better understanding of the effects of caring for a partner on personal relationships and health perception, followed by a quantitative study to explore changes in, and connections between, personal relationships and health perception over time.

A summary of the mixed methods approach, rationale for using this approach, and an overview of the research design of this project are provided below.

4.3.1 Mixed methods

Mixed methods research is sometimes referred to as the ‘third methodological movement’ (Teddlie and Tashakkori, 2003) and can be defined as *‘... the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches for the purpose of breadth and depth of understanding and corroboration*’ (Johnson et al., 2007, page 123). Proponents of the mixed methods approach commonly adopt a pragmatic approach to research, where the methods used are informed by the research question(s), rather than the research question(s) informed by the paradigm framing the research methods (Evans et al., 2011). The important feature of a mixed methods approach, as opposed to a series of separate studies, is in the integration of methods, which can occur anywhere from the design stage, to the analysis, sampling, or interpretation of findings (O'Cathain et al., 2007).

Mixed methods research has gained popularity in recent years (Bryman, 2006) and is now a common approach within health research (O'Cathain et al., 2007), and widely used within gerontology (Happ, 2009). The reasons for its popularity are because it can tackle complex, multifaceted questions which studies adopting single methodologies may not be able to answer fully, and it can provide a broader, more comprehensive picture of the research area (O'Cathain et al., 2007).

There are numerous mixed methods design classifications (Greene and Caracelli, 1997, Tashakkori and Teddlie, 1998, Patton, 1990), however Cresswell and Plano Clark (2007) identified four broad mixed methods design types: triangulation, embedded, exploratory, and explanatory. Briefly, triangulation designs use multiple methods to generate complementary data on the same topic (Morse, 1991). In general these multiple methods run concurrently and generally the different methods are given equal weight. Embedded designs refer to research where one method takes a supporting role to the main method employed, with the supporting method used to elicit information which would not be forthcoming using the main method, for example including qualitative questions within a quantitative study. Exploratory designs use qualitative methods initially to develop or inform the quantitative research, for example using qualitative methods to develop a quantitative questionnaire; while explanatory designs use qualitative results to develop or enhance results from quantitative methods.

4.3.2 Exploratory sequential mixed methods design

A sequential exploratory mixed methods design, an approach which has been used previously within the field of gerontology and caring (Lewis et al., 2015, Stirling et al., 2010), was used in this project. This approach was chosen because, as research in this area is limited, qualitative interviews would provide a better understanding of the experiences of partner caregivers, particularly in terms of the effects of moving into a caregiver role on personal relationships and health, before undertaking the larger quantitative study.

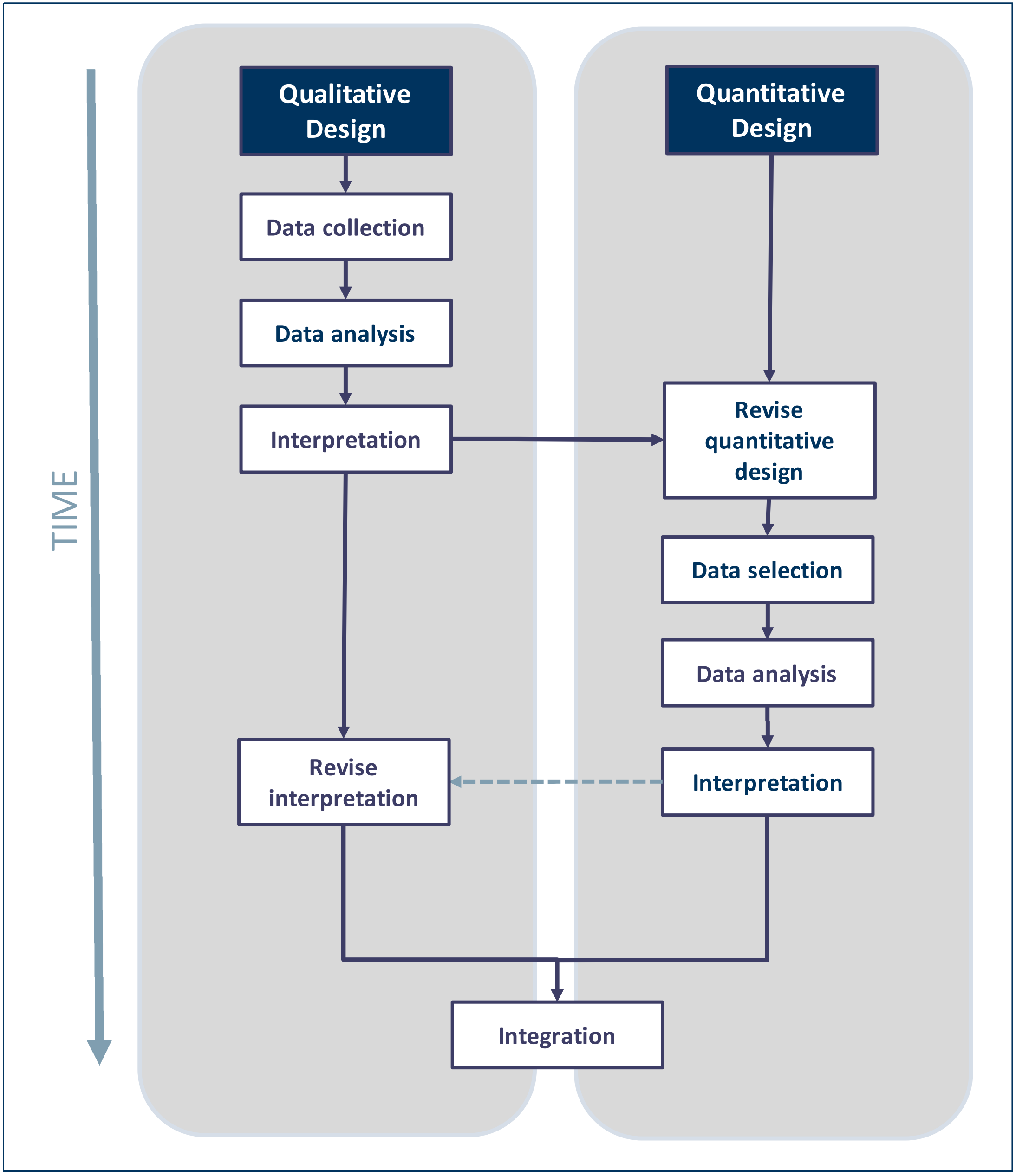
Figure 4-1 summarises the research design used for this doctoral project, in terms of the timings of the studies and the points at which the qualitative and quantitative studies were integrated; indicated by arrows crossing between the qualitative and quantitative studies and the final interpretation following the completion of both studies.

The diagram shows that both the qualitative and quantitative studies were designed at the start of the project. Initially a qualitative study was undertaken to gain a better understanding of the changes older caregivers experience in their personal relationships, and the health effects of caring, after taking on a caring role for their partner. This richer understanding of the experiences of older caregivers from the qualitative study was used to help refine the quantitative design (indicated within Figure 4-1 by a solid dark blue arrow coming horizontally from the interpretation of the qualitative study), by clarifying the variables to include within the analyses and the data analyses. The implications of the results of the qualitative study, on the quantitative design are described in section 6.6.5.

The quantitative study followed the qualitative study. The qualitative results were reassessed in light of the findings from the quantitative study (indicated in Figure 4-1 by a dotted light blue horizontal line coming from the interpretation of the quantitative findings). The reinterpretation of the qualitative findings, in light of the quantitative findings, is described in section 6.6.4.

The final integration of the results from the qualitative and studies are presented in Chapter 9 (identified in Figure 4-1 as the final step in the doctoral project). The integration of the findings was achieved by presenting, side-by-side, a brief summary of the results from both the qualitative and quantitative studies and assessing consensus and discord between these presented results.

Figure 4-1: Diagram showing exploratory research design used



4.4 Qualitative methods

As reported in the previous section the aim of the qualitative study was to develop a better understanding of the experiences of older adults who take on a caring role for their partner, with a focus on the changes experienced in their personal relationships with their partner, children, other family members, and friends; and any changes in their own perceptions of their health.

The methodology employed within the qualitative study is explained in detail in chapter five. Briefly, participants were interviewed about their experiences of caring for their spouse or partner. These in-depth interviews were transcribed and analysed, using framework analysis, to generate common themes around transitions when taking on a caring role for a spouse or partner.

This section describes the rationale for using interviews with participants and the use of framework analysis to analyse the data.

4.4.1 Interviewing participants

Interviews and focus groups are two common methods used within qualitative research to access the experiences of participants (Arthur and Nazroo, 2010). In-depth interviews were conducted in this study because it was important to gain a good understanding of the individual experiences of older adults caring for their partners. The interviews needed to cover, in great depth, the participant's accounts of their personal relationships with their partner, family, and friends, both before and after they started caring. It would have been difficult to gain the depth or richness of detail within a focus group, where the key feature is on the emergent consensus, conflict, and understanding between participants within the group (Finch and Lewis, 2010). In addition interviewing participants individually meant that participants could talk freely about areas of their life which they may have found difficult to talk about within a group setting, such as discussing the changes in the intimate relationships they shared with their partner.

4.4.2 Framework analysis

The qualitative data was analysed thematically, using the approach developed by Richie and Spencer in the 1980's (Ritchie and Lewis, 2010). Framework analysis is a flexible approach as it is not aligned with any particular epistemology, philosophical, or theoretical methodology (Gale et al., 2013). It uses a matrix system to compare data across themes within participants, and across participants within themes.

This approach was selected as it is an appropriate method to use when identifying similarities and differences between the experiences of participants. Framework analysis offers a structured approach which uses the whole corpus of data. It is particularly useful for researchers who are novices to qualitative analysis, as the use of matrices, in the form of spreadsheets, and the step by step approach to data analysis, means that each stage of the analytical process can be managed, and all of the steps taken by the researcher are transparent for other researchers interested in understanding how the results were generated. This approach has been used previously to explore the caregiver needs of family caregivers of stroke survivors (Cameron et al., 2013).

In this study the researcher had little experience in conducting qualitative studies. While the researcher conducted all parts of the analysis on her own, using such a transparent approach to the analysis enabled her supervisor, who has expertise in qualitative research, to understand the process undertaken by the researcher and offer guidance in the classification of themes. In particular the use of charts to summarise the data allowed for the developing analysis to be examined by the supervisor as it progressed and provided some transparency in the analysis approach.

4.5 Quantitative methods

As with the qualitative study the methods used in the quantitative study are explained in detail within the quantitative methods chapter (Chapter seven). Briefly, secondary longitudinal data from ELSA were used to compare personal relationships and perceptions of health between older adults who reported that they were caring for their partner, and older adults in relationships who did not report having a caring role for their partner. Associations between personal relationships and health perception, at one time point and changes over time were also investigated.

This section will explain the reasoning behind using secondary data, and in particular using data from ELSA, the methods utilised to reduce the large volume of data within ELSA related to personal relationships, and the methods used to analyse the data.

4.5.1 Use of secondary data

The motivation for undertaking this project was to explore transitions in health and personal relationships in older ages by utilising existing longitudinal data from ELSA.

Using existing datasets offers many advantages; not only in terms of the time it would take to plan, and the financial costs it would take to run, such a survey; but also in terms of having instant access to a wealth of data over multiple time points.

Using secondary data does, however, come with some limitations in terms of having no input in the wording of the questions or the possible responses available, changes in questions over time, and the timing and frequency of survey recurrence. In addition, large secondary databases can hold a huge range of variables which can make it tempting to include additional variables within the analysis which were not included in the original objectives.

It is important therefore to choose a secondary data source which has the characteristics suitable to address the objectives of the project.

4.5.2 Rational for using ELSA data

ELSA data was selected as the most appropriate dataset to use for the following reasons:

- ELSA has routinely collected information on health, personal relationships, and details about caring for others, which are the main interests of this study.
- ELSA is a longitudinal dataset, covering a period of over ten years and repeated every two years, which means that changes in participants' circumstances and the sequence of these changes can be assessed.
- ELSA collects equivalent information for spouses or partners living at the same address, so spouse or partner variables relating to their functional and health status can be included in the analysis.
- ELSA contains a large amount of other economic, social and health information, enabling other characteristics about the participants to be included in the analyses.

In addition while there are other equivalent longitudinal datasets which could also be used to address the aims of this study, such as the HRS and the SHARE, the participants in ELSA are based in England, and thus come from the same population as the participants who were recruited to the qualitative study.

Details about the ELSA study are provided in section 7.3.

4.5.3 Transformation of personal relationship data

ELSA include, in the self-completion questionnaire, over 40 variables relating to personal relationships which provide a wealth of information about the relationships participants have with their spouse/partner, children, family, and friends. While these variables provide a valuable insight into the relationships which are important to participants it would be inadvisable to include all of these variables within the same analysis as many of these variables are highly correlated. Including these variables together would introduce the problem of collinearity and the sheer volume of data would make the interpretation of any results difficult.

One method to overcome the issues of collinearity and to reduce the number of data items is to combine manifest (observed) variables which appear to be measuring the same unobserved, or latent, variable. The latent variables which were generated in this study were guided by the questions included in the self-completion questionnaire and the personal relationship attributes which partner caregivers described in the qualitative interviews.

As all the manifest variables within this study were categorical latent trait analysis, the Graded Response Model (GRM) (Samejima, 1969) was used to generate latent variables in this study.

In latent variable trait modelling the latent trait coming from the model represents the interrelationship between larger numbers of manifest variables. In this study the latent variables represent factor scores which denote the relative position on a continuum, based on the manifest responses, where higher values signify a more positive outcome and negatives values signify a more negative outcome.

A very common alternative approach, which could have been used, is to ascribe a value to each question response and sum these values to generate an overall score. This method was adopted by Stafford et al. (2011) who also used data from ELSA self-completion questions to assess the association between different types of social exchange and changes in depression score. While this technique is a simple, popular, and practical approach to generating latent variables, GRM was chosen for this study as this method makes no assumptions about the relative weightings of each manifest variable within the model and the latent variables which are generated are based purely on the associations between the manifest variable outcomes, such that, given the latent variables the manifest variables are independent.

4.5.4 Data analysis

The analysis used tables and graphs to describe the data. Data analysis was conducted using linear mixed effects modelling to take into account the longitudinal nature of the data, that is to take into account the random variation between multiple responses within participants over time.

A fixed effects model could have been conducted although this model would assume independence between responses, which is not the case when dealing with multiple responses over time within participants. Such responses are likely to be more homogeneous than responses between participants and consequently a random effects model was preferred, with responses clustered within responders modelled through a random intercept term for responders

4.6 Chapter summary

In summary this project aimed to explore transitions in personal relationships and health for older adults who have taken on a caring role for their partner. A mixed methods approach was adopted for the project, with qualitative interviews used to provide a better understanding of the experiences of older adults caring for their partners, and a quantitative study utilising existing secondary data to explore transitions over time.

Chapter 5 Qualitative methods

5.1 Introduction

Research exploring the effect of taking on a caregiver role for a partner on health and personal relationships with other family members and friends is limited.

This qualitative study represents a small exploratory study including seven participants. The intention was that this qualitative study would provide, through interviews with older caregivers, a better awareness of the experiences of older partner caregivers, which would supplement the existing literature to inform the design, analysis, and interpretation of the larger quantitative study which follows.

This chapter presents a detailed description of the aims of the qualitative study and the methods which were used to obtain and analyse the data.

5.2 Qualitative study aims

The aims of the qualitative study were to elicit a better understanding of:

- Caregiver's experiences of changes that have occurred in their personal relationships since starting to care for their partner.
- Caregiver's experiences of changes to their health since starting to care for their partner.
- Other influences which may have affected personal relationships and health.

5.3 Study methods

5.3.1 Eligibility

Table 5-1 shows the eligibility criteria used to select participants, and the rationale behind each criterion. Restrictions in the provision of translators was due to financial constraints, as translators would not be able to be paid for their services, and the limited availability of translators who were trained in qualitative methods, which Kapborg and Berterö (2002) recommend using.

Table 5-1: Participant eligibility

Criteria	Rationale
1. Adults aged at least 50 years	Corresponds with the eligibility criteria used in ELSA
2. Experience of caring for their partner within the last two years	Inclusive to allow for recently widowed caregivers
3. English as first or main language	Restrictions on the provision of translators

Decisions regarding the eligibility of participants were made at the initial contact stage.

5.3.2 Sampling approach

An opportunity sampling approach was used for this study. Partner caregiver's who responded to an advert in the Carers Leeds News Bulletin were screened for eligibility and then recruited. This method is a quick and fairly easy way to select participants; however the consequences are that participants are a self-selected sample. Using self-selected participants is likely to mean that the sample is not representative of all older partner caregivers.

It is acknowledged that this approach may have missed some caregiver's, especially more isolated carers and those providing round the clock care and with little outside support.

5.3.3 Recruitment

Participants were recruited from Carers Leeds, which is part of the Carers Trust. An advert (Appendix B.2), approved by the Chief Executive Officer (CEO) at Carer Leeds, appeared in the December/January edition of the Carers Leeds News Bulletin which was sent out to caregivers, and was available online via their website in early November 2013.

Potential participants were informed that they would receive £10 as a thank you for taking part in the study and all reasonable travel expenses would be paid. Paying participants is becoming more common within qualitative interviews (Head, 2009). In this study the inclusion of a token gift of £10 in cash was originally suggested by the CEO at Carers Leeds, and was used to show an appreciation to the caregivers that their time was valued, but was not such a large sum to encourage caregivers to participate purely for financial gain. As this group of people may be hard to reach, because of the demands made on their time, it was ultimately hoped that the £10 gift would encourage them to view the research, and the researcher, more favourably and encourage them to take part (Singer and Kulka, 2002).

Caregivers who were interested in participating in the study after reading the advert made contact via email or telephone. Caregivers who made contact were assessed for eligibility based on the inclusion criteria above. Caregivers who met the eligibility requirements to participant and who agreed to provide contact details, in terms of a home address or email address, were sent an information sheet (Appendix B.3), consent form (Appendix B.4) and short questionnaire (Appendix B.5). They were asked to read these documents and decide if they would like to take part. Eligible participants were also told that they could phone the researcher if they had any questions or wished to discuss the project further. All eligible participants responded within one week and did not require any further information. If eligible participants had not made contact after receiving the information sheet, consent form, and questionnaire, they would have been contacted by phone or email approximately one week later to identify if they would like to participant in the study.

5.3.4 Interview administration

Interviews took place between November 2013 and January 2014. The seven eligible participants who agreed to take part in the study were asked to complete the short questionnaire before the interview (Appendix B.5). The questionnaire requested basic information on age, sex, ethnicity, current employment situation, and if they were currently looking after their spouse or partner. This information was collected to provide a brief overview of the demographics of the participants included in the study.

Participants could choose to hold the interview in their own home, in another location suitable for them, or in a meeting room within the university. The choice of interview location has implications in terms of the social interaction between the participant and interviewer and the ability for the participant to speak freely (Elwood and Martin, 2000). It was anticipated however that participants within this study may have time or location limitations placed on them because of their caring role and so the choice of location was pragmatic, based on identifying a quiet location which was most convenient to them. One participant chose to be interviewed in a meeting room at the university, while the remaining six participants chose to be interviewed in their own homes. Of the participants who were interviewed in their own home, in most interviews their spouse was in the home at the time of the interview, and in two cases interviews were conducted while the participants' spouse was in the room.

Before commencing the interview and collecting completed questionnaires participants were taken through the information sheet and were given the opportunity to discuss any queries they may have. No participants had any specific additional questions about the study but a few participants were interested in finding out more about the background, in terms of why the researcher had chosen to focus on this topic and what the researcher thought they would identify from the results. On these occasions the researcher briefly described how the research had been motivated by an interest in how relationships and health change as people age, and explained that the researcher was interested in the participants own experience. An offer to discuss the background to the study in further detail after the interview was made. In one instance this led to a long discussion after the interview between the researcher and the participant, as this participant had an existing interest in research around successful ageing.

Informed consent was taken. Questionnaires were collected from participants and they were given £10. Travel expenses were not required by any participant.

5.3.5 Procedure

Relationship diagram

Before the interview commenced participants were asked to complete a relationship diagram (Appendix B.6). This method of eliciting the relative degree of closeness between participants and each member of their social network was first used within the convoy model (see section 1.6.2) (Antonucci, 1986). More recently Roseneil (2006) used relationship diagrams alongside in-depth interviews to explore contemporary meanings of intimacy and friendship between adults. In the Roseneil (2006) study participants were asked to include the names of anyone they felt they had a significant relationship with. Participants used different coloured pens to indicate the different types of relationship; and concentric rings were used to indicate the closeness the participant felt to each person, identified by the proximity of each individual to the centre of the circle.

In the current study it was intended that the relationship diagram would help participants identify people who were currently important to them which would assist them in describing changes in these relationships, from before they considered themselves caregivers for their partner, to the current day. The same method employed by Roseneil (2006), which is described above, was used in this study. It was explained to participants how to complete the relationship diagram and participants were allowed to update their relationship diagram throughout the interview, if they wished.

Development of a topic guide

A topic guide was created (Appendix B.7) to help ensure all the topics the researcher wanted participants to discuss during the interview were covered. Prompt questions were not included in the topic guide, but rather the topic guide provided areas for the researcher to cover during the interview. It was also intended that the topic guide would direct the sequence of discussions in the interview, however it became clear after the first interview that encouraging participants to tell their own story, and not restricting them to following a particular structure, provided a richer understanding of the connections participants were making between personal relationships and health. Thus after the first interview the topic guide was used principally in the later stages of the interview to help the researcher identify any areas the participants had not yet covered.

Interview

All interviews were undertaken by the researcher and were audio recorded, with the participant’s consent.

Interviews were in-depth. In all cases the interview was started by asking participants to provide a brief life story, in terms of their marriage (or partnership), children, family, and past or current jobs. Participants were then directed, as required, to discuss their partner’s past and current health experiences, their own health experiences, their relationship with their partner, relationships with others, and any changes in their health and personal relationships after taking on a caring role for their spouse or partner.

Two participants became upset during the interview when they were asked to discuss their spouse’s health and the effects of this on their relationship. In both of these cases the interview was stopped until the participants felt they were ready to continue.

Interviews lasted between forty minutes and two hours, the median length of time was one and a half hours.

5.3.6 Post-interview reflective practice

After each interview the researcher wrote a reflection of the interview. These reflections took the same format for all participants and briefly described the following: responses to the questionnaire; use of the relationship diagram, and a description of their family and friends; the interview setting; overall impressions of the participant within the interview; brief description of the participant and the participant's partner, in terms of health, work, interests, and their relationship; and a list of key points that the researcher had taken from the interview. These reflections were used in the data analysis phase as a basis to complete pen portraits for each participant, to help describe similarities and differences between participants, and to help in the interpretation of the themes the researcher identified from the transcripts.

5.3.7 Transcription

All interviews were transcribed verbatim.

The researcher transcribed three interviews and the remainder were transcribed by administrative staff working within the university who were familiar with transcribing interviews. The researcher compared all the transcripts with the original audio recordings to ensure they were an accurate account of the interview. Any names which were used in the interviews were replaced with generic terms within the transcripts, for example <husband>, or <health visitor> to ensure the transcripts were anonymised. Long pauses or nonverbal communication such as laughter, which would aid the interpretation of the text were included in the text, using square brackets.

Participants were given the option to receive a copy of their transcripts if they chose and were given three weeks after receiving the transcript to stipulate if there were any parts of the transcript they wished to be excluded from the analysis. Three participants requested copies of their transcripts. In all cases these participants did not request any parts of their transcripts to be excluded.

5.3.8 Security

Participants' contact details were entered in a password protected file and stored on the University's remote server. To retain the participants' anonymity, on entry into the study participants were given a unique identifier number, using a three digit random number, and provided with a pseudonym.

Paper versions of the participants' personal contact details, informed consent forms, and questionnaires were stored securely in a locked filing cabinet, within a room with restricted access. To ensure personal details disclosed by participants remained separate from contact details, paper copies included either the participant's name, or the participant's unique identification number, but not both.

Audio tape recordings were deleted from the Dictaphone once they were transferred onto a password protected file within the remote server. The participant’s unique identifier number was used to identify audio recording and transcriptions.

5.3.9 Sample size

This study is only one part of a larger mixed methods project. The intention was not to recruit enough participants to reach data saturation, that is to reach a point where no new data would be identified through undertaking additional interviews (Ritchie et al., 2003), but to get a better understanding of the experiences of older partner caregivers to help inform the quantitative study. A pragmatic approach was undertaken to estimate the number of participants to include within this study. Though interviewees were likely to vary, in terms of their caregiving experiences, the focus was on the effect of the change into a caregiving role, rather than differences in terms of the health condition of their partner, the duration of the illness, or the caring role they provide. Given that this was a small study it was hoped that the number of participants recruited would be more than five but less than fifteen.

5.3.10 Ethics

Ethical approval was obtained from the University of Leeds Ethical Review Committee (see Appendix B.1).

5.4 Analysis

The data was analysed using framework Analysis (Ritchie et al., 2003). Framework Analysis provides a systematic approach to analysing the data based on three broad stages: data management, descriptive accounts, and explanatory accounts. All transcripts were stored as word documents and the analysis was conducted within word and excel.

Both an inductive and deductive approach was used. As the aims of this study, and the interviews themselves, focused on changes in health and personal relationships a deductive approach to searching for common themes around health and personal relationships was undertaken. The data was, however, analysed to take in the full range of experiences described by the participants, and did not focus only on health and personal relationships. This allowed for other common themes to emerge inductively from the data.

The analysis was undertaken by the researcher, with guidance from a supervisor with extensive experience in qualitative research. The stages within this study closely follow the stages described in Ritchie et al. (2003) and are described below.

5.4.1 Data management

Identifying initial themes and concepts

The researcher completing the analysis was familiar with all of the participants as they had undertaken all of the interviews, transcribed some of the audio recordings, and checked through all of the transcripts for accuracy. To further help with familiarisation the researcher firstly completed the pen portraits for each of the participants using the transcripts, questionnaire responses, relationship diagrams, and the post interview reflections.

The researcher went through the three interviews that they had personally transcribed and highlighted any experiences, feelings, or opinions identified in the transcripts. This was done by highlighting any relevant text within the three transcripts and attaching a descriptive comment to the text. The researcher kept a list of the descriptive comments and used the same descriptive comment when different text seemed to be referring to a similar thing. Figure 5-1 provides an example of the type of descriptions which were applied to the text within the transcripts.

Figure 5-1: Example of descriptions applied to text

Text	Description
P: I think I found it much harder before he really had become dependent. When he needed me but it sort of frustrate activities that we were going to do. [1]	[1]-Negative feelings/Changing role
I think I had to get to a point when I realised life had to change. And that, you know, <husband's> condition had to be the first thing. [2]	[2]-Need to prioritise spouse needs
Because while it was just going downhill it was sort of like a nuisance that, you know. [3]	[3]-Deteriorating health/Negative feelings
Can you understand what I'm saying?	
I: Yes.	
P: I don't mean I was entirely unsympathetic, but we didn't understand it. We didn't know, how, you know, that everything was related. [4]	[4]-Time to adjust to changing role/ Uncertainty as to why spousal changes were happening /No diagnosis
And the reason for certain things.	
I mean the first time he fell we had, em, a friend here helping us put up a bathroom cabinet up. And <husband> was holding one end of it. And he just suddenly fell over while doing it. And, you know, I was cross with that. I couldn't think why he did it so. And it only became apparent afterwards. [5]	[5]-Negative feelings/ Uncertainty as to why spousal changes were happening
P: It was, you know, this condition coming on. So sometimes hindsight helps you to understand. So yes it was really difficult. [6]	[6]-Time to adjust to changing role/no diagnosis/ adjustment was difficult
And I found it difficult when we had to go and adapt the house and have all sorts of, you know, invalid aids coming in, and stair lift going in, and an adapted bath, [7]	[7]- Adaptations to house/difficult to adjust to changes
And you know it sort of seemed to be taking over. It didn't seem like home any longer. But now we're at terms with it and that's fine. Got used to it all. [8]	[8]- Overwhelming/No longer feels like home/time to adjust

I=Interviewer, P=Participant

The list of descriptive comments was large, including 162 different comments. The final list of descriptors was grouped into a smaller number of broad categories and sub categories based on recurrent descriptors and each sub category was given an index number. This initial list of categories and sub categories is presented in Table 5-2.

Table 5-2: Initial index of categories and sub-categories

Category	Sub category	
Health	1.1	General health
	1.2	Carer related health problems
	1.3	Carer related symptoms of stress
	1.4	Managing or improving health by exercise
	1.5	Managing or improving health by other means
	1.6	Things identified by participants that improve their health
	1.7	Things identified by participants that hinder their health
Spouse	2.1	Relationship with spouse before becoming their carer
	2.2	Relationship with spouse after becoming their carer
	2.3	Experiences of doing things together as a couple
	2.4	Changes to sexual relationship
Family	3.1	Closeness with family members
	3.2	Support from family members
	3.3	Regularity of contact with family members
	3.4	Support given to family members
Friends	4.1	Current friendships
	4.2	New friendships since becoming a carer
	4.3	Friendships lost since becoming a carer
	4.4	Closeness with friends
	4.5	Support from friends
	4.6	Regularity of contact with friends
	4.7	Reasons for less contact with friends or aquantances
	4.8	Things that have made friends closer
Contact with others	5.1	Experiences with professionals or paid care
	5.2	Experiences of continuing to work while caring
	5.3	Experiences of doing other social activities
	5.4	Other contacts
Carer experience	6.1	Feelings about the situation or being a carer
	6.2	Managing the carer role
	6.3	Spouses health and/or the impact of spouses health
	6.4	Impact of spouses social network to carer burden
	6.5	Other things identified that have reduced carer burden
	6.6	Other things identified that have increased carer burden
	6.7	Financial constraints

Labelling the data

The initial list of categories and sub categories presented above (Table 5-2) were applied to all seven transcripts, that is any text within each transcript which related to any of the sub categories were highlighted within word and a comment using the sub category index number were included. No new sub categories were identified from the four new transcripts, possibly reflecting the overly broad nature of the sub categories. This resulted in the names of several sub categories being changed to better reflect the text included within these categories. An example of how these sub categories were applied is presented in Figure 5-2.

Figure 5-2: Example of applying the index to text within the transcripts

Transcript	Comment
P: I'd love a really nice night's sleep, I really would. I go to bed early to compensate. Well early [laughs], I look forward to going to bed early, but I try and get little jobs done like ironing. Sometimes I just sit on the settee with something on my knee, and I'm just too tired to eat. And the carers go about seven at night...	1.2 1.5 5.1 6.3
I: So that's the last help. How many times do they come a day?	
P: Four times. In the morning they come about ten, he has an hour, then they leave about quarter past eleven. But because they haven't got many of what they call doubles on this run, they're back within half an hour, and we've got into routine where they get him up, shower him, put him back to bed. I give him a coffee, then at lunchtime they get him up in to his chair and then they arrive about quarter past four, get him up again, I give him his tea – I have to feed him now – at one time he could feed himself, but now I feed him with a spoon. And then they come at quarter past six and he goes back to bed. He's in bed about seven with his medication.	5.1 6.2 6.3
And usually sleeps well, but the last two nights have been interrupted with shouting and carrying on. So to have a bit of a life I watch a bit of television. Rubbish probably, but I can just stare at it. Then I get ready for the morning in the kitchen, do the dishes, do little jobs that everybody does. And then I go to bed. And then if I hear shouting I've got a little video...well it's a camera up there... but I don't use that one...	1.7 6.1 6.2
P: A monitor, on the bedside table, so I can look and see without getting out of bed. But normally because of the noise I get out of bed and go in to see what's wrong and calm him down. I give him a drink, settle him down and then get back to bed. But very often I can't get back to sleep then. So he bought me an Ipad, so I sit up looking at my Ipad, or reading a book, until I can feel sleepy.	1.6 6.2 6.3 6.5
P: I get up usually half six to seven to get my tablets. I'm on a lot more tablets than <husband> actually [laughs]! Because I'm on tablets for my heart, on tablets for the arthritis. I take those, have my breakfast, and then go in and wake him up and give him his drink out of those little mugs, breakfast, come out, get his Wheatabix or Oatabix or something that will act on the bowels.	1.1 6.2

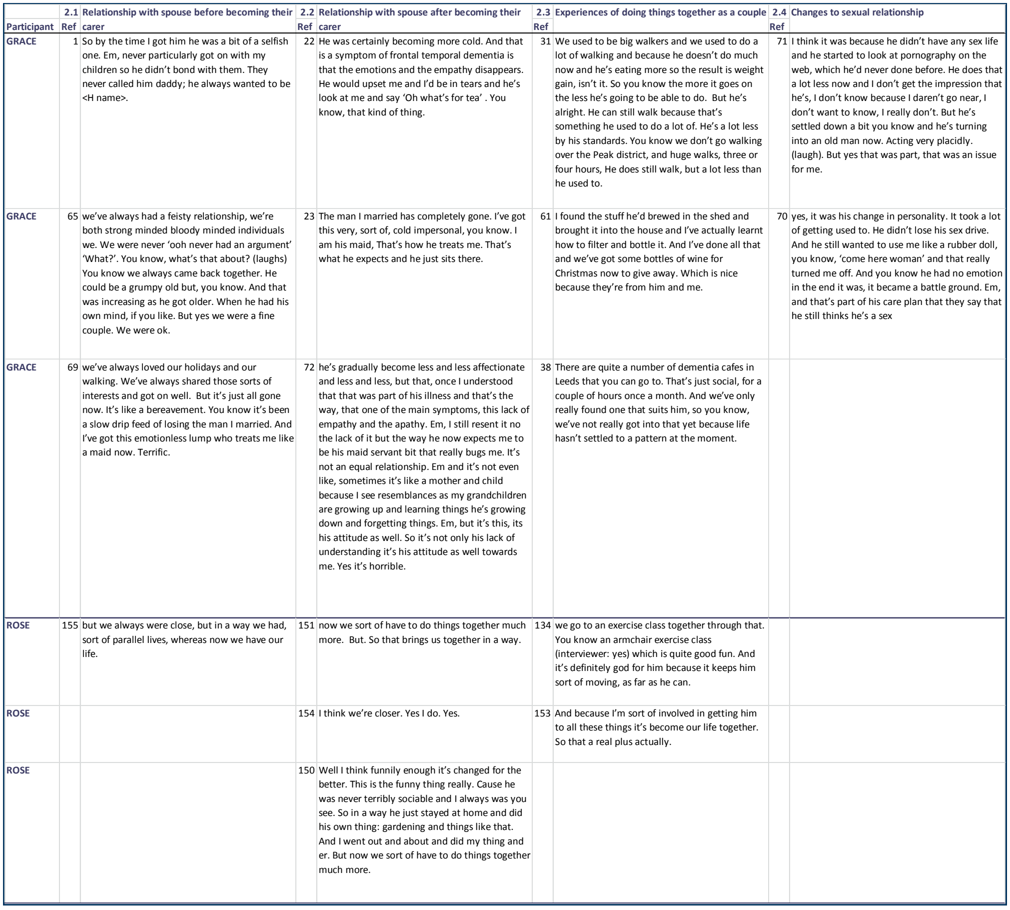
I=Interviewer, P=Participant

Sorting the data by category

Once all the sub categories had been tagged within the transcripts an excel document was created and all the tagged text within the transcripts were copied into spreadsheets within this excel file to form the matrices.

Each broad category was assigned a separate spreadsheet within the file, each sub category was included as separate columns and, to avoid summarising too early, all the text was pasted within separate cells underneath the relevant sub category columns. All text included within the spreadsheets was accompanied by the pseudonym of the participant and a reference number. The reference number linked to another spreadsheet within the excel file and identified the actual line numbers where the original text was identified. Figure 5-3 provides a snapshot of text which was included within the spouse category.

Figure 5-3: Selection of text from spouse category

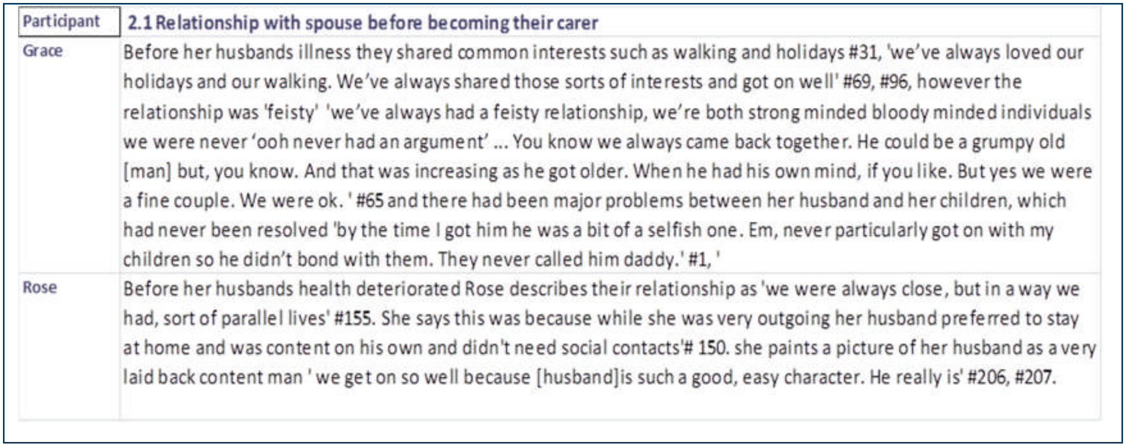


Participant	2.1 Ref	Relationship with spouse before becoming their carer	2.2 Ref	Relationship with spouse after becoming their carer	2.3 Ref	Experiences of doing things together as a couple	2.4 Ref	Changes to sexual relationship
GRACE	1	So by the time I got him he was a bit of a selfish one. Em, never particularly got on with my children so he didn't bond with them. They never called him daddy; he always wanted to be <H name>.	22	He was certainly becoming more cold. And that is a symptom of frontal temporal dementia is that the emotions and the empathy disappears. He would upset me and I'd be in tears and he's look at me and say 'Oh what's for tea' . You know, that kind of thing.	31	We used to be big walkers and we used to do a lot of walking and because he doesn't do much now and he's eating more so the result is weight gain, isn't it. So you know the more it goes on the less he's going to be able to do. But he's alright. He can still walk because that's something he used to do a lot of. He's a lot less by his standards. You know we don't go walking over the Peak district, and huge walks, three or four hours, He does still walk, but a lot less than he used to.	71	I think it was because he didn't have any sex life and he started to look at pornography on the web, which he'd never done before. He does that a lot less now and I don't get the impression that he's, I don't know because I daren't go near, I don't want to know, I really don't. But he's settled down a bit you know and he's turning into an old man now. Acting very placidly. (laugh). But yes that was part, that was an issue for me.
GRACE	65	we've always had a feisty relationship, we're both strong minded bloody minded individuals we. We were never 'ooh never had an argument' 'What?'. You know, what's that about? (laughs) You know we always came back together. He could be a grumpy old but, you know. And that was increasing as he got older. When he had his own mind, if you like. But yes we were a fine couple. We were ok.	23	The man I married has completely gone. I've got this very, sort of, cold impersonal, you know. I am his maid, That's how he treats me. That's what he expects and he just sits there.	61	I found the stuff he'd brewed in the shed and brought it into the house and I've actually learnt how to filter and bottle it. And I've done all that and we've got some bottles of wine for Christmas now to give away. Which is nice because they're from him and me.	70	yes, it was his change in personality. It took a lot of getting used to. He didn't lose his sex drive. And he still wanted to use me like a rubber doll, you know, 'come here woman' and that really turned me off. And you know he had no emotion in the end it was, it became a battle ground. Em, and that's part of his care plan that they say that he still thinks he's a sex
GRACE	69	we've always loved our holidays and our walking. We've always shared those sorts of interests and got on well. But it's just all gone now. It's like a bereavement. You know it's been a slow drip feed of losing the man I married. And I've got this emotionless lump who treats me like a maid now. Terrific.	72	he's gradually become less and less affectionate and less and less, but that, once I understood that that was part of his illness and that's the way, that one of the main symptoms, this lack of empathy and the apathy. Em, I still resent it no the lack of it but the way he now expects me to be his maid servant bit that really bugs me. It's not an equal relationship. Em and it's not even like, sometimes it's like a mother and child because I see resemblances as my grandchildren are growing up and learning things he's growing down and forgetting things. Em, but it's this, its his attitude as well. So it's not only his lack of understanding it's his attitude as well towards me. Yes it's horrible.	38	There are quite a number of dementia cafes in Leeds that you can go to. That's just social, for a couple of hours once a month. And we've only really found one that suits him, so you know, we've not really got into that yet because life hasn't settled to a pattern at the moment.		
ROSE	155	but we always were close, but in a way we had, sort of parallel lives, whereas now we have our life.	151	now we sort of have to do things together much more. But. So that brings us together in a way.	134	we go to an exercise class together through that. You know an armchair exercise class (interviewer: yes) which is quite good fun. And it's definitely god for him because it keeps him sort of moving, as far as he can.		
ROSE			154	I think we're closer. Yes I do. Yes.	153	And because I'm sort of involved in getting him to all these things it's become our life together. So that a real plus actually.		
ROSE			150	Well I think funnily enough it's changed for the better. This is the funny thing really. Cause he was never terribly sociable and I always was you see. So in a way he just stayed at home and did his own thing: gardening and things like that. And I went out and about and did my thing and er. But now we sort of have to do things together much more.				

Summarising the data

The text included in the spreadsheets were summarised for each participant to reduce the data into a more manageable size, while trying to maintain the essence of each participant's experience. The process of summarising the data led to sub categories which were capturing similar data merging, or categories or sub categories being renamed to better describe the nature of data they contained. The actual descriptions used by participants were maintained as much as possible and the reference numbers for any text used within the summary was provided so that the original text within the transcripts could be accessed. Figure 5-4 presents an example of the summaries for the sub category 2.1: Relationship with spouse before becoming their caregiver.

Figure 5-4: : Example of summary data



Participant	2.1 Relationship with spouse before becoming their carer
Grace	Before her husbands illness they shared common interests such as walking and holidays #31, 'we've always loved our holidays and our walking. We've always shared those sorts of interests and got on well' #69, #96, however the relationship was 'feisty' 'we've always had a feisty relationship, we're both strong minded bloody minded individuals we were never 'ooh never had an argument' ... You know we always came back together. He could be a grumpy old [man] but, you know. And that was increasing as he got older. When he had his own mind, if you like. But yes we were a fine couple. We were ok. ' #65 and there had been major problems between her husband and her children, which had never been resolved 'by the time I got him he was a bit of a selfish one. Em, never particularly got on with my children so he didn't bond with them. They never called him daddy.' #1, '
Rose	Before her husbands health deteriorated Rose describes their relationship as 'we were always close, but in a way we had, sort of parallel lives' #155. She says this was because while she was very outgoing her husband preferred to stay at home and was content on his own and didn't need social contacts'# 150. she paints a picture of her husband as a very laid back content man ' we get on so well because [husband]is such a good, easy character. He really is' #206, #207.

5.4.2 Descriptive accounts

The summary data was used to develop the final themes and sub themes presented within the results. This process was undertaken iteratively, by identifying key elements from the summaries both within and between participants, and within and between categories and sub categories, and taking into account the main objectives of the study. The process of writing a descriptive account of the results was started at this stage and it was this process, and referring back to the participant's original transcriptions, which enabled the themes to be clarified and the interpretation of the themes to begin.

5.4.3 Explanatory accounts

Once the themes and sub themes had been described the researcher went back to the original transcripts and pen portraits to enrich the meaning behind, or identify explanations for, the patterns which had emerged within and between themes.

Subsequent reflection on the importance and meaning of text within the transcripts was undertaken after the completion of the quantitative study, which followed this study.

5.4.4 Presentation of quotes

Direct quotes have been used within the results section to provide validity to the researcher's interpretation of the transcripts. When the researcher felt it was unclear who, or what, the quote was referring to, additional information has been added within square brackets, within the quote and immediately after the ambiguous term, for example "He [son]".

On occasions when very large pieces of text included pertinent points which were not adjacent to each other, three dots have been used to represent that text has been removed.

5.5 Reflections from the researcher

Reflexivity is an important tool within social science to enhance the credibility of studies by showing an open and honest approach to the potential influences the researcher, participants, and the environment, can play in the research process (Mauthner and Doucet, 2003).

This chapter includes descriptions of the setting and interview process. The qualitative results chapter, which follows (chapter six), provides a description and reflection of the participants, while the discussion section within chapter six provides a reflection of the approaches used within this study.

This section represent the researchers own reflections of their role within the study.

5.5.1 Characteristics of the researcher

As reported in chapter five I am a mature student with a varied background. Although my work colleagues have generally been similar, that is, well educated professional people, my nursing background has been instrumental in enlightening me to the diversity and the richness of cultures and experiences within our society.

Though I had some prior experience of interviewing participants, as part of a research project before starting my doctoral project, this experience was limited and I definitely felt I was coming into the qualitative study as a novice interviewer. I also have no direct experience of caring for someone who needs assistance because of health problems. Though working with patients and their family within a hospital setting had provided me with some understanding of the practical problems taking on a caregiving role could have, I had little knowledge, before embarking on this project, of the wider consequences of taking on a caregiver role.

I am a fairly organised person and I am most happy when I can apply order and structure to things. I think this is partly out of necessity because I have had to juggle multiple roles – mother, researcher, nurse, and student - for many years, but also reflects my statistical background.

5.5.2 Anticipated researcher effects

I anticipated that my nursing experience would benefit me when it came to the interviews. I am a good listener and I had developed skills, through my nursing career, in reading non-verbal cues and asking pertinent questions in a sensitive manner, which would, I felt, help me unravel and interpret the experiences of participants. I also felt that my nursing background would help me to deal with any sensitive issues which may arise.

I was concerned that my inexperience in interviewing participants may result in me coming across as very nervous to participants. I knew it was important that I put participants at ease, as having a nervous researcher could make the interview quite stilted and uncomfortable. I also had concerns that I would miss important issues or information because I would be too focused on covering all of the aspects I had included in my topic guide.

Finally I had some concern that my statistical background and general approach to managing data may hinder my ability to adopt a qualitative approach to analysing data. I felt my need to apply order would mean that I would view the data purely in quantitative terms, making the results superficial and of limited value in terms of providing meaning to the quantitative study.

5.5.3 Post-study reflections

I feel that while the anticipated benefits of my nursing experience did come to fruition I unexpectedly did experience one limitation to having a nursing background. Within nursing, listening and trying and understand the problems, concerns, or experiences of patients is an important part of the job. The reason for this is however so that, as a nurse, you can in some way provide help or seek assistance for the patient. In contrast, my quest for knowledge about the participant’s experience of caring within a research setting was only to get a better understanding about their experiences. While some participants may have benefited from talking about their experiences this was not an objective of the study. At times participants discussed issues such as access to services or funds, or described experiences which indicated that they could benefit from additional support. When this first occurred I felt I was not prepared and I had to fight against my instinct to offer help or advice. In this instance I managed to continue to listen to the participant and suggested at the end of the interview that they speak to the health professional in charge of their partners care. In subsequent interviews I felt more prepared. I wrote down if there were any issues or concerns raised during the interview and suggested they speak to their GP, health professional in charge of their partner care, or Carers Leeds, depending on the nature of the issue and the existing support available.

One perceived consequence of being a novice interviewer was that I felt I stuck too rigidly to the topic guide during my first interview and I may have missed some important information. I felt that at times my nervousness meant that I moved on too quick to the next topic instead of probing further the experiences they were describing. In the second interview I used the topic guide only to check, near the end of the interview, that I had covered all the topics I was interested in and I encouraged the participant to tell their story. I felt that this approach encouraged me to listen and concentrate on the experiences of the participant, and the interview felt less stilted. In addition I felt this approach resulted in a richer understanding of the caregiving experience and I adopted this, more conversational, approach for all subsequent interviews.

My statistical background and need to categorise and quantify did provide a stumbling block for me. It seemed to manifest in two ways. The first was, as I anticipated, in the need to categorise and quantify. In the end, using framework analysis helped me as the structured approach meant that I was able to feel I was categorising and organising. The second consequence was unexpected however. My experience as a statistician means that I am used to making decisions based around probability. I found that when the level of uncertainty was taken away I struggled to make decisions regarding the importance of the descriptions coming from the interviews. This made it difficult initially to identify commonality between participants as I was reluctant to let go of any subtle differences between quotes. The result of this was that I produced a list of 162 different types of comments from three transcripts. It was at this point that my supervisor, with expertise in qualitative methods, stepped in and provided me with additional one-to-one training in qualitative analysis. Her support and guidance in the difficult initial stages of the analysis helped me to step out of my comfort zone so that I could identify common themes between transcripts and start asking questions of the data, for example what were the participants actually saying here. Again framework analysis also helped in this process as the clear steps within the analysis and the well-structured data outputs at each stage meant that it was clear to my supervisor the process by which the themes and interpretations had been shaped.

5.6 Chapter summary

Seven older adults with experience of caring for their spouse or partner within the last two years were interviewed between November 2013 and January 2014. During the interview they were asked to describe their experiences of becoming a caregiver for their spouse or partner, particularly focusing on transitions in their own health and personal relationships. The interviews were audio recorded and transcribed and framework analysis was used to analyse the data from these transcripts. Further details about the participants and the results from this analysis are provided in the next chapter.

Chapter 6 Qualitative Results

6.1 Introduction

This chapter presents the results from the qualitative analysis. The first section uses pen portraits to provide an overview of the participants, their caring role, and their health. The main section explores the themes which have been identified from the interview transcripts, while the final section describes three distinct groups of participants.

6.2 Description of participants

6.2.1 Potential participants

Nine potential participants responded to the advert in the Carers Leeds Bulletin. Two were excluded at the initial contact; one was a parent looking after their child, who had health problems, and had no experience of looking after their spouse or partner; and the remaining potential participant was excluded because they could not speak English and would need an interpreter. The seven remaining participants all met the inclusion criteria, agreed to take part in the study, and completed an interview.

6.2.2 Use of the relationship diagram

Participants used the relationship diagram in different ways. One participant did not see the benefit of populating the relationship diagram and the interview commenced without it. Three participants spent time populating the relationship diagram with individual family members, friends, and other relationships, such as with health professionals. These participants used all of the concentric rings and the relationship diagram was referred to during the interview. Two participants also used the relationship diagram but had a smaller number of personal relationships to include and they did not refer to the relationship diagram during the interview. One participant only used the relationship diagram to list groups of personal relationships (husband, caregivers, friends, relations) but did not include these groups within the concentric rings.

6.2.3 Overview

Table 6-1 provides a brief summary of key participant details. Participants were aged between 60 and 80 years. All were married and had been married to their spouses for between 23 and 58 years. Of the seven participants six were female and six had retired, although two participants continued to work part-time. One participant was self-employed. All of the participants had children and all but one participant was caring for their spouse at the time of the interview. The health conditions affecting their spouses were dementia, neurological problems, heart problems, and a stroke.

Table 6-1: Summary of participant details

	Alice	Elizabeth	Grace	Heather	Julie	Neil	Rose
Age (years)	71	68	67	80	71	70	60
Sex	Female	Female	Female	Female	Female	Male	Female
Ethnicity	Jewish	White British	White British	White British	White British	White British	White British
Work (previous job)	Retired (shop work)	Retired (health visitor)	Retired works part-time (secretarial)	Retired (nurse)	Retired (library work)	Self employed	Retired works part-time (admin)
Years together	Married 52 years	Married 45 years	Married 29 years	Married 58 years	Married 40 years (separated 14 years)	Married 23 years	Married 23 years
Spouse morbidity	Heart disease,	Motor Neurone Disease	Dementia	Neurological disorder	Alzheimer's	Stroke	Alzheimer's
Currently caring	No	Yes	Yes	Yes	Yes	Yes	Yes
Children	Three daughters	One son	Two sons	Two daughters	One son	One son, one daughter	One son

6.2.4 Caring role

For most participants the time they spent away from their spouses was limited. Most helped their spouses with core activities such as washing, dressing, and helping to mobilise, and most were responsible for daily household chores such as cooking and cleaning.

Another important role which most of the participants played was to become a spokesperson for their spouse. It was usually the participants who communicated with family, friends, and health professionals on their spouse's behalf and participants commonly made decisions in terms of the support their spouses needed, the activities their spouses would participate in, and the environmental changes required to fulfil these roles.

6.2.5 Health

Given the participants ages it would be reasonable to expect at least some to be living with age related health problems.

Some perceived their health to be good and did not report any chronic health condition; however most reported at least one health condition which they had generally lived with for many years. In most cases these health conditions were managed by taking medication and did not impact on their ability to care for their spouse. The most common health problems were high blood pressure and diabetes.

A few participants were living with debilitating health conditions themselves such as heart problems and arthritis. These participants had lived with these conditions for many years and their health had deteriorated over an extended period of time.

6.3 Participant pen portraits

A more in-depth description of the lives of each of the individual participants are provided in this section.

Alice

Alice was in her early 70's. She and her husband had been married for over 50 years before his death, which occurred approximately 9 months before the interview. They had three daughters. Several years ago they had moved into a retirement community in a different city to be near one of their daughters. This was done as both Alice and her husband had health issues and they felt it would be easier if they ever needed help to be near one of their children. Their other two daughters did not live locally, though she spoke to them regularly over the phone. Alice was also close to her grandsons, who lived locally.

Her husband had his first heart attack when he was 40 years old. Following a heart bypass and having a pacemaker fitted he managed for many years, but his health slowly deteriorated over the last ten years of his life. Alice was her husband's constant companion, accompanying him on his hospital appointments and generally keeping an eye on him by making sure he took his medication and did not overly exert himself. Slowly over the years Alice also took over many of the jobs her husband used to do around the home, such as cooking and washing-up. Alice's health was also not good; she had diabetes and had a pacemaker fitted following a heart attack in 1996. Alice felt that she had neglected her own health when her husband was alive as her focus was on keeping him alive.

It seemed that their marriage had been very good. Alice reflected that her husband was 'the love of her life'. She reported that they had a traditional relationship, based on distinct roles, and they shared a lot of common interests, such as politics, current affairs, and art. They used to travel a lot through work but it seemed they had led a fairly sedentary lifestyle in their later years, reflecting their respective health problems. Alice reported that they did not have many close friends but were content to be in each other’s company.

Alice reported that she had no close friends. Though she and her husband used to participate in some of the social activities which took place within the retirement complex she felt that they didn’t fit in and she had little in common with the other residents. They lost touch with friends they had before they moved, but Alice felt they had been more acquaintances than friends.

Elizabeth

Elizabeth and her husband were both in their late sixties and had been married over forty years. They had one son who lived abroad and she had one sister who did not live locally. They had a close relationship with their son, who they managed to see at least twice a year. Elizabeth also spoke to her son and her sister regularly.

Her husband was diagnosed with motor neurone disease approximately six years before. At the time of the interview he was able to carry out some tasks but he required a wheelchair and Elizabeth assisted him with washing, dressing, mobilising, and preparing a soft diet for him. His speech had also been affected by the disease. They had sitters who came in two afternoons a week and Elizabeth was able leave her husband in the house alone, but only for only short periods of time. She was an active member of a local art group but felt that she would soon have to give that role up because she could no longer commit so much time. Elizabeth also continued to swim occasionally but although she and her husband used to be members of a walking group she now rarely joined in any walks. Elizabeth had been taking medication for high blood pressure for many years and reported that she felt that at times she did not cope as well as she would usually with problems. She felt this was partly due to caring for her husband and partly because she was now responsible for many of the household tasks which her husband used to deal with.

Elizabeth described their relationship as warm and close. They previously shared a lot of mutual interests, which they could no longer do, but they still enjoyed spending time together. She reported that she turned to her husband for emotional support and that she would also feel reluctant to burden anyone else with her problems.

Elizabeth had a couple of close friends and her husband continued to see a few of his long term friends, but she was very aware that as their friends were all of the same age group they were all dealing with various health problems too. She reported that she did feel supported by her friends but it was based on mutual support.

Grace

Grace and her husband were both in their mid-sixties and had been married approximately thirty years. Grace had two grown-up sons from her first marriage. Her eldest son had two children and lived away while her youngest son lived locally and had one child. She was in regular contact with both sons though neither got on well with her husband. She received more support from her younger son because he lived nearer and because her eldest son also had health problems and she didn’t wish to burden him. She had an elderly mother who lived in a care home who she saw and spoke to regularly. Grace provided support to her mother and felt that her mother tried to support her as best she could. She also had a brother who lived locally. She had become closer to her brother since her husband’s illness as he had previously worked in a care home and could provide practical support based on his knowledge of the support available to caregivers. For example, he helped Grace to access incontinence supplies and mattress protectors through his knowledge of, and contacts within, social services.

Her husband was diagnosed with dementia six months ago, although she felt that the signs started to appear approximately two years before. Grace was particularly saddened that the main effects of the dementia had been personality changes, which she felt had left him cold and emotionless. She reported that he also exhibited compulsive behaviour, inappropriate social behaviour, gluttony, and incontinence. Grace supported all her husband’s care needs in the house, including washing, dressing, laundry, and toileting. He attended a day care centre twice a week and Grace received respite care when she needed some time off. Grace continued to work part-time some evenings and could leave her husband in the house on his own for short periods, but no longer attended regular exercise classes as she didn’t want to leave her husband for longer periods. Grace had suffered from disrupted sleep for many years. This had improved as she had actively sought techniques to improve her sleep patterns because she felt supporting her husband’s needs and not sleeping would be too much to cope with. Grace had gained weight since looking after her husband but she felt her main health problem was stress brought about by a combination of trying to do too much and trying to cope with a husband who now showed little emotion.

She felt that they had had a good marriage but it was at times tempestuous. They used to enjoy doing things together which was no longer possible, though they did go for short walks now and again. Grace felt that because of her husband's personality changes he now viewed her as no more than his maid and he showed her no love or respect. Grace felt she was grieving for the man she married who was no longer there.

Grace had many friends who she felt had always been supportive. A few friends had become closer since her husband's illness and encouraged Grace to do enjoyable activities when she could. Grace felt her friends helped her cope with stress. Grace felt her husband's friends, and friends who were in couples who she and her husband socialised with together had disappeared.

Heather

Heather and her husband had been married for nearly 60 years and were both in their early 80's. They had two daughters who did not live locally. Alice spoke to her daughters often and they visited regularly. Her younger daughter was instrumental in helping Heather claim the allowances she was entitled to, to help care for her husband.

Heathers husband was diagnosed with a progressive neurological disorder several years ago following deteriorations in his mobility and memory. His condition had deteriorated to the extent that he now needed help with all of his care needs. Her husband had also recently started to experience difficulty swallowing and suffered from night terrors, which were part of his condition. Their bungalow had been adapted to accommodate hoists and wheelchairs and paid carers came in four times per day to help with washing, dressing, toileting, and feeding. Heather spent all of her time caring for her husband and he could not be left on his own. His night terrors meant that Heather did not always get the rest she needed and she reported she had lost weight since caring for her husband. Heather had health problems too. She had a heart bypass fifteen years ago and had suffered with arthritis for the last ten years, which meant she could no longer walk long distances.

The description Heather painted of their marriage was of a loving and close relationship. They used to participant in activities together, such as bowling, but now she and her husband rarely left the house. She reported that she felt very protective of him but felt more like a mother figure rather than a wife.

Heather had some old friends, who she spoke to on occasion. She reported that she did feel isolated however and she felt that she was now closest to some of the paid carers who looked after her husband who she had got to know very well and considered friends.

Julie

Julie and her husband were both in their early seventies and married over forty years ago. They had been separated over 14 years but never got divorced. They had separate houses, however Julie now stayed with her husband most of the time, returning home only once per week to check everything was ok. They had one son. Although he lived locally they had little contact with him and this relationship had been difficult for many years.

Julie’s husband was brought back into her life approximately three and a half years ago when he was diagnosed with Alzheimer’s, as he had no one else and Julie had remained his next of kin. The circumstances surrounding the diagnosis were quite traumatic for Julie and she believed her husband had always suffered from mental health problems, exacerbated by heavy drinking. His memory was now severely affected, to the extent that he did not always recognise Julie. This confusion left him very distressed and upset at times. Julie needed to constantly remind her husband to do things, including washing, dressing, and how to use a knife and fork. Though her husband had a social worker Julie felt that they had received little help. She could leave her husband for short periods but needed to call him at regular intervals while she was out to reassure him. Julie was retired. She attended dance classes and a singing group and tried to maintain a life outside of caring for her husband. Her health was not good. She had diabetes, high blood pressure, and was partially sighted, due to macular degeneration. She also reported that she had put on weight since looking after her husband.

She reported that her husband had always been abusive and aggressive throughout their marriage. She felt her husband was less aggressive now that his Alzheimer’s was advancing, which was making life a little easier for her, though she felt the situation was still very difficult.

Julie reported having no close friends or family.

Neil

Neil was seventy and had been married to his third wife for over twenty years. Neil had two grown up children from a previous marriage. Neil was close to both of his children and he confided in his daughter who he spoke to the most.

Neil’s wife had a stroke three years ago which left her with paralysis down her right side and communication difficulties. Neil initially organised for paid carers to come in four times a day to look after his wife, and employed an occupational therapist to work with his wife to maximise the use of her right side. His wife’s mobility and level of independence had improved considerably over the three years and Neil had been able to stop the paid carers altogether. Physically his wife could now take care of herself, although Neil did the cooking and shopping. They also had a cleaner, who was employed before his wife’s stroke. The main problem was communication difficulties. Neil reported that he struggled to understand his wife, and since her stroke they had not been able to have a conversation. Neil was self-employed. He had a wide range of outside interests which had continued since his wife’s stroke and he was a keen runner. Neil reported that he had always had good health but since his wife’s stroke he had suffered from minor illnesses such as colds which he felt may be stress related.

Neil reported that the marriage had deteriorated considerably in the few years leading up to the stroke. Neil reported that he had built a life for himself since the stroke and he felt that, as his wife had no-one else to turn to, the stroke had taken away his choice to remain with his wife or start a new life,.

Neil had many friends and he enjoyed socialising. He reported that he had grown closer to a couple of friends and he confided in them but he and his wife no longer saw some mutual friends who they were previously close to. He attended a stroke support group which he found a great support.

Rose

Rose was in her early sixties and looked after her husband, who was in his mid-seventies. They had been married for over twenty years and had one son together. Although he no longer lived at home, he saw his parents regularly, and Rose described him as supportive. Her husband also had a son from his first marriage who lived further away and contact was infrequent.

Her husband was diagnosed with Alzheimer’s approximately four years ago. Rose helped him with washing, dressing, and toileting and did all the cooking and cleaning. Because her husband was at risk of falls, he could not be left alone for long. He attended a day care centre twice a week and they also employed sitters. Rose did leave him alone for short periods in the morning to go running; an activity she had taken up since her husband took ill. She also worked part time, volunteered at her local primary school, and was an active member of her church. Rose had made a conscious decision to continue with her outside activities and, though she expressed guilt over this, she felt it helped her to cope. Rose had always maintained good health, but since taking on a caring role she felt tired more often and attributed this to taking on too much.

Rose said that she and her husband had always been close but in the past they tended to do a lot of things separately as she was very sociable whilst he was content to stay at home. She felt that her husband's illness had brought them closer as they were now spending a lot more time together and doing more shared activities.

Rose had a wide circle of family and friends. The couple did not have relatives living close by, but she felt her relatives provided a lot of emotional support, and she had grown closer to her sister since her husband's illness. She had less contact with close friends than before her husband's illness, but despite this she felt they were still close. She had grown closer to some people who were previously just acquaintances and received a lot of support from members of her church. Their community matron provided practical advice and support, identified support services available, resourced financial support, and helped them gain access to health professionals. The community matron was also instrumental in enabling Rose to continue with her outside interests.

6.4 Themes

Five themes were identified from the interviews. Four of these themes: Health transitions, Family support, Friendship selectivity, and Changes in spousal relationship relate to the main aims of the study and were identified a priori from the literature and early engagement with the ELSA data. Adjusting to the caregiver role is an additional theme which was inducted from the interviews as an important aspect of caring. All of the themes include sub themes which focus on distinct features within the themes.

Figure 6.1 provides an overview of the themes and sub themes. Each of these themes will be discussed in more detail below.

Figure 6-1: Themes from the participant interviews

6.4.1 Health transitions

This theme focuses on the changes in health which participants experienced, which they attributed, at least to some extent, to looking after their spouse; and the health management strategies they adopted to reduce the health burden of caring.

Sub theme: Health consequences of caring

Both psychological and physical health problems attributable to looking after their spouses were identified by participants, however psychological health problems were the most common problem reported.

In particular most felt that caring for their spouse had resulted in increased feelings of stress, and for some this was identified as the main caring related health problem.

> ***Researcher:*** *"Do you think your health has changed at all since you've started looking after your husband?"*

> ***Grace:*** *"Yes I've had an awful lot of stress"*

Some participants did not use the term stress but described symptoms which could be attributed to stress, such as feeling under pressure, or indicating that they felt that they were juggling too much.

In the main there was a sense that all participants accepted that they would feel stressed at times because of the extra responsibilities involved in caring for their spouse. Elizabeth provided more insight into her feelings about how she coped with her stress.

> *"Well I think I'm quite good at dealing with stress most of the time … but there are times when things [get too much], and I suddenly go over the top and, and that's not really me at all … [I'm usually] very easy going really" (**Elizabeth**)*

Elizabeth described that the times she had gone 'over the top' were when she needed to undertake an additional job which would previously have been carried out by, or with, her husband, such as carrying heavy furniture, organising workmen, and managing luggage when they travelled abroad. It seemed that while part of the inability to cope at these points were related to actually having too much to do, in part it also reflected an increased awareness, at that time, of the changing roles in the relationship between herself and her husband. An awareness that her husband could no longer provide the support she once had.

Tiredness, or sleep disturbance, were also common health concerns. These were commonly attributed to having too much to do, in terms of caring for their spouse while also managing the day to day tasks of looking after a home.

> *"But the thing I suffer from is tiredness, you know, when I get over tired that's really awful … it happens when I sort of burn the candle at both ends"* ***(Rose)***

Elizabeth and Heather felt that their sleep disturbance was at least in part related to having to change their sleep patterns to meet the demands of caring for their spouse.

> *"I'm a morning person and he's an evening person, so that's, that's when we have problems, it's when he doesn't want to go to bed until late and I'm finished at ten o clock … he needs a hand to get to bed so I've got to hang around until he's ready for bed, so that can be a problem area"* ***(Elizabeth)***

Grace, Heather and Julie all mentioned that their weight had changed since looking after their spouse. The reasons for this varied. Grace has stopped attending her regular exercise classes because she didn't feel she could regularly leave her husband alone.

> *"I'm not getting as much exercise as I used to so my weights going up a bit as well because I used to go off to the gym on the days he didn't want to do*

> *anything [before his illness]. I had something I could go to and I ended up doing quite a lot of exercises classes … Take me out for a walk or something like that and I don't get enough of that any more..”* ***(Grace)***

Heather had lost weight because she was always busy and this had had a detrimental effect on her eating patterns.

> *“Sometimes I just sit on the settee with something on my knee, and I'm just too tired to eat”* ***(Heather)***

While Julie felt that when she first started looking after her husband she lost interest in her appearance, which may indicate that she experienced low mood when she first started to care for her husband.

> *“I've put on an awful lot of weight but I think I realise it's comfort eating. Em, I went through one stage where I thought it wouldn't matter how I looked, and I've had to discipline myself a little more now”* ***(Julie)***

Finally Neil and Elizabeth both mentioned that they thought they were more susceptible to colds since caring for their spouse, which again they attributed to having too much to do.

> *“Somehow I got all these bloody bugs … I said to <wife> some point last year, I said ‘I'm not going to have another winter like this. I can't look after you and look after this bloody house', which is huge. ‘at the same time. Something's got to go'”* ***(Neil)***

Sub theme: Health management

The majority of the participants reported that they were more aware of the need to look after themselves. Most participants were either planning or had already instigated initiatives to try to improve their health; or, like Neil, they were trying to continue with healthy activities, such as exercise, which they found beneficial.

> *“When I was ill with whatever it was all over Christmas … so I couldn't run, and that's very important to me because that helps me to cope enormously by running”* ***(Neil)***

All participants except Heather and Alice were engaged in some form of exercise. For most this required planning to ensure their spouse was safe while they participated in exercise, but in all cases these participants indicated that they recognised the importance of exercise and the health benefits, either in terms of helping them to cope, or in terms of maintaining their physical health.

> *“And you go and run five kilometres, get timed, and go home, and you do it 9 o'clock, you're finished by twenty to ten you see. I get back home by ten. So I'm trying to do that every Saturday, and that does me good I'm sure”* ***(Rose)***

Heather was the oldest participant and it is likely that her non participation in exercise, to a large extent, reflected her own health limitations which included arthritis. It was clear however that Heather was very aware of her need to maintain her own health so she could continue to look after her husband

> *“But I feel as long as I can keep going, I’m just worried if I do get ill, you know, what would happen? Because everyone, they’d all go ‘Oh [name of participant.], you must keep well, because everything is pivoting on you’. If I wasn’t well, where would we be?”* ***(Heather)***

Other approaches were also introduced to help cope. For Grace, managing her sleep patterns was very important to her so that she would feel able to look after her husband during the day.

> *“I was always [before caring] waking up, half past one, three o’clock, half past five, you know four times in the night. I’ve actually cured that to some extent now. I’m improving that by taking, again listening to good advice, non-medical interventions. So I’m actually sleeping better than I ever was … That was a deliberate effort on my part because I knew I had to do something because the stress during the day and not sleeping at night was just, you know, I’m trying to settle down”* ***(Grace)***

In contrast to the other participants Alice felt that she disregarded her own health when she was caring for her husband and put all her effort into looking after her spouse.

> *“Even though in ’96 I had a heart attack, it just went in to the background, I just didn’t think about it. I’d become diabetic during that period too … but I had totally ignored them, because the only thing that counted was keeping him alive”* ***(Alice)***

Summary: Health transitions

All participants thought looking after their spouse had affected their health in some way. The extra demands of the caregiver role commonly resulted in symptoms of stress in participants. The caregivers usually seemed able to cope with these feelings of stress but sometimes struggled when extra demands were placed upon them. Periods of increased stress were at times related to instances when they were required to take on additional tasks which would have usually been completed by their spouse; reflecting the increased burden of taking on additional work and possibly reflecting an increased awareness of the loss of the spousal support they once had.

There did appear to be a beneficial health effect through taking on a caregiver role as most participants were more aware of the need to look after their own health and many had actively instigated health related routines into their life. The reasons given for this were an appreciation that managing their own health would help them to cope with the caregiver role and would mean that they could continue to provide care for their spouse.

The experience of one participant suggested that this was not universally the case however and it may be that some caregivers, particularly those who may have existing debilitative health problems, may choose to ignore their own health needs so that they can focus on caring for their spouse.

6.4.2 Adjusting to the caregiver role

This theme relates to the feelings, attitudes and approaches participants used to adapt to their role of a caregiver for their spouse. Four sub themes are included within this theme: emotional adjustment, role acceptance, approaches to caring, and identity outside caring.

Sub theme: Emotional adjustment

Participants described feelings of frustration, guilt, sadness, and resentment. It was clear from the transcripts, however, that these emotions not only reflected their feelings about caring for their spouse but also involved feeling towards their spouses' deteriorating health, and the resulting changes in their marriage.

Participants commonly felt frustrated in the early stages of their spouses' illness, especially when they had no official diagnosis or when they were still adapting to their spouses changing abilities and behaviour.

> *"I think I found it much harder before he really had become dependent. When he needed me but it [would] sort of frustrate activities that we were going to do"* ***(Rose)***

For some, these initial feeling were replaced by feelings of guilt about their behaviour towards their spouse before they realised the extent of their spouses illness.

> *"During the time he was responsible for the kitchen I could be so mean to him. Because he couldn't see very well … he washed up by hand and he would miss bits. And I would go to get a plate out and I would yell at him, because I'm a yeller! Poor chap … I could be so mean to him"* ***(Alice)***

Feelings of sadness were common amongst participants. This was sometimes directed at the loss of their old relationship.

> *"We've always loved our holidays and our walking … but it's just all gone now. It's like a bereavement, you know, it's been a slow drip feed of losing the man I married."* ***(Grace)***

Or, like Rose, was an expression of sadness for what their spouse was going through, in terms of losing skills or suffering *"I'm sad because <husband> is suffering"*.

A feeling of resentment was also common, although the reasons differed. In most cases resentment was directed towards the restrictions that the caregiver role placed upon them, rather than their spouse.

> *"I suppose there was a bit of resentfulness, and feeling it was restricting things, and just not understanding"* **(Rose)**

Participants who described aspects of their relationship with their spouse which were difficult before their spouse took ill however seemed more forthright in directing some resentment towards their spouse.

> *"He's gradually become less and less affectionate … once I understood that that was part of his illness and that's the way, that one of the main symptoms, this lack of empathy and the apathy. I still resent … the way he now expects me to be his maid servant bit that really bugs me"* **(Grace)**

> *"The consultant, when I talked to her about it, said almost certainly this [his wife's stroke] was brought upon by the alcohol. So in other words this kind of made it worse. So she'd had the stroke but she's responsible for the stroke as well"* **(Neil)**

Sub theme: Role acceptance

Through the participants' descriptions of the caring role they provided, it was apparent that while some participants seemed to fall naturally into the caring role, others struggled, at least in the early stages, to recognise or acknowledge themselves as a caregiver.

Participants who seemed to take caring in their stride came from nursing backgrounds or had experience of caring for other elderly family members. These participants tended to focus on the practical aspects of caring for their spouse and did not tend to dwell on the feelings they had about caring.

> *"Last year on two occasions when he had a chest infection and he was at death's door, … So we went off to hospital, he was on a drip for a good couple of days, got another bedsore, and then came out and got better … I was up day and night, ... On the Friday the doctor came at lunchtime. I opened the door and he said, 'How is he', and I said 'Well just come in and have a look', and he came in 'Good morning!' he [doctor] went 'Wow! What a difference!' and I just said 'Good nursing and care doctor', and I thought, well I'll get that in!"* **(Heather)**

For some, the change from non-caregiver to caregiver had been quite gradual and they recognised that there was a period of adjustment before they realised that they needed to adapt to fulfil this role.

> *"I think I had to get to a point when I realised life had to change and that, you know, <husband's> condition had to be the first thing. Because while it was just going downhill it was sort of like a nuisance, you know"* **(Rose)**

For others, however, the role of caregiver had not come naturally. Neil openly acknowledged that he was not a natural caregiver and it had taken him a long time to accept the label, and for him being a caregiver was not his primary role.

> *"I finally had to admit to myself, in the last couple of years, that … I'm now a carer. I refused to say that for quite a long time… But I don't define myself as a carer. That still to me doesn't seem to be who I am. Because I don't think I'm a natural carer"* ***(Neil)***

Sub theme: Coping styles

Participants reported different approaches to caring for their spouse. Some participants actively managed their spouses care needs by organising daily activities and additional support, and controlling their spouse's environment to minimise the risk of additional health problems; while others responded to problems as they arose. The approach adopted seemed to reflect how much organisation was needed, either because of the nature of their spouse's illness or due to the need to fit in other outside interests.

Participants who were still working commonly adopted a more proactive approach, as they had to plan their time to ensure their spouses' needs were cared for. For example Rose continued to work part time; an activity she enjoyed and was reluctant to give up, but to continue to work Rose needed to be very organised:

> *"On a Monday morning he goes to an art class for people with dementia, and I manage to get him there and drop him off before I go to work … and [after the art class] they [taxi] will pick him up and actually see him into the house. And then we have a sitter … arrives before he comes back and then helps him in from the taxi man and looks after him till I get back from work. So that's one day. And then the other day he goes to <day care centre>, and they come and collect him and bring him back"* ***(Rose)***

These participants also seemed to be more likely to utilise support from health professional or social services and had set clear priorities for their spouse's health.

> *"He had a hearing test and yes there was some level of hearing loss but it was my choice in the end. I said 'look I don't think he'll manage hearing aids and I don't think he'll be able to tell me that the batteries are running out'. My mother has hearing aids and I know it's a weekly faff about them …. It's just an extra job for me"* ***(Grace)***

> *"I'll do whatever it takes, spend whatever it takes, to help her get literally on her own two feet"* ***(Neil)***

Heather also adopted a proactive approach because her spouse's health was such that he required paid carers to come in four times a day. Heather described a need to manage her husband's care with almost military precision, because her husband health was very poor and he was susceptible to infection.

> *"The last two times he's been in hospital it was with a chest infection, in the winter due to probably carers working with colds. They arrive with a cold [they say]'It's alright I've got a mask', well [participant says] 'Don't breathe on <husband> please he's only just finished a course of Penicillin for a chest infection'. I'm like a tiger, I have to be guarding the door"* ***(Heather)***

In contrast a few participants managed their caregiving role by taking each day as it comes and were reluctant to look too far ahead into the future. These participants were largely managing the care of their spouse on their own and most of their time was spent with their spouse.

> *"I manage by ignoring things, you know, I just sort of like focus in and ignore things"* ***(Elizabeth)***

> *"He [husband] said 'You're not going to have to do this for ever are you? Can you?' and I said 'Look we can do it now and we'll, what we'll do, when things get worse, we'll have a rethink about what we're going to do. We'll think about it then, not now'"* ***(Julie)***

Sub theme: Identity outside 'caregiver'

Most of the participants conveyed how important it was for them to continue to engage in activities outside of the caregiving role. Participants tried to continue with the activities they enjoyed before becoming a caregiver, but over time they often found that their caregiving role impinged on their ability to continue with these activities.

Elizabeth had been an active member of an art group for many years. Although she didn't manage to attend as often as she used to, due to her caring responsibilities, she felt it was important for her own well-being that she could continue to do something she loved.

> *"I don't go down as much, I'll only go down to the club if I really, really want to be there for something, and I go down at the last minute, you know, just before the activity starts so I don't, I'm not there 'til seven thirty and I'll leave early and I make sure that he has got his phone on him, because the way I look at it is that I've got to look after me, if I don't look after me, I can't look after him and so I just said to him 'well that's' I know it's hard 'that's the deal' "* ***(Elizabeth)***

Some participants also continued to work or were members of other non-caregiver related groups. Grace, Rose, and Neil all continued to work. For Grace and Rose continuing to work part-time had involved a lot of planning to ensure their husbands were taken care. Both felt that this effort was worth it as they enjoyed their jobs and, their work roles seemed to help them cope by providing an important opportunity to communicate with other people.

> *"I'm desperately trying to cling onto that [part-time job] because it gets me out of the house. Talk to normal people if you like"* ***(Grace)***

While some felt that simply spending time away from the caring role, doing something they enjoyed, was beneficial to their own sense of well-being a few participants, in particularly Neil and Julie, also conveyed the importance they placed on retaining an identify outside of the caregiving role.

Neil worked on different work projects which regularly took him away from home, and he also participated in voluntary work. Neil took a while to admit to himself that he was a caregiver for his wife, but first and foremost he identified himself by his other roles *"When people say 'what do you do?'... I go 'I do this, this, and this, oh my wife's a stroke survivor so I'm also a carer'."*

Julie regularly attended several dance classes during the week. Julie also recognised how important doing something outside the caring role was for her.

> *"Well I do all sorts now actually! ... I've picked them back up again and said no! This is happening. Yes we don't know how long this will go on for but it is Wednesday morning and at 1 o'clock I go line dancing! That is it. I've had to discipline myself a little bit."* ***(Julie)***

Summary: Adjusting to the caregiver role

Participants described a range of emotions they felt when they first took on the caring role. Frustration was a common emotion experienced during the early stages of their spouse's illness, highlighting that this time represented a period of uncertainty and adaptation for caregivers. For some this was replaced with feelings of sadness, reflecting both sadness about what their spouse had to endure and a feeling of grief at the loss of their old relationship with their spouse. It was only those participants who had experienced a difficult relationship before their spouse became ill who directed feeling of resentment towards their spouse.

The time taken to accept the role of caregiver varied between participants and was related to the nature of their spouse's health condition and their experience of, and aptitude to, caring for others. For most there was a period of adjustment, as they adapted to accommodate their spouses deteriorating health, before they acknowledged themselves as caregivers. The experiences of one participant suggest that caregivers who have previously not thought of themselves as having a caring nature may be more reluctant to accept the caregiver role.

Participants described the different approaches they took to looking after their spouse. Most participants adopted an organised approach to caring for their spouse however the reason for this varied. For one participant the complex needs and fragile health of their spouse required them to be constantly vigilant, while for others maintaining outside interests meant that they needed to plan their time and source additional support to ensure their spouses care needs were met. Caregivers who described a less regimented approach to caring for their spouse were supporting all of their spouses care needs on their own. These participants seemed to focus on the here and now and seemed reluctant to delve into the future.

Engaging in activities outside of the caregiving role was important to participants overall sense of well-being. For some this was simply an appreciation that time doing something they enjoy outside of the caregiving role made them feel better, while for a few retaining an identity outside of caregiving seemed to help them to feel in control of their life.

6.4.3 Changes in spousal relationship

This theme focuses on the changes which participants described, with regards to their relationship with their partner.

Three sub themes emerged. The first focuses on the different changes participants experienced in their relationship with their spouses. The second theme focuses on the closeness between participants and their spouses. The final sub theme explores doing things together as a couple.

Sub theme: Changing relationship balance

All participants described a change in the balance of the relationship with their spouse. Most described an increased feeling of responsibility for their spouse and all spoke of taking over some of the roles their spouse used to fulfil within the relationship. Their descriptions suggested a fundamental shift in the balance of support they had previously experienced before their spouses became ill, with many of the roles now falling to them. Some participants also revealed that there had been a loss of intimacy in the relationship since their spouse became ill.

All participants described a feeling of increased responsibility towards their spouses and most recognised that their spouse needed them.

> *"It's made me feel stronger because I have this adult and I am responsible for him so I have to be the strong one. I have to make sure that all the bills are paid. I have to make sure, you know, that things are right"* **(Julie)**

Others felt that their spouse also recognised how dependent on them they had become.

> **"***I do think he worried that I would leave him. I don't know where he thought I'd go! I think it was because he was so dependent now upon me"* **(Alice)**

While Neil's description of the responsibility he felt suggests that he felt trapped or coerced into taking on the caregiving role as there was no one else his wife could turn to.

> *"As long as she's helpless it's kind of difficult for me … because sadly there is no-body else, she doesn't have children, her parents have died"* ***(Neil)***

All of the participants had experienced a marked deterioration in their spouses' abilities. Grace and Elizabeth equated these changes to the reverse of watching a child learn new skills and their descriptions provide a sense of the loss they feel, as though they felt that their husbands' were slowly disappearing.

> *"Sometimes it's like a mother and child because I see resemblances as my grandchildren are growing up and learning things he's growing down and forgetting things"* ***(Grace)***

> *"I've got to get him dressed in the morning and I've got to say to him like 'lift this leg up' 'lift this leg up' you know, he kind of doesn't automatically do it, so it's a bit like, you know how children develop, and they do something more each day, well it's like going in the opposite direction, it's quite sad really"* ***(Elizabeth)***

All participants described a change in the roles they played within the marriage, in terms of what they now did for their spouses, the household chores they had now taken over from their spouses, and the new skills they had developed so that they could take over these new roles. For some there was a sense of pride at the new skills they had developed and a sense that they were trying to find positives out of the situation.

> *"I've changed … certainly from a do it yourself point of view, <husband> has always done everything, you know, … now even if a light bulb needs changing, it's me and so I've, I've actually got quite skilled at DIY so that's been, some of these changes have been actually quite positive"* ***(Elizabeth)***

Although not included in the topic guide nearly half talked about their intimate relationship with their spouse and the changes they had experienced. All of the participants who were open about this aspect of their relationship confided that there was no longer any sexual activity between themselves and their spouses. For Neil it seemed the loss of sexual intimacy had started before his wife became ill. For Elizabeth and Grace however the loss of intimacy had occurred since their husbands became ill, and for both this was initiated by the participants themselves. The reasons for this however varied.

> *"The more intimate side of our relationship has dropped off, and I think that's more me than <husband>, cause I find it quite difficult to go from being a full time carer to have an intimate relationship, you know"* ***(Elizabeth)***

There is a feeling from this description that Elizabeth now struggled to view her husband in a sexual way as she saw her primary (full time) role as that of his caregiver. This did not mean, however, that there was no longer any affection between herself and her husband and Elizabeth described a relationship which was still warm and loving.

> *"He's got a hospital bed downstairs, so we don't sleep together anymore but … I'll bob in, in the morning, and you know have a cuddle"* ***(Elizabeth)***

For Grace the withdrawal from intimacy was due to a large extent to her reaction to the changes in her spouse's personality, which had been affected by his illness.

> *"It was his change in personality, it took a lot of getting used to. He didn't lose his sex drive … and you know he had no emotion in the end it was, it became a battle ground. … But he's settled down a bit you know and he's turning into an old man now, acting very placidly. But yes that … was an issue for me"* ***(Grace)***

Sub theme: Maintaining closeness

Although all of the participants had experienced fundamental changes in their spousal relationships the sense of closeness or togetherness that participants described with their spouses since taking on a caring role seemed to reflect the relationships they recollected having before their spouses took ill. That is not to say that the feeling of closeness or togetherness did not change, for many it did, but those that described a close, supportive relationship remained close, while participants who described a relationship which had some problems before remained problematic.

Rose, Alice, Elizabeth, and Heather all described close relationships with their spouses which have remained close. For Rose and Alice they felt that their relationships had grown stronger because they spent more time together.

> *"Well I think funnily enough it's changed for the better. This is the funny thing really. Cause he was never terribly sociable and I always was you see. ... But now we sort of have to do things together much more. And because I'm sort of involved in getting him to all these things it's become our life together. So that a real plus actually"* ***(Rose)***

Though as Alice's husband had experienced a slow deterioration in his health over many years Alice didn't think it was becoming his caregiver which had made them closer but rather when her husband retired they could spend more time together.

> *"We got closer from 2004 [when they both retired]… definitely I wouldn't say his illness made us closer ... it was just there, but it'd been there for so long"* ***(Alice)***

Elizabeth described a close relationship with her husband before he took ill. Since his illness he could no longer take charge and provide the support he used to, which upset him.

> *"He was amazingly good in a crisis situation, you know, ..., it was done, but although he's still very supportive, he can't, he just can't physically do it, and he feels so bad about that, you know"* ***(Elizabeth)***

She felt however, that he was still very supportive and that he would be the person she would talk to when she needed emotional support

> *"I'd probably just speak to <husband>, he's very understanding"* ***(Elizabeth)***

Heather also painted a picture of a close loving relationship where they shared many activities together.

> *"<Husband> retired February '93, I retired December '93 which was lovely, we had a lovely time. Went abroad, we always travelled"* ***(Heather)***

Although Heather primarily described her current relationship with her husband in terms of the care she provides, rather than closeness, this reflected that her husband needs almost constant care. Heather recounted the experience of the health care which her husband had received when he had been admitted to hospital leading up to, and during, her husband's illness; which had resulted in pressure sores, urine infections, and other complications. This meant Heather was very protective of her husband. Heather's words below, reflect this, however it is also clear that she feels very close to her husband and his needs are paramount.

> *"I've had to struggle really hard to get him to the state he is now. Because there's so many people coming along interfering, you know, he's my husband, I'm here 24-7 and I know what helps him."* ***(Heather)***

In contrast Grace, Julie, and Neil all described relationships which had problems before their spouses became ill. Julie and Neil's relationships were the most problematic.

Though still married, due to his aggressive behaviour Julie had been separated from her husband for many years before taking on the caregiver role. Julie described the difficulties she'd faced with her husband when they were together. She reported that the dementia had made him easier to cope with *"for me it's a little bit easier because I don't think he's quite as aggressive"* but she saw her current role purely in terms of feeling a great sense of responsibility for him.

> *"It's been a very, very, very difficult journey with him! He has been obnoxious! He has. Everything you could imagine. He has. And even after 40 some years I'm still there at his side! .... And if I did have any love for him 40 years ago, that love has gone to responsibility"* ***(Julie)***

Neil's wife had a stroke shortly after they had discussed ending their marriage. After his wife's stroke Neil's first objective was to get his wife well enough so that she could look after herself and he could decide if he wanted to walk away from the marriage, free in the knowledge that she would be ok.

> *“Part of my thinking was, well how long do I need to go on doing this for. I’ll do whatever it takes, spend whatever it takes, to help her get literally on her own two feet“* ***(Neil)***

Though Neil and his wife still live together he now leads a separate life *“basically I do whatever I want and she can’t stop me. I go out when I want, I see who I want, she can’t stop me. So I’ve got used to that level of freedom.”*

While Grace described a relationship with her husband where they shared interests and had happy times, she also reported that “*by the time I got him he was a bit of a selfish one”.* Her husband never got on with her sons, which caused difficulties for Grace, and she described their relationship before her husbands’ illness as *“feisty”.* Her husbands’ illness had had a serious negative impact on how he interacted with Grace and she reported that she no longer felt at all close to her husband, though she seemed to mourn the loss of the husband she once knew.

> *“You know it’s been a slow drip feed of losing the man I married. And I’ve got this emotionless lump who treats me like a maid now“* ***(Grace)***

Sub theme: Doing things together

This sub theme considers the changes experienced with regards to doing shared activities as a couple. While some described how they could no longer do some of the shared activities they used to enjoy doing together, they also talked about how they had actively sought other activities, and the overall feeling was that most participants placed great importance on continuing to share experiences with their spouses outside of the caring role.

Most participants made an effort to continue to go on outings with their spouses even though this sometimes required a great deal of planning and extra work. Elizabeth, Rose and Alice described the enjoyment they got out of sharing everyday activities, such as shopping or going out for something to eat, with their husbands. Grace and Julie both needed to take a more considered approach because of their husbands’ behaviour, and they needed to assess how well their husbands would cope with the situation. For Julie the main concern was how well her husband would cope cognitively with the change in environment.

> *“We go swimming. I will take him so that he can see me in the water and he’ll just sit there… he’ll just sit there. ... we’ve got back sometimes, he’ll say ‘where have we been?”* ***(Julie)***

Grace and Elizabeth both described previously being active members of walking groups with their husbands and they both spoke with regret that they could no longer attend the walking groups and go on long walks because of their husband's health condition.

> *"We've always loved our holidays and our walking. We've always shared those sorts of interests and got on well. But it's just all gone now"* ***(Grace)***

Grace also felt limited due to her husband's cognitive, incontinence, and mobility problems and she recognised that she needed to be flexible in her approach.

> *"They have the dementia cafe and that's the one that <husband>likes to go to. Again we've had incidents there because you've got to walk up two flights of steps and the exercise triggers his bowels and he refused and wouldn't let me help him so I had to turn him around and bring him straight back home again"* ***(Grace)***

Only Elizabeth described how she and her husband still go on holiday together to visit their son, who lives in Spain. Elizabeth described the extensive organisation involved in ensuring her husband had everything he needed for the trip

> *"It's a palaver when we go on holiday, I mean I need a holiday when we get back to be honest. <Husband> doesn't take his wheelchair abroad but he takes his mobility scooter and we have a case and now he has his breathing equipment, ... and he has a machine to help him cough, so he's got his cough assist ..., and his walker goes as well, so you can imagine can't you? "* ***(Elizabeth)***

Though organising this trip was clearly difficult for Elizabeth they do this approximately twice per year. It was clear that being able to continue to go on holiday together and visit their son was important to both of them, not only in terms of continuing to be able to do things they've always done together, but also possibly in showing that they were still very much united as a couple. This need to retain an identity as a couple was also demonstrated in the following quote from Grace.

> *"I found the stuff he'd brewed in the shed and brought it into the house and I've actually learnt how to filter and bottle it. And I've done all that and we've got some bottles of wine for Christmas now to give away. Which is nice because they're from him and me"* ***(Grace)***

Grace, Rose, and Julie all spoke of joining organised activities with their spouses since they became caregivers that were specifically designed to include people with health problems. In all cases these participants and their husbands seemed to gain a lot of enjoyment out of participating in these activities.

> *"We go to an exercise class together, you know an armchair exercise class which is quite good fun. And it's definitely good for him because it keeps him sort of moving, as far as he can"* ***(Rose)***

> *"We go to singing for the mind. ... I'd advise anyone to go. It's really good. ... we sing all the old songs and ... and we have a cup of tea"* **(Julie)**

Heather and Neil did not discuss sharing any outings with their spouses. For Heather planning an outing with her husband would be very problematic due to her own health limitations and the continuous care her husband requires throughout the day.

Neil attributed the lack of shared outings with his wife to her communication problems following her stroke, however it is clear that his lack of effort in trying to find other ways to communicate with his wife also reflects his general withdrawal from the relationship "*I never take her out on her own for the simple reason it is just so boring ... because what's the point in sitting there in silence".*

Summary: Changes in spousal relationship

Their spouses' ill health had resulted in participants not only taking on a caregiver role but also many of the other domestic tasks which had previously been the domain of their spouse. Though some expressed in positive terms the new skills they had acquired, the shift in the relationship balance meant that many expressed an awareness of their spouses' dependence, and they all reported an increased feeling of responsibility towards their spouse. Loss of intimacy was reported by some participants. While the reasons for this were very individual there was a suggestion that becoming a full-time caregiver for a spouse may impact on the ability to view the care receiver in a sexual way.

The closeness participants felt with their spouses before they became their caregiver were reflected in their experiences after: participants who were in close relationships remained close, while participants in difficult relationships remained difficult.

Most participants tried to continue to do shared activities with their spouse despite the practical difficulties such activities could cause. For some it was clear that doing things which defined them as a couple was important. Participants who were caring for spouses with cognitive or behavioural problems seemed to feel more comfortable attending organised activities with their spouse which were geared towards their spouses' condition. The experience from one participant suggests that caregivers may be reluctant to engage in shared activities if the relationship with their spouse has broken down.

6.4.4 Family support

This theme explores the support participants received from relatives and the changes in these relationships since their spouses became ill and includes two sub themes, someone to lean on and practical support.

Sub theme: Someone to lean on

The support participants received from family was mainly through having someone to talk to and feeling that they have someone they could turn to if they needed them. Participants commonly felt that this type of support had been there before their spouses became ill but there was a sense that they appreciated this more now and the support they received from family helped them to cope with the situation.

> *"He's [son] always been really understanding and really supportive. And I suppose I've leant on him quite a lot and he's someone I can talk to about it"* ***(Rose)***

Participants generally had most contact with family members, predominantly children, who lived nearby, and it was usually these family members who participants spent the most time talking about during the interview. Participants seemed more integrated into the lives of these close-by relatives and being there for one another appeared to be already well established before their spouses became ill.

For example, Grace described her younger son, who lived locally, as *"one of my rocks"* and spoke at length about the close relationship they had and how much she relied on him. In contrast her eldest son lived down south and had health issues. Though she reported that he was supportive and concerned about her, his health problems meant that he could not visit and she was reluctant to burden him with her problems. Grace's mother and brother also lived locally. She saw her mother at least once a week and was in regular contact with her brother. She spoke of a relationship with her brother which was mutually supportive.

> *"When he had his knees replaced he would have simply starved if I hadn't gone and seen to him because there was nobody; he had no bus stop, he couldn't drive, he had no shop within two miles of where he lives"* ***(Grace)***

She also helped look after her mother, who lives in a care home, and she described how her mother tried to be supportive and tried to understand the demands placed on Grace.

> *"And my mother actually supports me. She tries very hard, you know. She doesn't want to be a burden … bless her, you know, she's good to talk to"* ***(Grace)***

Neil also had two children, and his daughter lives locally. He described his relationship with his daughter as very close, and it seemed that at times she was his confidante.

> *"I meet my daughter outside the house mostly, not least of which because I spend a lot of time talking about my situation, you know" (***Neil***)*

Like Grace, Neil also described a mutually supportive relationship with his child.

> *"My relationship [with daughter] has always been close. If anything it's probably closer cause she's gone through quite a traumatic time as well. Marriages and stuff like that. So we are actually very close" (***Neil***)*

Elizabeth and Heather have no children living nearby. Both reported that despite the geographical distance between them and their children they were in regular contact with them and felt that they could turn to them if they needed them. Their recollections, however, did not have the same feeling of being embroiled in the lives of their children compared with participants with children nearby.

> *"If there was a problem we'd contact him straight away… I phone him cause I've got free phone calls to Spain and I'd just be on the blower straight away. But er…and we go over there and stay, and stay in the… same area as them, you know and we see them you know three or four times a week when we're over there"* ***(Elizabeth)***

Other family members who did not live nearby were mentioned by some participants, however commonly they also acknowledged that these relatives had their own lives and there was a sense that generally they provided little support.

> *"They're (brothers and sisters) not, sort of in touch all the time but, … of course everybody's busy and, you know, time does lapse"* ***(Rose)***
>
> *"She (sister) always says to me 'oh whenever you need me, you know just, I'll come straight down' and erm later on in the conversation she says 'well I'm just going out to see <sisters daughter> for six weeks in September and erm' then she's got her son in New Zealand and she's …[always busy]"* ***(Elizabeth)***
>
> *"The boys [grandsons] instead of being little and coming to see their grandma, they're in their twenties. So they've got all their lives in front of them, and although I still get texts I see them not as often of course. So you do feel you're in a bit of a backwater... They're bound to get other interests. I mean when I look back with my grandparent, who were like really old people, I didn't see as much of them once I started nursing. You know they're there, but you don't go around and see them as much. Regretfully, looking back I wish I had, I wish I'd done lots of things now that I didn't at the time. I didn't do. But it'd be nice to have a really close family, but now there's just <husband> and I"* ***(Heather)***

In addition, some family members were highlighted by participants as unsupportive. Julie's son lived locally but their relationship began to break down many years ago *"I think he wanted to re-write history and just write us out but that is the way it is!"*, and since then their relationship had steadily deteriorated *"I didn't particularly have support from my son but he's stepped even further away"*.

Grace described a relative on her husband's side who had been very negative about Grace having some respite time. This comment clearly upset Grace however she realised that it was important for her to have some time for herself.

> *"She thinks it's the work of the devil that I'm putting my husband into a care home for a week while I go for respite care. I should be looking after him myself and nobody else should look after your loved ones... I don't feel guilty about that; she's no idea what it like"* ***(Grace)***

Sub theme: Practical support

Although no participants reported family members helping with the direct care for their spouse, for example in terms of helping with washing, or looking after their spouse while they carried out activities outside the home, Alice, Grace, and Heather all described practical support provided by family members.

For Alice and Grace this practical support related to their daughter and brother, respectively, having experience of working in the caring professions. Alice and her husband moved to be near their eldest daughter, partly because of their daughter's experience working as a nurse. Although in the end they didn't need their daughter to help with the caring needs of her father, her practical experience meant that when her father became ill she remained calm and sorted out all the things necessary to make sure he got the help he needed.

> *"We came here because she [eldest daughter] was the only one, first of all she's got the practice in caring, so that's important. When we've had to call her because something's gone wrong, she's very practical about how she approaches it. So when <husband>'s machine went off and threw him across the kitchen here and hit his head, <eldest daughter> came over and she was very good. In all of his illnesses, in some ways I think each time, whatever's happened to him I've not been as practical as I could have been, I've let emotions...she's much better at being practical"* ***(Alice)***

Grace found that her brother's experience working in sheltered housing and working with dementia patients meant that he was a good source of knowledge in terms of access to services, such as incontinence support, and dealing with people with dementia.

> *"He has some knowledge which is of benefit to me and he's got great experience of dealing with people with dementia because he's worked in sheltered housing"* ***(Grace)***

The practical support Heather's daughter provided was in using her knowledge of the law which helped to ensure her parents received the financial support they were entitled so Heather's husband could receive the care support he needed.

> *“Because <youngest daughter> is a lawyer, she studied law, she looked in to it and said ‘Mum, I’m sure you’re entitled to continuing care’, so after a few months she looked in to it and we saw the joint care manager, and she went before this committee, and it was granted. No problems at all”* ***(Heather)***

Grace was the only participant who reported feeling closer to a family member as a result of caring for her husband. This may reflect the changing dynamics of the relationship Grace has with her brother as Grace acknowledged that she is the person that others generally turn to and now she is in a position where she needs her brother’s support.

> *”He’s always on the end of the phone and he makes me laugh … I have more contact with him than I used to. Cause he can help. He knows that … Yes we’re closer now. Definitely” (**Grace**)*

Summary: Family support

Participants had most contact with, and felt closest to, their children. Some of the participants mentioned siblings and other relatives, especially grandchildren who were also important to them. Not unexpectedly, family who lived nearby provided the most contact.

Participants primarily spoke of support from relatives in terms of having someone there for them and having someone to talk to. There was a sense that this type of support was greatly appreciated by participants and it made them feel they were not on their own; that there was someone there if they needed them, which helped them to cope with the situation. Some participants also received practical support from relatives. This was most often provided by family members living nearby and tapped into the practical stills or experiences of the relative.

In general participants felt that the closeness they felt towards their relatives had not changed since they started looking after their spouses, suggesting that the nature of these relationships were based on long established roles.

6.4.5 Friendship selectivity

Most participants experienced considerable changes in their relationships with friends. Most sub themes reflect the different types of changes which participants experienced after they started caring for their spouse. An additional sub theme reflects that some participants were without any friendships.

Sub theme: New friends who understand

Heather, Rose, and Neil all spoke of people they now considered to be friends who were not in their life before their spouse’s became ill. In all cases these new friendships were with people who the participants felt had an insight into what they were going through. They trusted these people and there was a sense that they felt that they didn't need to explain themselves, they would understand. New friendships were with people with similar experiences or health professionals who had been involved in the care of the participants' spouses from the beginning, and so had been on the journey with the participant.

Due to the combination of Heather's poor health, the round the clock care her husband required, and paid carers coming in four times per week, it is little surprise that Heather considered some of the paid carers who looked after her husband to be the people she was closest to.

> *"I mean that's the trouble really, all my friends now, they're either carers or they're sitters. I'm closer to them probably, apart from my daughters, than anybody" (**Heather**)*

Some of the paid carers have been looking after her husband from the start. It took a while for Heather to trust them, because of the bad experiences her husband had gone through in hospital, however Heather realised that *"if they're going to be coming in four times a day, I'm going to have to get to know them".* Over time the long-term paid carers had gained Heather's trust and she considered them to be friends, and it was clear that Heather was also important to the paid carers.

> *"My birthday they collected, ... they came up and said 'This is from us', and it was an envelope. And when I opened it, they'd each given twenty quid. And they don't earn a lot" (**Heather)***

Rose also identified a health professional, her community matron, as one of the most important people in her life. The community matron entered Rose and her husband's life when her husband was first diagnosed and Rose explained that because the community matron knows what's going on and was there to help and advise, she considered her a friend and she would be one of the first people she would contact if she needed support.

> *"We look forward to her coming and you know if things are difficult we sort of think 'oh it'll be alright when <community matron> gets here', you know. It's somebody to talk to, somebody who really understands" (**Rose**)*

Neil has met new people through the stroke support group he joined after his wife's stroke. Neil felt he received a lot of support from this group and had made friends who he met up with after the meetings or for occasional meals out. Neil has found the group provided an opportunity to share thoughts, feelings and practical things such as accessing services.

> *"We help each other enormously, cause someone will say 'Do you know you can get this?', or 'Do you know you can do that?'. And I'm still discovering new*

> *things. And when newer people are coming and I'm finding, because I'm in there so long now, I can tell people a lot about, you know what you do to get a blue badge, and do you know you can get into the cinema free, and you know lots of that kind of stuff. You can get this kind of help for nothing." (**Neil**)*

Like Rose, he also felt that he could confide in the other members and discuss aspects of his life he wouldn't want to discuss with others, because he felt these people had a better understanding as *"they've all experienced what you've experienced"* whereas his old friends *"would empathise to a degree, but they don't actually know in the way that these people do."*

In all cases these new friendships played a central role in the participants' lives and seemed to be fundamental to how well the participants were able to manage in their current situation.

Sub theme: Friendships based on mutual support

The friendships that participants described as particularly close were often with long-term friends who were currently also going through problems and needed support, or who the participant had supported in the past and this support was now being reciprocated. These friendships were deeper than others because they were based on mutual support, trust, and shared confidences.

Grace was particularly close to one friend, at least in part because meeting up gave them both the opportunity to have time away from their husbands.

> *"She was part of a couple and she is very much, she has a similar relationship in that her husband has got his marbles but she doesn't get on with him very well. … They live in the same house so she's more or less on her own" (**Grace**)*

Rose described how she arranged respite care for her husband so she could visit a friend who had been diagnosed with cancer.

> *"I speak to her quite regularly but I don't see her as much because she's got cancer. She's developed that since <husband's> been ill. So that was why I had my first respite care week because I wanted to go and see her. She lives down south you see. So you know, there's other factors, aren't there in other people's lives as well" (**Rose**)*

Like Rose most participants recognised that support from friends was a two way thing and they were not the only ones who were experiencing problems.

> *"To be honest we support each other, I mean I'm not the only one that needs support, you know, I mean <friend's> husband died of prostate cancer within the last couple of years and so she was the one that needed support. So we used to go up together and see her. So it's, it's, I try not to make it a one way valve you know, it's erm, it's, it's certainly still a two way thing" (**Elizabeth**)*

It seemed that participants were more willing to take the time to see friends who they knew needed their support, and they tried not to burden others with their problems.

> *"In a sense I'm conscious that I whittle on about my husband and my problems and I try hard not to do that because I'm an optimistic person and everybody's got their own problems, so I try, you know, not to be stuck in a rut. But they are aware of my needs to get out and do stuff, you know. And will come and see me during the day and [they'll say] 'right when is he going to the day centre, let's have our girly lunch'. Things like that, you know. So I do rely on my friends" (**Grace**)*

Sub theme: Friends who make an effort

Participants recognised that their time was more limited now that they were caring for their spouse. Friendships were more likely to be maintained with existing friends who had taken the lead in maintaining the friendship, and it seemed that this extra effort was recognised and appreciated.

> *"Unfortunately I'm not able to take the lead and ring them and call them. I haven't time to be ringing, calling and popping around to see them, I have to let them make all the moves. And some of them have done, some haven't. You know, some have just faded in to the distance" (**Heather**)*

> *"<Friend>, the one who lives locally took me out, she wanted to take me out on the Friday before Christmas and I thought I might be in Cornwall. So last Friday she took me for a spa day in the Crowne Plaza, cause that was my Christmas treat. Because she thought that would be good for me. And it was, you know. And it was lovely of her to do that so, and that was a practical way of doing it" (**Grace**)*

For some these friends were not close before but had become closer because they had been so supportive, while in contrast some previously close friends had become less important in the participants lives because they had not provided the support that participants expected.

> *"Some people I would have expected to get a lot of support from haven't really been there. Other people, who may have been marginal, em I can certainly think of two people, two guys, who I was quite friendly with but they're now my best friends, and they've just gone out of their way to look after me" (**Neil**)*

Sub theme: Loss of couple friendships

Most participants described a decline in the friendships they had previously shared with their spouse. Often these friendships were with other couples

> *"There are a couple of couples that we used to see quite a bit of. One we used to go walking with occasionally. They've just kind of disappeared." (**Neil**)*

Others were friendships which had occurred during shared activities with their spouse. For example, Elizabeth and her husband were members of a walking group before he became ill but when they could no longer participate they lost contact with many from the group

> *“we weren’t going walking cause he couldn’t do it, you know. I mean that stopped quite early on and we still do have very occasional contact with the group but erm I think my, our relationship with many people in that group has definitely changed and it was a big group” (**Elizabeth**)*

Overall participants felt that these friendships had disappeared because of the consequences of their spouse’s health problems. For Elizabeth it was because her husband was no longer mobile so could no longer participate in the walking group. Grace and Neil however both felt that this loss could be attributed to their own reluctance to meet with mutual friends because they felt there were aspects of their spouse’s condition which were socially unacceptable, though it was unclear however whether withdrawing from friends was to protect themselves, their spouse, or their friends.

> *“They are definitely couples and if I go on my own it’s not right and if I take him it’s not right so you know I think I’m backing off it rather than them. And if you take somebody somewhere and they poo their pants (it’s embarrassing)” (**Grace**)*

Grace’s description below of her reasoning behind withdrawing from some friends sheds some light on this and suggests that it was not only to spare their old friends the difficulty of trying to engage with her husband but also to spare her husband the ordeal of spending time with people who he would recognise as friends but who are now unable to engage with him.

> *“we have a couple of friends who are couples, you know, three (couples) particularly, and they occasionally come but there’s nobody there who does anything with him … his wife said he wouldn’t be able to cope with him now. It’s a blokey thing, isn’t it? For men, that they talk about cars and women and whatever and, you know, when somebody’s changed that much they can’t talk about what they used to do. They can’t deal with it, or his friends can’t” (**Grace**)*

Sub theme: Isolated caregivers

Two participants expressed feelings of isolation as a consequence of having no-one they would consider to be a friend. This did not appear to be a result of taking on the caregiver role however, but seemed to be a situation they had lived with for many years.

Alice and her husband had moved to another city to be nearer one of their daughters. They had moved into sheltered housing which included evening activities laid on for residents but they had generally kept themselves to themselves. Since her husband died Alice sometimes participated in the activities on offer but she felt there was no-one with whom she had a connection with.

> *"I get on with a lot of them as I'm on the committee here. I find them very boring. Isn't that a terrible thing to say? I've nothing to talk to them about… I feel isolated. We came here so that I wouldn't be, but I didn't realise how different I would be from the people who lived here" (**Alice**)*

Alice and her husband had moved around a lot during their marriage and it seemed that they were very different to the other residents; however it is interesting to note that they had not kept in touch with any old friends. Alice recollected a period of time early in their marriage which had resulted in a close friend scamming them out of all their money.

> *"I'm so unforgiving and because of that I'm not interested in any close relationships with people. And now I'm suffering for it" **(Alice)***

This was clearly still a very painful memory for Alice and it is likely that this experience contributed to the couple subsequently keeping people at arm's length through the remainder of their marriage.

Julie had also been badly let down by a friend in the past and felt that while she had some acquaintances she had no friends she felt close to.

> *"I'm a joiner! There's not getting away from it… If a door opens I'm at the back of it. (But) at the end of the day as you go home, face your problems, they go home you know and live the rest of their life. And they are people that you meet through life, not friends, just people you meet as you're coming through life" (**Julie**)*

There was a sense from Julie that she struggled to let people get close to her however it was difficult to unpick whether this in some way reflected aspects of the abusive marriage she endured for many years or if it reflected an aspect of her personality.

Summary: Friendship selectivity

Participants appeared more selective, due to the time demands and restrictions placed on them through their caregiver role, preferring friends who made time for them and who seemed to understand what they were going through. Support from friends was universally in terms of having someone outside of the caregiving role who they felt comfortable with and who they could talk to. Friends who were considered close were generally those whom the participants saw or spoke to most frequently, whom they could confide in, and whom they felt understood their situation.

Friendships that the participants and their spouses had with others couples tended to disappear but new friendships with people who they felt understood their current situation blossomed.

A few participants reported having no close friends, however this was not a consequence of their caregiving role but a situation they had lived with for many years.

6.5 Chapter discussion

6.5.1 Main findings

The increased day to day responsibilities participants coped with when they moved into providing a caring role for their spouse had an adverse effect on their health, particularly in terms of feelings of stress. Participants were generally more aware of the need to look after themselves however, and most had actively put in place routines to support their health.

The adverse health effect appeared to be linked not only to the increased demands of caring but also because participants had taken on some of the roles their spouses used to fulfil. All participants described a change in the balance of responsibility between themselves and their spouses, with participants taking on the lion’s share of the day to day tasks. For many, the nature of the relationship had changed and the intimacy they used to share had gone. Despite this the closeness participants shared with their spouse’s before they became ill, in the main, remained. Difficult relationships also remained difficult however and these participants tended to feel more resentful about their change in circumstance than participants in close relationships.

Support from family and friends helped the participants to cope with the caregiving role. The closeness participants felt towards family members generally remained the same. Children and other family members who lived nearby usually provided the most support. Though some relatives did provide practical support, support was commonly in terms of having someone to talk to and knowing there was someone there if they needed them. In contrast, friendships changed considerably. Friendships which participants and their spouse’s had with other couples tended to disappear, while friendships which remained or blossomed were with friends who made an effort to keep in touch or who had an understanding of what the participants were going through.

Having an identity outside of the caring role seemed to be important to participants’ overall sense of wellbeing. For participants who did not see their primary role as caring this was fundamental, while for others it was a chance to take themselves out of the caring role.

Finally the sample included participants who were in poor health and had little support from family or friends. These participants, and their spouses, appeared vulnerable as they did not appear to have a safety net should their health deteriorate to the extent that they could not look after their spouses.

6.5.2 Evidence from existing qualitative studies

An appraisal of the findings from this thesis in relation to theories around social networks and lifespan models will be presented in chapter nine following the integration of the qualitative and quantitative studies. This section will explore the outcomes from the qualitative study in relation to what is already known from other qualitative studies which have explored the experiences of partner caregivers.

Health transitions

Health transitions do not appear to be commonly explored within qualitative studies but instead more general terms, such as coping are more often used. Common findings in qualitative studies, such as (Coombs, 2007) who interviewed caregivers looking after stroke survivors, are symptoms of stress, fatigue, and sleep problems amongst caregivers, which correspond to the findings presented here. Feelings of depression were also reported by some caregivers looking after spouses with psychiatric disorders, which also accords with existing evidence (Murray and Livingston, 1998).

Adjusting to the caregiver role

Guilt has previously been identified as an emotion experienced by caregivers as older adults adjust to the caregiver role (Coombs, 2007), though in Coombs' study this was based around feeling guilty that they remained in good health and guilt when they left their spouses alone; rather than guilt at the way they had treated their partners when the extent of the health limitations of the care recipient was not fully appreciated, as identified in this study.

Feelings of loss have also been reported in several qualitative studies (Coombs, 2007, Davis et al., 2011). A qualitative systematic review exploring the impact of dementia on marriage (Evans and Lee, 2014) found that caregivers not only felt that they were losing their partner but some caregivers also questioned whether they could still consider themselves to have a marriage.

Having an identify outside of the caregiver role was identified as a main theme in a recent meta-synthesis of qualitative studies that explored the experiences of partners caring for stroke survivors (Quinn et al., 2014). Eleven of the twelve studies included in the meta-synthesis identified the importance of have an identity outside of the caregiver role; for some this seemed to be purely in terms of having a distraction which would help them relax, while others perceived it to provide caregivers with a sense of normality.

Changes in spousal relationships

Most previous qualitative studies exploring the experiences of partner caregivers have focused on the changes in the relationship between the couple.

As with this study, previous qualitative studies have also identified that moving into a caregiver role results in a change in roles and responsibilities within the relationship, with caregivers taking on many of the domestic and financial duties as well as taking over the decision making (Murray and Livingston, 1998, Coombs, 2007, Ussher et al., 2011, Quinn et al., 2014, Evans and Lee, 2014). A feeling of responsibility was also apparent in some studies (Coombs, 2007, Quinn et al., 2014).

Shim et al. (2012) analysed interviews with caregivers looking after a spouse with dementia and found that the nature of the relationship before the spouse required care directly influenced how the caregivers perceived the relationship after, which reflects the sub theme of ‘Maintaining closeness’ within this study.

In terms of doing things as a couple Murray and Livingston (1998) and Evans and Lee (2014) both found that outings and holidays were restricted for couples who were dealing with psychiatric illness, which corresponds to the findings in the present study from participants who were looking after spouses with dementia. These studies also found that the caregivers still enjoyed doing things as a couple.

Additional evidence on a loss of intimacy between couples was identified by Bunn et al. (2012) who interviewed caregivers of people with cancer. Bunn et al. (2012) found that for some participants taking on the caregiver role resulted in them becoming detached from the intimate side of their relationship as they now viewed their partner as someone they needed to look after.

Family support

There was also limited evidence about the role of support from family.

Previous studies exploring partner caregivers looking after stroke survivors have identified family support as important (Quinn et al., 2014). The study by Coombs (2007) found, consistent with this doctoral study, that though family did not necessarily take an active role in caring for the ill partner, the psychological support from family, in terms of knowing there was support there if they needed it, was very important to caregivers.

Friendship selectivity

Evidence for the role of friends, from previous qualitative studies, was limited.

The meta-synthesis by Quinn et al. (2014) found that some studies within the synthesis identified that social support from family and friends were important. One additional study (Cecil et al., 2011) identified long-term friendships and support groups as particularly important which corresponds to the sub themes of ‘New friends who understand’ and ‘Friendships based on mutual support’ within this study.

6.5.3 What this study adds

This study enriches the existing evidence from qualitative studies on how caregivers feel the caregiver role has affected their health and provides a greater insight into the nature of support caregivers may receive from other family members

The absence of qualitative studies which have focused on how friendships change after becoming a partner caregiver suggests that this study is the first study to explore this important area in such depth.

6.5.4 Interpretations from the quantitative study

The initial themes which emerged from the qualitative interviews were reassessed in light of the findings from the quantitative results (chapters seven and eight). Consensus was evident between the themes and findings, however one important re-interpretation of the qualitative findings resulted, through interpretations of the quantitative study.

Initially the ‘Changes in spousal relationship’ theme included only two sub themes: ‘Maintaining closeness’, and ‘Doing things together’. Aspects around the message from participants that they were fulfilling not only the caregiver role but had also taken on additional duties which had previously been fulfilled by their partner was not included as a theme, but had only been included as a description of the roles each participant played. The reason the researcher included these only as descriptors were because she had interpreted these as part of the caregiver role and not an effect of the role. It was clear from the quantitative results, however that the perceived quality of partner relationships were adversely affected after taking on a caregiver role. As this measure of relationship quality is based on perceptions of both closeness and support the researcher could see that an important aspect of the changes in the spousal relationship had not been picked up sufficiently well during the initial analysis of the qualitative data. It was clear that the qualitative themes needed to be re-examined to better capture the changes which had occurred in the roles each partner played in the relationship.

Reassessing the data resulted in an additional sub theme emerging which captures the changes in the balance of the roles both partners play in the relationship. The findings presented in this study include this additional theme resulting from this reassessment.

6.5.5 Implications for the quantitative study

This study formed part of a mixed methods project and one of the outcomes from the qualitative interviews was to inform the design and analysis of the quantitative study which follows. Findings from this study influenced the methods adopted in the quantitative in the following ways.

This study suggested that the main health effects for participants caring for their spouses were psychological in nature rather than physical. The original intention was that the quantitative study would include one general self-rated measure of health. ELSA does include many different measures of health, however, including measures of psychological health and quality of life. As a result of this qualitative study two additional health measures, a measure of psychological health and a measure of quality of life, were added to the quantitative study.

The original intention within the quantitative study was to create one latent variable for each relationship type. The qualitative interviews suggested however that the relationship between changes in the amount of contact and changes in quality of relationships were not necessarily clear cut and was worthy of more exploration. Thus it was decided to create two latent variables each for children, family and friends, representing the overall quality and level of contact in these relationships.

In addition economic activity was originally going to be the only measure of activity outside the home within the quantitative analysis however because having an identity outside the home seemed to be important to participants an additional variable, that of membership of an organisation, was also included.

6.5.6 Reflections on approaches used

Paying participants

As reported in the methods section all participants were given £10 as a thank you for taking part. The reason for including a small monitory incentive was to show that the researcher valued their time, which would hopefully encourage caregivers to think positively about the study and encourage them to take part.

Head (2009) summarised the main concerns with providing monitory incentives within research, that of the potential for coercion and corruption. In terms of coercion the contention is that free and informed consent cannot be said to be given if there is a possibility that the level of monetary gain is such that participants feel compelled to take part. The concern about corruption is related to the possibility that paying participants for information turns research into a monetary exchange. So in some way the information participants provide is biased as participants may feel compelled to provide information they think researchers want to hear.

In this study the monetary incentive was set low to avoid the problem of coercion and it was made clear within the information sheet that the money was a gift to show an appreciation of their time. In actual fact none of the participants seemed keen to receive their £10 gift and several reported that they would donate the money to charity. Their responses supported the belief that they had not been coerced into taking part because of the monetary gain, and the information they provided, in terms of their experiences, had not been altered because they felt they were being paid for a service.

Although the participants responses to receiving the £10 may infer that on reflection there was no need to offer a gift within this study, it may still have been the case that the £10 gift showed the participants that the researcher was aware that their free time was limited and valuable and it may have encouraged them to think positively about the research. Thus the value of providing a small gift in this study is unclear as the motivations for agreeing to take part in the study were not discussed with participants.

Location of interview

Given the other demands placed on participants and the limitations on their free time the needs of the participants had to be foremost when determining the best place to conduct the interviews. Elwood and Martin (2000) suggests that providing participant’s with a choice of interview location is beneficial in readjusting the possible power imbalance between participants and researcher, which hopefully encourages a nonthreatening setting where participants feel able to freely share their experiences.

Most participants chose to be interviewed within their own home as this was most convenient to them, while one participant chose to come to the university to be interviewed. Although the researcher could control the setting for the interview conducted within the university, ensuring a quiet setting where confidentiality could be safeguarded, the researcher had little control over the home setting.

In terms of interviews which took place within participant’s homes: on two occasions the participant’s spouse was in the room while the interviews were conducted, on another occasion a workman was working within the participant’s home while they were being interviewed and the interview had to be stopped twice while the workman discussed jobs with the participant. In several interviews phone calls or callers interrupted the interviews. In the cases of most of the home interviews, however, these interviews would not have been able to take place under other circumstances.

The researcher felt that all of the participants seemed to be comfortable and able to talk freely within the interviews, irrespective of where these interviews were based or what interruptions took place. One noticeable difference, however, was in the interviews with participants while their spouses were in the room. In contrast to many of the other participants, who had been interviewed on their own, these participants did not discuss any aspect of the intimate relationship they had with their spouse. This suggests, as other studies have found (Taylor and de Vocht, 2011, Allan, 1980), that participants are able to talk more freely when they are interviewed on their own.

The areas covered within the topic guide (Appendices B.7.) were broad, asking participants to describe their relationship, any positive or negative aspects of the relationship and their feelings about the relationship, so spousal intimacy was not a specific area to be covered within the interviews and it was up to the participants whether they wanted to discuss it or not. As this area was not picked up as a specific area it is unclear whether this was not mentioned by these participants because they would have felt uncomfortable talking about such matters in front of their spouses, did not want to talk about this generally, or if it was just overlooked.

Relationship diagram

Relationship diagrams are a common method used within qualitative research to illicit information about the relative importance of different relationships surrounding participants (Bagnoli, 2009). They are useful tools to generate information which may otherwise have been difficult to elicit verbally. The method by Antonucci (1986) was chosen as it represented a simple concept which, it was felt, most participants would understand and be willing to complete. Though the study was interested in changes in relationships, it was felt that asking participants to visually represent their current relationships, and their relative importance, would provide a good starting point to discuss how each of these relationships had changed since taking on a caregiver role. Timelines could have been used instead, however it was felt this method would be more time consuming and complex for the participants and would not have provided an understanding of the relative importance of different relationships to the participant. Bagnoli (2009) also noted that for some people completing a timeline is more problematic as they do not view their life in linear terms.

Using the relationship diagram within the interview was very variable. For some participants, principally those with many friends and family members, the diagram did provide some assistance during the interviews to keep track of different relationships. For other participants however the benefits of using the relationship diagram seemed limited and for many of these participants producing a simple list before the interview would have sufficed.

6.5.7 Limitations

Participant recruitment

The recruitment of participants was opportunistic, based on utilising a caregiver's support organisation to publicise the study. While this method was fruitful, it did mean that all of the participants were at least aware of a support organisation they could use. Caregivers who were unaware of the services such organisations provide and who may have been harder to reach were excluded from this study. It is likely that only caregivers who were in a position to volunteer for the study and who had an interest in participating were included.

The characteristics of those recruited to the study did cover a range of ages, had a range of health issues, and had a wide range of caring roles, but shared many common experiences in terms of transitions in their personal relationships and health and adjusting to the caregiver role.

Excluding non-English speaking participants

An additional constraint imposed on participant eligibility was in limiting participants to only those who could speak English. Excluding non-English speaking participants was unavoidable given that including such participants would have meant using an interpreter, which would have imposed additional costs and would have generated additional threats to validity in terms of translations between researcher to interpreter (Kapborg and Berterö, 2002). It needs to be acknowledged, however that older adults living in England who are caring for their spouse or partner and who do not speak English are likely to have different experiences to the participants included within this study.

Exploring transitions over time

A limitation of any study which requires participants to reflect on their experiences is the potential for recall bias (Raphael, 1987). To try and help participants to recall changes in their personal relationships, relationship diagrams were included in the interview. Though some participants, in particular those with many family and friends, found these helpful, others could see no use for them and the diagrams were not used during the interview. It is possible that though some participants found the diagrams useful, their use was primarily in helping to keep track, to ensure all family and friends were discussed, rather than in reflecting the changes in these personal relationships. It was also clear that recalling changes which had occurred after taking on the partner caregiver role was particularly problematic for one participant. Her husband had died several months before the time of the interview and she had cared for her husband for many years, as his health slowly declined. The grief she was experiencing through the loss of her husband was clear and it is very likely that her recollections were affected by the loss of her husband.

6.5.8 Study quality

Issues around how to assess the quality of qualitative studies has been much debated (Murphy et al., 1998). Three methods were adopted in this study to try to provide transparency and rigour to the research process. Framework analysis (Ritchie and Lewis, 2010) was used in the analysis of the data. This method uses a systematic approach to analysing the data which provides clarity, as each step of the analytical process is defined, and progress between each step can be tracked. The methods section within chapter five describes each of the steps and includes examples to aid in clarifying how the themes emerged. Reflexivity was used throughout to help provide an insight into how the participants, researcher, and interview settings may have influenced the interviews. Finally, to ensure all important aspects of the study had been described in enough detail, the COREQ checklist was used (Tong et al., 2007) to check for omissions in reporting.

6.6 Chapter conclusion

Older adults who moved into caring for their spouse or partner commonly experienced adverse health effects, particularly in terms of feelings of stress, due primarily to the increased demands placed on their time. Despite the increased work and responsibility associated with caring for a spouse or partner, having another role outside of the caring role seemed to help with their overall feelings of wellbeing.

Commonly it appeared that while the strength of relationships these caregivers had with their partner and other family members remained fairly stable, friendships seemed to experience considerable change. Friendships which flourished seemed to be with people who had an understanding of what the caregiver was going through, or with existing friends who made an extra effort to keep in touch.

Chapter 7 Quantitative methods

7.1 Introduction

The quantitative study used data from ELSA to explore how health and personal relationships change when older adults start caring for their partner. Results from the qualitative study identified that psychological health and well-being were particularly important when looking at the health transitions experienced when taking on a partner caregiver role. This insight resulted in the quantitative study exploring, not only self-rated health, but also changes in psychological health and quality of life. Analyses were based on associations within the ELSA data within one time point, across two consecutive waves, and within three consecutive ELSA waves.

This chapter will present a detailed description of the aims of the quantitative study, the ELSA datasets which were used in the study, and the methods used to explore this data.

7.2 Aims

The aim of the quantitative study was to explore health and personal relationships for older adults taking on a caring role for their partner, focusing on transitions over time to identify if any directional associations can be inferred from the results.

This aim was addressed by the following objectives:

Health

- Compare health outcomes between older adults who (1) reported caring or not caring for their partner at one time point, (2) transition into the partner caregiver role or remain non caregivers over two consecutive waves, and (3) become longer term caregivers or transition into and out of the caregiver over three consecutive waves.
- Explore connections between health outcomes and other demographic factors for older adults who (1) report caring for their partner at one time point, and who (2) move into a caring role over two consecutive waves.

Personal relationships

- Compare personal relationship outcomes between older adults who (1) reported caring or not caring for their partner at one time point, (2) transition into the partner caregiver role or remain non caregivers over two consecutive waves, and (3) become longer term caregivers or transition into and out of the caregiver over three consecutive waves.
- Explore connections between personal relationship outcomes and other demographic factors for older adults who (1) report caring for their partner at one time point, and who (2) move into a caring role over two consecutive waves.

Health and personal relationship connections

- Explore connections between personal relationship and health outcomes for older adults who (1) report caring for their partner at one time point, (2) move into a caring role over two consecutive waves, and (3) become longer term caregivers for their partner.

Connections between different personal relationship types

- Explore connections between different personal relationship types for older adults who (1) report caring for their partner at one time point, (2) move into a caring role over two consecutive waves, and (3) become longer term caregivers for their partner.

7.3 ELSA overview

Data from ELSA (2012), waves 1 through to 5, were used. The rationale for choosing ELSA is described in section 4.5.2. Further details of the ELSA study are described below.

7.3.1 ELSA Funding

ELSA is funded by the US National Institute of Aging and a number of British Government departments including the Department for Transport, Department for Work and Pensions, and the Department of Health. It resulted from collaborations between University College London, the Institute of Fiscal Studies (IFS), and NatCen Social Research.

7.3.2 Data collection

ELSA data is collected approximately every two years. As at the beginning of October 2014 ELSA included five waves. ELSA wave 6 was made available in October 2014 however this was too late to be included in this study. Wave 1 interviews took place in 2002-03, wave 2 in 2004-05, wave 3 in 2006-07, wave 4 in 2008-09, and wave 5 in 2010-2011. ELSA data is primarily obtained through interviews. All first ELSA interviews (wave 1 and new refreshment cohorts in waves 3 and 4) were conducted in person with the respondent however subsequent interviews could be conducted by a proxy if the respondent was physically or cognitively impaired, or if they were in care at the time of the interview. Proxy responders could be any adult who could provide information about the respondent in their absence.

Each wave also includes a self-completion questionnaire which is given to responders who complete the full interview in person. The self-completion questionnaire is usually left at the end of the interview and returned by post. The self-completion questionnaire was an important source of information for this study as details of participants’ perceptions of their personal relationships were collected within the self-completion questionnaire.

The information collected within the ELSA interview and self-completion questionnaire predominantly remains the same for each wave, though some minor amendments or additions were made between waves. The study data dictionary, in Appendix C.2, details any changes which were undertaken in this study to ensure consistency within each variable across waves. Any other changes to the variables provided by ELSA before they were included within this study are described in section 7.4.

7.3.3 Participants

ELSA contains a nationally representative sample of non-institutionalised adults aged 50 years or over. The original ELSA cohort members were taken from responders to the Health Survey for England (HSE) in the years 1998, 1999, or 2001 who were born up to 29 February 1952 and who agreed to be contacted again in the future. Refreshment cohort samples were included for waves 3 and 4. The refreshment sample for wave 3 included a cohort of people born between1 March 1952 and 29 February 1956, selected from HSE 2001 to 2004 to provide a representative sample of people aged 50 to 53 years. The refreshment cohort sample for wave 4 were born between 1 March 1933 and 28 February 1958 and were selected from HSE 2006 to provide a refreshed sample of people aged between 50 to 74 years.

As well as these core responders, identified through HSE, any partners who reside with core responders at the time of ELSA interviews were also included, irrespective of age. In addition while wave 1 included only responders who resided in private households, individuals who moved into institutions after wave 1 were retained for future waves.

The ELSA datasets, wave 1 through to wave 5, contains 52,626 responses from 16,765 ELSA responders. Table 7-1 shows that overall 91.1 per cent of ELSA participants were core responders, selected through the HSE. The percentage of non-core responders increased through each wave, possibly reflecting new partners.

Table 7-1 : Number and percentage of ELSA participant responses by core responder status and wave

		Wave					Total
ELSA core responder		**1**	**2**	**3**	**4**	**5**	**responses**
Yes	Numbers	11,391	8,780	8,810	9,886	9,090	47,957
	Percent	94.1%	93.1%	90.2%	89.5%	88.5%	91.1%
No	Numbers	708	652	961	1,164	1,184	4,669
	Percent	5.9%	6.9%	9.8%	10.5%	11.5%	8.9%

It can be seen from Table 7-2 that 33.6 per cent of ELSA responders responded to all five ELSA waves, 8.2 per cent responded to four waves, 15.1 per cent responded to three waves, 24.7 per cent responded to 2 waves, and finally 18.3 per cent responded to only one wave.

Table 7-2 : Number and percentage of waves ELSA participant's responded to, by the wave upon entry into ELSA

		Wave participant joined ELSA					Total
No. waves responded		**1**	**2**	**3**	**4**	**5**	**responders**
Responded to one wave only	Numbers	2110	26	320	478	142	3076
	Percent	17.4	24.1	18.5	17.8	100	18.3
Responded to two waves	Numbers	1623	18	303	2210		4154
	Percent	13.4	16.7	17.5	82.2		24.8
Responded to three waves	Numbers	1405	21	1105			2531
	Percent	11.6	19.4	63.9			15.1
Responded to four waves	Numbers	1328	43				1371
	Percent	11.0	39.8				8.2
Responded to five waves	Numbers	5633					5633
	Percent	46.6					33.6
Total	Numbers	12099	108	1728	2688	142	16765
	Percent	100.0	100.0	100.0	100.0	100.0	100.0

7.3.4 Response rates

ELSA provides a separate index file which details the response outcome, by individual and household, for all eligible individuals within households.

The percentage of eligible persons selected for inclusion within ELSA, including core members or core member partners, who provided a partial or complete interview in person or by proxy ranged from 67.4 per cent to 82.6 per cent (see Table 7-3). The percentage of eligible households which resulted in at least one partial or complete interview, in person or by proxy, ranged from 72.6 per cent to 86.3 per cent.

Table 7-3 : Participant and household eligibility and response rates by wave

	Wave				
ELSA response rates	**1**	**2**	**3**	**4**	**5**
Number of eligible households[1]	10811	6890	7508	8942	7568
Number of responding households[2]	7850	5948	6127	6809	6186
Percentage of responding households	72.6%	86.3%	81.6%	76.1%	81.7%
Number of eligible participants[3]	17952	11424	12719	15216	13006
Number of interviews	12099	9432	9771	11050	10274
Participant response rate	67.4%	82.6%	76.8%	72.6%	79.0%

Notes:- Numbers calculated from the ELSA Index file (version 4) responses where person=1.
[1] Household address eligible, traceable and at least one eligible participant appears to be residing at the address , [2] At least one eligible person was at least partially interviewed, in person or by proxy, [3] Participant alive, eligible this wave, traceable, outcome known

Focusing on responses to the self-completion questionnaire, Table 7-4 shows the percentage of ELSA participants who returned at least a partially completed self-completion questionnaire was reasonably high, ranging from 84.4 per cent in wave 4 to 90.8 per cent in wave 1.

Table 7-4 : Number and percentage of ELSA participants who submitted self-completion questionnaires by wave

Wave	**Self- completion questionnaires received[1]**	**Total number of ELSA responders**	**Percentage of ELSA responders with self-completion questionnaire responses**
1	10989	12099	90.8
2	8360	9432	88.6
3	8244	9771	84.4
4	9342	11050	84.5
5	9030	10274	87.9

Note: [1] And at least partially completed

7.3.5 Ethics

ELSA has ethical clearance through the National Research and Ethics committee for all ELSA waves. At the time of data extraction ELSA data was stored within the Economic and Social Data Service (ESDS), which is now integrated into the UK

Data Service. Access was only given following registration of the study, and acceptance of the End User License agreement (ESDS). This quantitative study was registered with ESDS (SN 5050, usage number 69131) before data was downloaded.

7.3.6 Datasets

ELSA include a range of datasets containing responses from interviews and questionnaires, financial information, life history information, biomedical and physical measures, response and mortality information, as well as derived variables. All datasets include identifier variables which link datasets so that different variables included across datasets can be matched by participant and wave. The following datasets were used within this study.

Core datasets

Each ELSA wave includes one core dataset which contains all variables included within the interview questionnaire and the self-completion questionnaire.

IFS datasets

There is one IFS dataset for each ELSA wave. These datasets provide consistency across waves and include commonly used variables from the core dataset and variables which have been derived from other variables.

Index dataset

ELSA provides one index file containing information on all eligible and ineligible individuals living within households identified for inclusion in ELSA from the HSE (Phelps and Wood, 2013). In total this file contains information for 37,949 individuals. The variables included within the index file include details of eligibility, inclusion status, and mortality status.

7.3.7 Weighting factors

To ensure that the responses from core responders within ELSA are generalisable to the population of older adults living in England, ELSA provide cross-sectional and longitudinal weighting factors to adjust for non-response. While ELSA recommends the use of these weighting factors whenever possible, there are occasions when it is not appropriate to apply these. Winship and Radbill (1994) recommend not applying weighting factors to regression analyses where sampling is not based on the dependent variables and the variables included in the production of the sampling weights are included as covariates within the multivariable analysis.

These conditions all apply to this study, supporting the decision not to apply the weighting factors. There were further reasons why weighting factors were not used.

While weighting factors should be applied if the intention is to produce outcomes or models which are generalisable to the population, the intention for this study was not to generalise, but to explore transitions experienced by a subset of ELSA participants. It was also felt that it was important to maximise all the information contained within ELSA, and not restrict based on how participants were originally selected. The cross-sectional weighting factors relate only to core members, that is only participants who were recruited from the original HSE samples (waves 1 and 2) or refreshment samples (waves 3 to 5); all other ELSA participants receive a weighing factor of 0. Using these weighting factors would result in all eligible participants who were not recruited as core responders being excluded from the analyses.

In addition the longitudinal weighing factors are provided for waves 3 through to 5 only, and relate to core sample members who responded to all three (wave 1 to wave 3), four (wave 1 to wave 4) or five (wave 1 to wave 5) ELSA waves. This would exclude all participants who were not core members recruited at wave 1 and who did not respond to at least three consecutive waves starting at wave 1. This would severely restrict the number of participants eligible to be included in the analyses using two and three consecutive waves.

7.4 Study methods

Data from ELSA waves 1 through to 5 inclusive are included in the analyses. As participants can be included in multiple waves this section describes the inclusion criteria applied to select participant responses, rather than individual participants. Throughout this study the term ‘participants’ will be used to describe individuals within the study, irrespective of how many waves they responded to, and the term ‘responses’ will be used to describe individual responses, such that participants may have multiple responses within the same analysis.

The data items from ELSA which have been included in this study are described below and are presented in the study data dictionary in Appendix C.2.

7.4.1 Participant response eligibility

ELSA participants were assessed independently for inclusion into this study at each wave. Thus a participant may have responded to all five ELSA waves but only the waves in which their responses match the eligibility criteria would have been included in the analyses.

To be eligible for inclusion participant responses had to report that they were aged at least 50 years and they had a partner, i.e. they were married or co-habiting, using the derived data item *<couple>* =1 from the IFS datasets.

The total number of participant responses included in this study is 35,416, completed by 12,013 participants. The breakdown of included responses by wave is presented in Table 7-5. Overall just over two thirds of all ELSA responses, for waves 1 to 5, were included in this study.

Table 7-5 : Number and percentage of responses included in this study, by wave

Responders	**Wave**					**Total**
	1	**2**	**3**	**4**	**5**	**responses**
Numbers	7961	6331	6456	7571	7097	35,416
% of ELSA total	65.8%	67.1%	66.1%	68.5%	69.1%	67.3%

7.4.2 Data

The ELSA data used in these analyses were based on the datasets released by Ingest Services on 30 April 2013.

A study dataset was created to store all variables pertinent to this study, for all responses, across all waves. This study dataset was stored within SPSS and was arranged as a long file. Each record within this file relates to one response at one ELSA wave. So, for example, an ELSA participant who was eligible for inclusion within this study for three ELSA waves will have three records within the dataset, representing one record for each wave in which they were eligible for inclusion.

7.4.3 Variables

The variables included within the study dataset are described below, while details of the codes used and associated labels, the source of these variables, and the ELSA data files in which the original data were stored are reported in Appendix C.2.

Variables were either extracted directly from ELSA and left unchanged, extracted directly from ELSA but transformed, or newly created based on one or more ELSA data items. Details of simple transformations are described in the study data dictionary. The adaptation of the self-rated health variable and the creation of latent traits; which reflect the quality and level of contact participants experienced with their partner, children, family and friends; are described in detail below.

The variables included in the study dataset are of the following types: identifier variables, demographic variables, attrition variables, caregiver status variables, health variables, and personal relationship variables.

Identifier variables

Five identifier variables were included. The identifier *<wave>* identifies the wave in which the data was extracted. The unique participant number *<idauniq>* identifies individual participants across all waves. *<wave>* and *<idauniq>* were used to differentiate multiple responses from the same participant. A couple identifier number *<couple_id>* uniquely identifies couples across all waves; ELSA provided a unique couple identifier for each coupling where a participant has had multiple partners across waves. The unique participant number for participants' partners *<idauniq_p>* was included to allow for data items relating to partners at each wave to be added to the participants' responses. The variable *<elsa>* identifies participant responses by core ELSA sample members.

Demographic variables

Demographic variables provided by ELSA which were included within this study were all collected through the HSE or through the main interviews. The study dataset includes a variable to identify if responders were part of a couple *<couple>* which was used in the selection of eligible responders.

Demographic variables relating to age *<ageg10>*, sex *<sex>*, ethnic origin *<nonwhite>*, economic activity *<work>*, qualifications *<edqual>* and financial situation *<findiff>* were selected as potential confounders. The variable *<ageg10>* was also used in the selection of participants.

ELSA provides a wealth of different measures to describe the financial circumstance of participants, however for this study a single subjective measure of financial difficulty *<findiff>* was used. The reason for choosing a simple measure was because the focus of this study was not on responders' finances. This demographic characteristic was included only to highlight any differences in financial situation between groups and to control for this in the analyses.

The number of categories available in the demographic variables *<work>, <edqual>* and *<findiff>* were reduced, due to either problems with small numbers or problems with convergence during the analyses.

Following the analysis of the qualitative interview transcripts one additional demographic variable, relating to membership of an organisation *<Member-org>,* was included. One of the key messages from the qualitative interviews was that participants placed importance on doing things outside the home. ELSA participants are asked about their membership in a range of organisations, which are listed in Table 7-6. The variable included in this study is a summative variable which identifies responders who reported they were a member of at least one of these organisation groups, that is, it identifies participants who reported they were a member of any organisation, club, or society.

Table 7-6: List of organisations included within the self-completion questionnaire

Are you a member of any of these organisations, clubs or societies?
Political party, trade union or environmental groups
Tenants groups, resident groups, neighbourhood watch
Church or other religious groups
Charitable associations
Education, art or music groups or evening classes
Social club
Sports clubs, gym, exercise classes
Any other organisations, club or societies

Attrition variables

Two attrition variables, which reflect the longitudinal nature of the data, were included to identify participant response in the next wave. These variables were derived from the Index file and identify if participants died before the next wave *<Died>*, and if participants responded in the next wave *<InterNW>*.

The variable within the Index file relating to eligibility and inclusion status for each participant, for each wave, was extracted and reformatted to produce a participant response file identifying eligibility and inclusion status for the current and the next wave. Eligibility and inclusion status was grouped into broad categories (see Table 7-7) and were used to identify the two attrition variables above.

Table 7-7: Response categories

Category	Specific categories included
Interview	Full interview in person, Full proxy interview, Partial interview in person, Partial interview by proxy, Institutional interview in person, Institutional interview by proxy
Died	Died (between previous and current wave). The eligibility status of 'Died' for a particular wave will result in all subsequent waves having an eligibility status of 'Not eligible for this wave'.
Not fit for interview	Ill at home during survey period, Away/in hospital during survey period, Physically or mentally incompetent, In an institution (Not interviewed)
Not eligible this wave	New partner not yet in household, Member/partner of later cohort, Non-eligible (not a sample member or partner), Not issued in this wave, Not eligible for this wave, Ineligible - partner who is now not living with Core Member Ineligible (issued in error)
Eligible but not included	Refusal before interview, Refusal during interview, Broken appointment, Office refusal, Respondent requested data deletion No contact, Untraced, Moved – out of Britain, Moved – unable to trace, Language difficulties, Lost productive, Other unproductive

There were two anomalies identified when merging the Index file data with data from the Core files. One participant (Participant_ID = 164645) was not included in the Index file but had a response in the Core file for wave 5. Wave 3 Index file reported 9772 participants included but only 9771 records are available in the wave 3 Core file. The participant who is reported as providing a full interview but is not included in the wave 3 core file is participant 112584. This participant responded to waves 1, 2, 4, and 5 and their records were available for these waves.

Caregiver status variables

Two caregiver variables were included within this study. The main caregiver variable identified if the responders reported that they cared for their partner in the previous week *<Carer_partner>.* An additional variable identified responders who reported that they had cared for someone, who was either not their partner or unidentified, in the previous week *<Carer_other>*.

Health variables

It was intended, when the research question was first ascertained, that there would be only one health outcome variable, which would be a subjective measure of participants overall general health. Analysis of the qualitative transcripts revealed, however, that participants most commonly felt the main health effect of looking after their partner was psychological rather than physical, in particular feelings of stress. It was also apparent that their overall sense of wellbeing was also important. As a result two additional health measures were included, a measure of psychological health and a quality of life measure. Health variables relating to the type and severity of their partners' health condition were also included.

Self-rated health variables

It was anticipated that the self-rated health question responses reported in the main ELSA interview would be used without the need for transformations or adjustments to the responses. Unfortunately upon examining the self-rated health question, and possible responses, for waves 1 through to 5, it was clear that while waves 2, 4 and 5 asked the same question, which was 'Would you say your health is excellent, very good, good, fair, or, poor?' at the start of the health questions, waves 1 and 3 used different approaches.

Wave 1 was the only wave to include a self-rated health question both at the start and at the end of the health questions section. Two different self-rated health questions were asked:

- 'Would you say your health is excellent, very good, good, fair, or, poor?'
- 'How is your health in general? Would you say it was very good, good, fair, bad, or very bad?'

Participants in wave 1 received both questions, but they were randomly allocated to receive either of the questions at the start of the health questions and the remaining self-rated health question at the end. The implications for this were that only responses from participants who were asked 'Would you say your health is excellent, very good, good, fair, or, poor?' at the start of the health questions were directly compatible with the self-rated health responses from waves 2, 4, and 5. Although the remaining participants were also asked the same question, this question appeared at the end of the health questions. As question order has been shown to be important, and previous responses to specific health and disease questions may influence responses to the self-rated health question (Bowling and Windsor, 2008), it was decided to include in this study only responses to the self-rated health question placed at the start of the health questions.

A further complication was that wave 3 asked a different self-rated health question. All participants in wave 3 were asked at the start of the health questions: 'Would you say your health is very good, good, fair, bad, or very bad?'.

Thus there were three possible self-rated health questions, reported in Table 7-8.

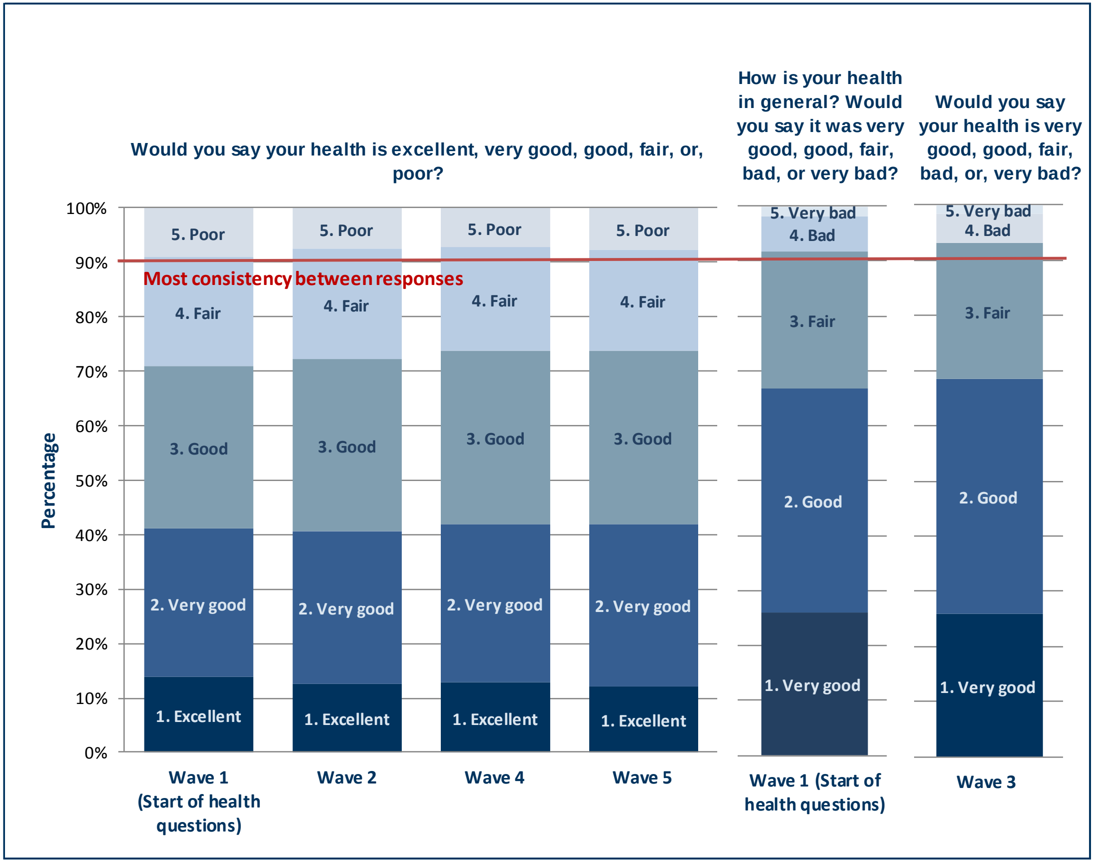
Table 7-8: Self-rated health questions

Waves	Question
1(start), 2, 4, 5	'Would you say your health is excellent, very good, good, fair, or, poor?'
1(start)	'How is your health in general? Would you say it was very good, good, fair, bad, or very bad?'
3	'Would you say your health is very good, good, fair, bad, or, very bad?'

Figure 7-1 shows the percentage of responses to each of the five possible valid options, and shows that there were two clear response distributions. Ultimately in order to include self-rated health within the study there needed to be a way to combine these responses. It was decided to use a simple method, based on combining responses in such a way that the distribution of responses would be similar across all waves. The rationale for this was based on a study by Hernández-Quevedo et al. (2005) which used the British Household Panel Survey (BHPS). This study encountered the same problem, with differences in wording and categories in the self-rated health between waves. By combining self-rated health categories they investigated if the differences in responses between waves were due to heterogeneity or measurement error. Their conclusions were that the differences in responses between waves was due to measurement error and combining self-rated health categories to produce a common categorisation scheme across waves was a reasonable approach. This approach also had the advantage of keeping the integrity of the responses participants provided.

Figure 7-1 shows that the only position in which responses could be combined to provide consistency in responses between waves was between Fair and Poor, for responses to the question 'Would you say your health is excellent, very good, good, fair, or, poor?'; and between Fair and Bad for responses to the other self-rated health questions asked at wave 1 and wave 3.

Figure 7-1: Self-rated health responses, waves 1 to 5



This resulted in a binary self-rated health variable *<SRH_bin>*, with over 90 per cent of valid participant responses reporting their health as ‘Fair or better’, and less than 10 per cent reporting their health as Poor, bad or very bad. An additional variable *<SRH_bin_flag>* was also created to identify if *<SRH_bin>* was based on the excellent to poor scale (waves 1, 2, 4, and 5) or the very good to very bad scale (wave 1 and wave 3).

Psychological health measure

ELSA includes the eight item Center for Epidemiological Studies Depression Scale (CES-D8) (Radloff, 1977, Liang et al., 2010) questions within the main interview. The revised eight item CES-D8 scale used in ELSA has been validated against the full CES-D scale for older adults (Turvey et al., 1999). The eight questions included within ELSA are reported in Table 7-9. In each wave participants were asked if they had experienced any of the following symptoms over the past week

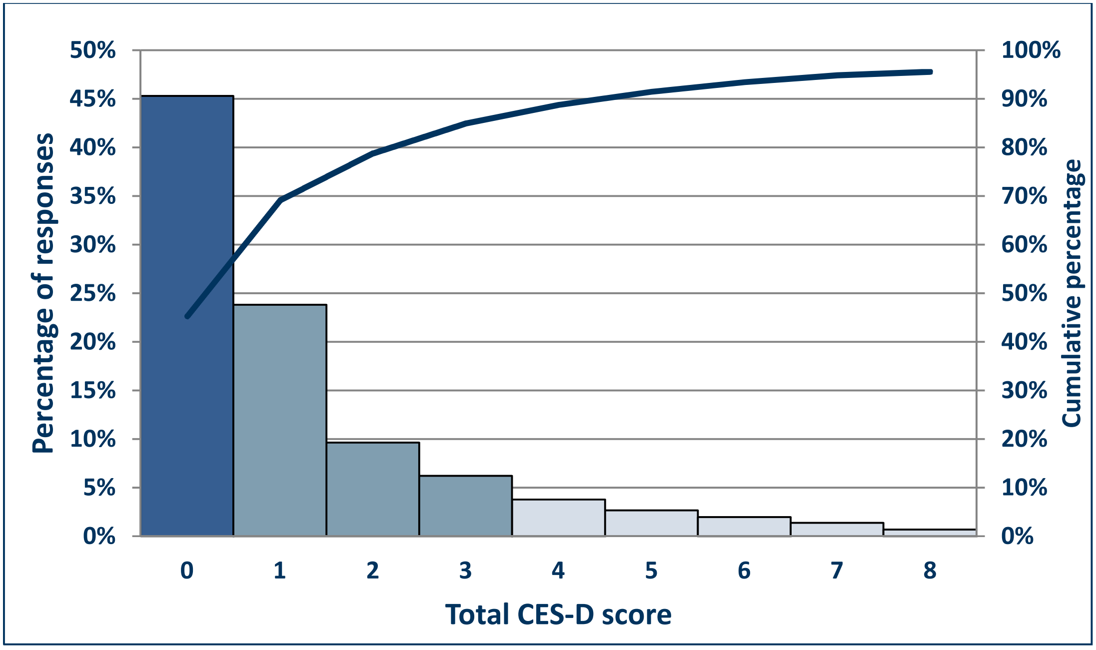
Table 7-9: CESD question included within ELSA

CESD questions	Positively or negatively worded
Much of the time during the past week, have you felt depressed?	Negative
Much of the time during the past week, have you felt that everything you did	Negative
Much of the time during the past week, has your sleep been restless?	Negative
Much of the time during the past week, were you happy?	Positive
Much of the time during the past week, have you felt lonely?	Negative
Much of the time during the past week, have you enjoyed life?	Positive
Much of the time during the past week, have you felt sad?	Negative
Much of the time during the past week, could you not get going?	Negative

Participants in each wave responded 'Yes' or 'No' to each of the questions. A variable reflecting the total score for CES-D8 *<CESD_TOTAL>* was calculated by adding up all the negative responses to the questions; that is a response of 'Yes' to the negatively worded questions, and a response of 'No' to the positively worded questions, resulting in a total CES-D8 score of between 0 and 8, with higher scores reflecting more depressive symptoms. Only responders who included valid responses to all eight questions were given a total CESD score, all other responders were recorded as 'Information not available'.

Figure 7-2 shows that the CES-D8 total scores for responses are positively skewed, with 45% of responses receiving a total CES-D8 score of 0, and only 10% of responses generating a total score of 4 or more. This skewedness in the data means that this variable could not be included in the model as a continuous dependent variable as the normal distribution assumption does not hold. As an alternative approach an additional categorical CES-D8 variable *<CES-D8Cat>* was created, which splits CES-D8 total scores into no depressive symptoms (total score=0), few depressive symptoms (total score=1 to 3), and significant depressive symptoms (total score 4 or more). Deciding to differentiate between scores of 3 or less and scores of 4 or more was based on previous studies which have used a total score of 4 or more to indicate significant symptoms of depression (Stafford et al., 2011, Hamer et al., 2009). It was decided to include an additional cut-off point of 0 to explore if participant responses reporting no depressive symptoms were associated with different partner caregiver experiences, compared to participant responses reporting at least one depressive symptom.

Figure 7-2: Distribution of responses by total CES-D8 score



Quality of life

ELSA includes questions from the CASP-19 within the self-completion questionnaire (Hyde et al., 2003). The CASP-19 measures quality of life in older adults, using 13 positively worded questions and 6 negatively worded questions, which can be grouped into four domains: control, autonomy, pleasure, and self-realisation (see Table 7-10).

ELSA participants were required to select one of the following responses to each question: ‘Often’, ‘Sometimes’, ‘Not often’, ‘Never’. Corresponding with the methods used in previous studies (Sim et al., 2011), responses were given values of 0,1,2,3 respectively for negatively worded questions; and values of 3,2,1,0 for positively worded questions. The resulting values attributed to each question were added together to give a total CASP-19 score *<CASP19_TOTAL>* of between 0 and 57, where higher scores represent better quality of life. Responders who did provide valid responses for all 19 questions were not given a total CASP-19 score.

Table 7-10: CASP-19 questions included within the ELSA self-completion questionnaire

Domain	CASP19	Positively or negatively worded
Control	My age prevents me from doing the things I would like to	Negative
	I feel that what happens to me is out of my control	Negative
	I feel free to plan for the future	Positive
	I feel left out of things	Negative
Autonomy	I can do the things I want to do	Positive
	Family responsibilities prevent me from doing what I want	Negative
	I feel that I can please myself what I do	Positive
	My health stops me from doing things I want to do	Negative
	Shortage of money stops me from doing the things I want to	Positive
Pleasure	I look forward to each day	Positive
	I feel that my life has meaning	Positive
	I enjoy the things that I do	Positive
	I enjoy being in the company of others	Positive
	On balance, I look back on my life with a sense of happiness	Positive
Self-realisation	I feel full of energy these days	Positive
	I choose to do things that I have never done before	Positive
	I feel satisfied with the way my life has turned out	Positive
	I feel that life is full of opportunities	Positive
	I feel that the future looks good to me	Positive

Partner's Activities of Daily Living

ADL is a common validated measure which has been used since the 1960's (Katz et al., 1970) to identify difficulties in carrying out common daily tasks. Within the main ELSA interviews participants were asked to report if they thought they had difficulty in any of the following aspects of ADL (see Table 7-11).

Table 7-11: ADL questions

Activities of Daily Living (ADL)
Difficulty dressing, including putting on shoes and socks
Difficulty walking across a room
Difficulty bathing or showering
Difficulty eating, e.g. cutting up food
Difficulty getting in and out of bed
Difficulty using the toilet

Each ADL factor which was reported as a problem was given a value of 1; factors reported as not being a problem were given a value of 0. A total ADL variable *<Partner_ADL>* was created which identified, for partners who had valid responses for all ADL factors, those who reported no problems with any ADL factors, and those who reported a problem with at least one ADL.

In this study ADL was used as a means to identify functional problems experienced by partners. The *<unique_p>* variable, alongside *<wave>* was used to link the ADL responses for partners to participant responses.

Other spouse or partner health variables

Other partner health measures included in the study dataset were if they had ever been diagnosed with a stroke *<Partner_Stroke>*, ever been diagnosed with any heart condition *< Partner_Heart >*, received cancer treatment in the last two years *<Partner_Cancer>*, ever been diagnosed with any emotional, nervous, or psychiatric condition *<Partner_Emot>*, or ever been diagnosed with Alzheimers or dementia *<Partner_Alz>.* Like ADL, *<unique_p>* and *<wave>* were used to link these health outcomes from partner responses to participant responses.

Personal relationship variables

Key to this study was identifying variables within ELSA which described different characteristics of personal relationships which surrounded responders. Within the self-completion questionnaire ELSA includes questions relating to different aspects of personal relationships with partners, children, other family members, and friends. In total there were forty-one different personal relationship questions included within the self-completion questionnaire, which were asked consistently throughout all waves.

Including all these variables within the same analysis would be problematic due to potential problems with collinearity and difficulties with interpreting such a volume of variables included within the same analysis. To overcome these problems it was decided to combine all these variables using latent trait analysis. Appendix C3. provides details of the methodology which was used to create the latent variables.

One latent variable, *<PartQual>*, was created to reflect the overall quality of relationship participants reported having with their spouse or partner at each wave. Two latent variables were produced for each other type of relationship, reflecting the overall perceived quality of relationships and the perceived level of contact. The latent variables for children were *<ChildQual>* and *<ChildCont>*, for family were *<FamQual>* and *<FamCont>*, and for friends were *<FrdQual>* and *<FrdCont>*, reflecting the quality of relationships and level of contact respectively.

Table 7-12 and Table 7-13 present the distribution of latent trait scores across waves 1 to 5.

Table 7-12: Summary of the distribution of quality of relationship latent variable scores across waves

	Spouse/partner	Children	Family	Friends
Mean	-0.07	-0.05	-0.01	-0.04
St Dev	0.78	0.75	0.78	0.78
Min	-3.39	-3.2	-2.25	-2.74
Max	1.13	1.38	1.59	1.29

Table 7-13: Summary of the distribution of level of contact latent variable scores across waves

	Children	Family	Friends
Mean	0.01	0.01	0
St Dev	0.67	0.73	0.71
Min	-2.25	-1.89	-2.31
Max	1.39	2.55	2.67

The decision to create two latent variables for each relationship type, rather than combining all manifest variables for that personal relationship type, was primarily because the qualitative interviews suggested that the relationship between changes in the amount of contact and changes in quality were not necessarily clear cut and was worthy of more exploration. In addition it was fortuitous that the questions included within ELSA were clearly split by quality and level of contact.

Latent variables were created for all participant responses, irrespective of whether they completed the self-completion questionnaire, provided responses for all relevant questions, or reported having a spouse or partner, children, family, or friends. Latent variables for participant responses who did not submit a self-completion questionnaire, or who reported not having children, family or friends were calculated as zero. To differentiate between latent variables calculated for participant responses who submitted and completed a self-completion questionnaire and participants who did not respond or did not submit a self-completion questionnaire, an additional variable was created for each personal relationship type; that is *<ParValid>*, *<ChdValid>*, *<FamValid>* and *<FrdValid>*.

A further variable was also created for each latent variable, to identify latent variables created using complete data and latent variables created with missing data. Thus seven additional variables were created, representing the completeness of data for participants responses about their partner (*<ParQualInd>*), children (*<ChdQualInd>* and *<ChdCondInd>*), family (*<FamQualInd>* and *<FamContInd>*) and friends *<FrdQualInd>* and *<FrdContInd>*).

Further details about the completeness of responses to the personal relationship questions are available in Appendix C.3.

7.4.4 Analysis plan

The analyses within this study were extensive and included comparisons in demographic, health, and personal relationship variables between different patterns of partner caring over one, two, and three consecutive waves; and comparisons between demographic, health and personal relationship variables for partner caregivers at one time point, moving into the partner caregiver role over two consecutive waves, and moving into and becoming a longer term partner caregiver over three consecutive waves.

Thus three distinct types of data were included in the analyses, reflecting responses at one time point and patterns of responses over two and three consecutive waves.

One time point (Cross-sectional)

The objective of the analyses based on one time point was to describe associations between variables. Two types of analyses were undertaken:

- Compare participant responses reporting being a partner caregiver and responses not reporting being a partner caregiver, in terms of attrition, demographic factors, health outcomes, and personal relationships. While it would be more usual in this type of analysis to place the demographic, health, and personal relationship characteristics as dependent or outcome variables, as the analyses was based on identifying associations only, the choice of outcome variable was arbitrary. To simplify the analyses and make it consistent across multiple comparisons, the outcome variable used was *<Carer-partner>,* that is whether participant responses reported that they were caring for their partner.
- Associations between demographic, health and personal relationship variables for participant responses reporting being a partner caregiver. In these analyses health and personal relationship variables were included as outcomes variables.

Two consecutive time points (Longitudinal)

Two consecutive time points were included in the analyses to explore changes over time.

A separate dataset was created which included demographic, health, and personal relationship variables at two time points (time 0 and time 1) for all consecutive participant responses over two waves. Thus four time frames were included in this dataset representing wave 1 to wave 2, wave 2 to wave 3, wave 3 to wave 4, and wave 4 to wave 5.

Consecutive responses were categorised into the following four distinct partner caring classifications using the *<Carer_partner>* variable; representing:

- Consecutive responses reporting not caring for a partner at both time points (Non-caring)

- Not caring for a partner at time 0 but caring a partner at time 1 (Started-caring)
- Caring for a partner at time 0 but not reporting caring a partner at time 1 (Stopped-caring)
- Reporting caring for a partner at both time points (Caring).

It is worth noting at this point that responders who were classified as Stopped-caring still reported having a partner at time 1; otherwise they would not be included within the study dataset for this time point. Thus the reason for reporting no longer having this role was not due to becoming widowed.

Two types of analyses were undertaken:

- Comparisons in demographic, health, and personal relationship characteristics at time 0, and change from time 0 to time 1, between Started-caring and Non-caregivers. The outcome variable in these analyses were the partner caring classification Started_caring and Non_caring, as the interest was in identifying associations between variables at time 0, and changes in variables between time 0 and time 1, and the likelihood of moving into a partner caregiver role.
- Associations between demographic, health, and personal relationship characteristics at time 0, and change in health or personal relationship characteristics between time 0 and time 1, for consecutive responses in the Started _caring group. The outcome variables in these analyses were health and personal relationship characteristics at time 1, including, as covariates, the matched health and personal relationships variables at time 0.

Three consecutive time points (Longitudinal)

Three consecutive time points were included in the analysis to explore changes, and the sequence of changes, over time.

A dataset was created for all consecutive participant responses categorised as Started_caring over two consecutive waves. This study dataset was used to add time 2 demographic, health, and personal relationship variables, to represent variables in the third consecutive wave. Missing time 2 responses were categorised as missing at time 2. The *<Carer_partner>* variable at time 2 was used to identify if participant responses indicated they were still caring for their partner (Long-term caregivers) or no longer caring for their partner (Short-term caregivers).

The following analyses were undertaken:

- Comparisons in time 0 and time 1 demographic factors, and change in health and personal relationship variables between time 0 and time 1, between Long-term caregivers and Short-term caregivers, using Long-term and Short_term caregiver status as the outcome variable.
- Exploration of the sequence of change in health and personal relationships variables for Long-term caregivers.
- Exploration of the sequence of change in different personal relationship variables for Long-term caregivers.

7.4.5 Software

Microsoft Excel 2010, SPSS version 22, and R version 3.0.1 (2013-05-16), accessed under R studio version 0.97.551, were used to analyse the data.

7.4.6 Models

The ELSA data used in this study is longitudinal, with multiple responses within participants. It would be inappropriate to analyse the data using simple fixed effects models as fixed effects models assume independence between responses, when the multiple responses within participants are likely to be more homogeneous than responses between participants. To take into account the random variation within participants across waves linear mixed effects models, which enabled both fixed and random effects to be taken into account, were used to analyse the data. The variable relating to participants (*<idauniq>*) was included as the random variable. In the early stages of this study the couple identifier (*<couple_id>)* was also included as a random effect to take into account random variation within couples, however this resulted in most models failing to converge. Ultimately it was decided to exclude *<couple_id>* from the final models as the difference in results between including and excluding couples as an additional random effect appeared negligible. All other independent variables were included as fixed effects within the analyses.

The linear mixed effects models take the form:

$$y_{ij} = \beta_0 + \beta_1 x_{1ij} + \beta_2 x_{2ij} + \ldots + \beta_k x_{kij} + b_i z_{ij} + \varepsilon_{ij}$$

Where: y_{ij} *is the dependent variable value for the jth observation in the ith participant;* β_0 *is constant;* β_1 *to* β_k *are the fixed effects coefficients,* x_{1ij} *to* x_{kij} *are the fixed effects variable values 1 to k;* b_i *is the random effects co-efficient for the ith participant, assumed to be normally distributed;* z_{ij} *is the random effects variable for the jth observation in the ith participant; and* ε_{ij} *is the error for jth observation in the ith group, assumed to be multivariate normally distributed.*

The library lme4 (version1.1-7) (Bates and Maechler, 2014) within the statistical package R was used to generate the models.

Both univariable and multivariable analyses were undertaken to assess the effects of controlling for confounding factors on the models. For consistency the confounders included in the multivariable analyses were the same for all analyses and were: sex *<sex>*, age *<age10>*, ethnic origin *<nonwhite>*, economic activity *<work>*, highest qualification *<edqual>*, and financial situation *<findiff>*.

Dependent variables were either dichotomous or considered to be continuous. Although the variable CES-D8 included three valid categories, when this variable was used as the dependent variable two separate dichotomous analyses were undertaken: one or more depressive symptom versus no depressive symptoms, and significant depressive symptoms versus no or few depressive symptoms. The decision to undertake two logistic models, rather than one ordinal logistic model for this data was because it was felt that the assumptions of proportional odds, that is the odds of increasing from category i to i+1 is the same as from j to j+1, for all ij, may not hold in this case.

The *glmer* command was used to fit generalised mixed effects models for dichotomous dependent variables, while the *lmer* command was used to fit linear mixed effects models for continuous dependent variables. Below is an example of a glmer command used within the analyses, where 1/idauniq represents the random intercept for participants:

```
model <- glmer(Carer_partner ~ CESD_TOTAL + sex + ageg10 + work + edqual +
findiff + (1|idauniq), family=binomial(), data = dataset)
```

There were quite a number of occasions within the analyses when the generalised mixed effects models would not converge to an acceptable level. When these models continued to fail to converge, despite changing the optimizer used, increasing the number of iterations within the control parameters, reducing the number of options within problematic categorical variables, and removing couple as a random effect, simple fixed effects logistic regression models were used as a substitute, using the R library rms (version 4.2-1) (Harrell, 2014) and the *glm* command. The reporting of results from analyses which did not account for the random effects within participants are identified in the results using the symbol §. It was anticipated that the main effect of using fixed effects models instead of mixed effects models would be an underestimation of the variations between responses, and an overestimation of the significance of results.

Odds ratios were calculated using the parameter outcomes from the logistic mixed effects, or fixed effects models. Means, and confidence intervals were calculated for continuous variables using univariable linear mixed effects models (unless otherwise stated), with the variables for which means were to be calculated included as dependent variables and the caregiver status included as the independent fixed variable.

7.4.7 Missing data

Most variables included within this study are categorical. Missing or invalid responses for each categorical variable were coded as 99 to indicate that the information was not available. Where categorical variables were included in the analyses as independent variables, all responses, including missing responses were included.

Where the categorical variables self-rated health and the CES-D8 was included as dependent variables, only valid participant responses were included; that is categorised as ‘fair or better’ or ‘poor/bad/very bad’ in the case of self-rated health; and no depressive symptoms, few depressive symptoms, and many depressive symptoms in the case of CES-D8.

For this study the CASP-19 score was treated as a continuous variable. The percentage of missing total scores for the variable CASP-19, over the five waves, was 15.9%. The higher percentage of missing CASP-19 scores reflects that these questions were collected within the self-completion questionnaire, which was not submitted by approximately 10% of participants. Only valid responses were included within the analysis for CASP-19, both when this variable was included as an independent or dependent variable.

Latent variables representing responder relationships were calculated for all responses, whether they completed the self-rated questionnaire; reported having, or not having, children, family, or friends; or completed responses to all relevant questions. To identify latent variables based on wholly or partially missing data additional categorical identifier variables were created. These are explained in section 7.4.3. and in Appendix C.3. To reflect the completeness of the data when personal relationship variables were included as independent variables, the associated categorical identifier variables were also included alongside the personal relationship latent variables. Personal relationship variables included as dependent variables were only included if these values were based on complete data.

While the methods used in this study are traditional and current recommendations are to use techniques such as multiple imputation or maximum likelihood estimations (Allison, 2002, Johnson and Young, 2011), bias is likely when data is missing, irrespective of the methods used. These traditional methods were used for a number or reasons. Firstly the number of variables and the number of analyses undertaken was large. Adopting more complex methods to deal with the missing data would have been very time consuming, given that this is a mixed methods, and not a purely quantitative, doctoral project. As reported in section 7.3.7 the intention was not to produce generalisable results but to explore changes in health and personal relationship experienced by a subset of ELSA participants. Adopting a technique to maximise the number of responses included in the analyses meant that no observations were excluded from the analyses. In addition including missing values provided an opportunity to observe associations between missing values and the outcomes of interest.

7.4.8 Presentation of statistical significance

The original intention was to provide confidence intervals around odds ratios and β coefficients to provide an indication of the precision of parameter estimates, however due to the restriction in space within tables and the large number of tables presented this proved to be problematic.

As an alternative p values representing less than 0.1, 0.05, and 0.005 are presented throughout the results, represented by the symbols •, * and ** respectively.

The p values were used as an aid to help infer relationships or differences between variables. For models which included both fixed and random effects a p value of less than 0.05 was considered statistically significant. For analyses based on only fixed effects, where the non-independence of responses with participants had not been accounted for, p values were used only as an indication of a possible relationship between variables and were not referred to as statistically significant.

7.4.9 Sample size

As this analysis is based on secondary data the sample sizes are already fixed.

As an example of the number of participants required, consider the sample sizes required to observe a statistically significant difference in the increase in the number of depressive symptoms reported between time 0 and time 1, using the CES-D8 total score, between Non-caregiver responses and Started-caring responses; based on a statistical significance (two tailed) of 5 per cent, a power of 80 per cent, and a ratio between Non-caregivers to Started-caring of 100:3, using the following information:

Scenario 1 (10 percentage point difference between groups)

Proportion experiencing an increase in depressive symptoms

Non-caregiver group= 25% versus Started-caring group= 35%

Sample sized required Non-caregiver group=5,648, Started-caring group= 170

Scenario 2 (5 percentage point difference between groups)

Probability of an increase in depressive symptoms

Non-caregiver group= 25% versus Started-caring group= 30%

Sample sized required Non-caregiver group=21,459, Started-caring group= 644

As the actual numbers in the sample are 20,705 in the Non-caregiver group and 627 in the Started-caring group, this shows that the data is powered to detect between a 5 per cent and 10 per cent difference in the percentage of consecutive participant responses showing more CES-D8 symptoms, between Non-caregivers and Started-caring, based on 5 per cent significance and 80 per cent power.

This example does highlight, however that the analysis based on three time points is likely to be underpowered as repeating scenario one based on equal sample size shows that 627 responses are required in each group to obtain a statistically significant result, while the actual number of Short-term and Long-term caregivers is only 200, and 119 respectively.

7.5 Reflections from the researcher

Though reflexivity is used routinely in social science research it is not used routinely within quantitative research (Ryan and Golden, 2006). This chapter has described in detail the methods which were used to select and analyse the study data and provides reasoning behind these approaches. As secondary data is used in this study the researcher had no control over the recruitment of participants, the collection of data, or the selection of variable, however it is worth reflecting on how participants may have influenced the results, and how the researcher may have influenced the study.

7.5.1 Participants

Participants required a great deal of commitment to continue to participate in the ELSA study every two years, given the sheer volume of questions which ELSA participants are subjected to and the nursing visits, which would likely take up a great deal of time. ELSA calculate weighting factors to account for non-response, and reviewing the technical report for wave 1 (ELSA, 2007) shows that non-response was influenced by age, sex, household composition, employment, and the health of members of the household. As this study focuses on older adults caring for their partners it is possible that these participants were more likely to drop out compared to older adults who were not caring for their partners. The qualitative interviews provided me with an insight into how much commitment looking after a partner requires. I suspect that ELSA participants who moved into a caring role and needed to provide a lot of care for their partner would be reluctant to continue to participant in the ELSA study. Thus the ELSA study may not adequately represent those participants who are struggling with the amount of work they have to do to look after their partner. It may be that ELSA participants who are caring for their partner who also have adequate support from family and friends, and professionals may be the caregivers who continue to participate in ELSA.

7.5.2 Formation of the latent variables

The latent trait analysis required subjective judgements, in terms of what variables to include in the latent trait analysis. Details of the latent trait analysis are presented in Appendix C.3.

I found it easy to identify the variables to include within the analysis as I used the pertinent variables included in the self-completion questionnaire. I felt I was on safe ground with these variables as they have been used in previous studies (Stafford et al., 2011, Rafnsson et al., 2015). I also included additional variables to represent people who participants lived with, as the data on level of contact included in the self-completion questionnaire referred only to people the participants did not live with. I felt that it was important to capture this information as I felt participants who had other children, family or friends in the household would be getting daily contact with these people.

I had to make decisions when running each analysis as to which variables to leave in the formation of the latent variable. Details about the overall fit of each latent model are provided to help with this decision but ultimately it was down to me to decide. In the majority of cases I used the model fit details, alongside graphs displaying the level of fit, to make these decisions. Again I felt I was on safe ground here as my decisions were backed up by the data. On several occasions, however I decided to leave in a variable which was adding nothing, or reducing the fit of the latent variable. The variables related to living with children, family, and friends added nothing to the overall latent variable scores representing level of contact. I was surprised by this as I had felt including an indicator to represent people who lived with the participant would be an important variable. I considered for quite a while whether to take this variable out in each of the analysis and ultimately I decided I could not take it out even though it added nothing. So in this case my subjective reasoning as to what I thought should be in the latent variable for level of contact overruled the information coming from the model fit.

7.6 Chapter summary

ELSA data was used to explore the connections between health and personal relationship when older adults take on a caring role for their partner. Variables from waves 1 to 5 were selected and transformed to provide consistent variable attributes across waves. This data was used to compare demographic, health, and personal relationship outcomes for different caregiver patterns over one, two, and three consecutive waves; and explore connections between health and personal relationships for responses from participant caring for their partners, responses from participants moving into a partner caregiving role over two consecutive waves, and participants who started to provide long-term care for their partners, over three consecutive waves.

Chapter 8 Quantitative results

8.1 Introduction

This chapter presents the results from the quantitative analyses exploring connections between health and personal relationships for older adults who are caring for their partner, move into a caregiver role for their partner, or become long-term carers for their partner, over one, two, and three consecutive time points.

As an aid to understanding the analysis undertaken within this chapter, and to help with the interpretation of the results; Figure 8.1 below provides a conceptual diagram of the analysis conducted within sections 8.4 to 8.10, including the analysis design (cross-sectional or longitudinal), and the direction of the associations assessed.

Information on attrition, number of responses, and demographic and social factors are also presented in sections 8.2 and 8.3.

Figure 8-1: Conceptual diagram of quantitative analyses

KEY:

∆ = Change over time, ⟷ = Bi-directional analysis, ⟶ = Uni-directional analysis

8.4 Demographic and social factors

8.4.1	Cross-sectional	Demographic factors ⟷ Caring for a partner
8.4.2	Longitudinal	Demographic factors (time 0) ⟶ Started caring for a partner ∆ Demographic factors (time 0 to time 1) ⟷ Started caring for a partner
8.4.3	Longitudinal	Demographic factors (time 0) ⟶ Become a long-term partner caregiver Demographic factors (time 1) ⟶ Become a long-term partner caregiver

8.5 Health comparisons between partner caregivers and non-caregivers

8.5.1	Cross-sectional	Health ⟷ Caring for a partner
8.5.2	Longitudinal	Health (time 0) ⟶ Started caring for a partner ∆ Health (time 0 to time 1) ⟷ Started caring for a partner
8.5.3	Longitudinal	∆ Health (time 0 to time 1) ⟶ Become a long-term partner caregiver

8.6 Associations between health and other factors for partner caregivers

8.6.1	Cross-sectional	Demographic factors ⟷ Health
8.6.2	Longitudinal	Demographic factors (time 0) ⟶ Health (time 1)

8.7 Personal relationship comparisons between partner caregivers and non-caregivers

8.7.1	Cross-sectional	Personal relationship characteristics ⟷ Caring for a partner
8.7.2	Longitudinal	Personal relationship characteristics (time 0) ⟶ Started caring for a partner ∆ Personal relationship characteristics (time 0 to time 1) ⟷ Started caring for a partner
8.7.3	Longitudinal	∆ Personal relationship characteristics (time 0 to time 1) ⟶ Become a long-term partner caregiver

8.8 Associations between personal relationships and other factors for partner caregivers

8.8.1	Cross-sectional	Demographic factors ⟷ Personal relationship characteristics
8.8.2	Longitudinal	Demographic factors (time 0) ⟶ Personal relationship characteristics (time 1)

8.9 Connections between personal relationships and health for partner caregivers

8.9.1	Cross-sectional	Personal relationship characteristics ⟷ Health
8.9.2	Longitudinal	Personal relationship characteristics (time 0) ⟶ Health (time 1) Health (time 0) ⟶ Personal relationship characteristics (time 1)
8.9.3	Longitudinal	∆ Personal relationship characteristics (time 0 to time 1) ⟶ ∆ Health (time 1 to time 2) ∆ Health (time 0 to time 1) ⟶ ∆ Personal relationship characteristics (time 1 to time 2)

8.10 Connections between different personal relationships for partner caregivers

8.10.1	Cross-sectional	Personal relationship characteristics ⟷ Personal relationship characteristics
8.10.2	Longitudinal	Personal relationship characteristics (time 0) ⟶ Personal relationship characteristics (time 1)
8.10.3	Longitudinal	∆ Personal relationship characteristics (time 0 to time 1) ⟶ ∆ Personal relationship characteristics (time 1 to time 2)

8.2 Study attrition between partner caregivers and non-caregivers

As this study is exploring transitions in health and personal relationships for partner caregivers it is worth considering if older adults, who report caring for their partner in any ELSA wave, participate in the next wave, compared to older adults who did not report caring for their partner.

This section will use ELSA responses for waves 1 to 4 to compare the likelihood of dying before the next wave and participating in the next wave between responses reporting caring or not caring for a partner. Only waves 1 to 4 were included as the ELSA index file includes eligibility for inclusion, and actual inclusion, in each wave, for waves 1 to 5 only.

In total 35,416 participant responses, from 12,013 individual ELSA participants, were included in this study. Of the 28,319 participant responses from waves 1 to 4, 27,528 were responses from participants who were recorded as eligible for inclusion in the next ELSA wave; 791 responses were recorded as ‘Not eligible for this wave’ in the next wave. The following analysis assessing the likelihood of dying before, or participating in, the next wave is based on these 27,528 study responses.

8.2.1 Died before next wave

Overall, for the waves 1 to 4, 1.3 per cent of participant responses were from participants who died before the next wave (see Table 8-1). The percentage dying before the next wave was similar between participant responses reporting caring for their partner and participant responses not reporting caring and, after controlling for random variation within participants.

Table 8-1: Death status for responses from ELSA waves 1 to 4 by partner caregiver status

Reported caring for partner	**Died before next wave**			**OR**	
	Yes	**No**	**% Yes**		
No	325	25593	1.30%	1	
Yes	23	1587	1.40%	1.14	NS
Total	**348**	**27180**	**1.30%**		

NS = $p \geq 0.1$; OR=Univariable odds ratio of dying before next wave compared to not dying before next wave; OR=1:Reference category.

8.2.2 Interviewed next wave

Table 8-2 shows that overall 84.3 per cent of participant responses in waves 1 to 4 could be linked, by participant, to consecutive responses for the next wave. The percentage interviewed in the next wave was lower for participant responses reporting that they cared for their partner and, after adjusting for random effects within participants, this difference was statistically significant at the 5 per cent level. Thus participant responses reporting caring for their partner were significantly less likely to be included in the next ELSA wave.

Table 8-2: Interview next wave status for responses from waves 1 to 4 by partner caregiver status

Reported caring for partner	Interview next wave			OR	
	Yes	No	% Yes		
No	21888	4030	84.5%	1	
Yes	1313	297	81.6%	0.85	*
Total	**23201**	**4327**	**84.3%**		

**p<0.05, OR=Univariable odds ratio of providing an ELSA interview in the next wave compared to not providing an ELSA interview in the next wave (including died before next interview); OR=1:Reference category.*

8.2.3 Summary of findings

There was no significant difference in the likelihood of dying before the next wave between those who reported caring for their partner and those who did not. Those who reported caring for their partner were however significantly less likely to participant in the next ELSA wave.

8.3 Responses by wave

This section compares the number and percentage of responses, by partner caregiver status, across waves; over one, two and three consecutive waves.

For comparisons over one wave, participant responses reporting being a partner caregiver were compared with participant responses not reporting being a partner caregiver. For comparisons over two waves (time 0 to time 1), consecutive responses reporting starting caring for a partner in the second consecutive wave (Started-caring) were compared with consecutive responses reporting not caring for a partner in both waves (Non-caring), caring for a partner in the first consecutive wave only (Stopped-caring), and caring for a partner in both consecutive waves (Caring). For comparisons over three consecutive waves (time 0 to time 2) responses reporting starting caring for a partner in the second consecutive wave and continuing to care for a partner in the third consecutive wave (Long-term caregiver) were compared with responses reporting starting caring in the second consecutive wave but not reporting caring for a partner in the third consecutive wave (Short-term caregiver).

8.3.1 Responses at one time point

Table 8-3 shows that overall 6.0 per cent of participant responses reported caring for their partner. This percentage changed across waves, from 10.2 per cent in wave 1 to 4.4 per cent in wave 4. After controlling for the random variation within participants, participant responses in wave 1 were significantly more likely to report being a caregiver for their partner, compared to responses in all other waves.

Table 8-3: Number and percentage of responses by partner caregiver status and wave

Wave	Reported caring for partner			OR	
	Yes	No	% Yes		
Wave 1	737	7224	10.2%	1	
Wave 2	321	6010	5.3%	0.27	**
Wave 3	289	6167	4.7%	0.35	**
Wave 4	321	7250	4.4%	0.42	**
Wave 5	342	6755	5.1%	0.75	*
Total responses Waves 1 to 5	**2010**	**33406**	**6.0%**		

**p<0.05, **p<0.005; OR=Univariable odds ratio of caring for a spouse or partner compared to not reporting caring for a spouse of partner; OR=1:Reference category.*

This increased likelihood of reporting being a partner caregiver in wave 1 may be related to the significantly decreased likelihood of participants who reported caring for a partner taking part in the next ELSA wave, as reported in 8.2.2.

8.3.2 Responses over two consecutive ELSA waves

A total of 9,057 participants who were included in the study dataset responded at least once in two consecutive waves, providing a total of 22,461 consecutive responses over two time points. Most (92.2 per cent) of these consecutive responses were categorised as Non-caring, while 2.8 per cent were categorised as Started-caring, 2.9 per cent were categorised as Stopped-caring, and 2.1 per cent were categorised as a Caring in both consecutive waves (see Table 8-4).

Table 8-4: Number and percentage of responses by partner caring status over two consecutive waves

Variable	Partner carer role two waves				Total
	Non-caring	Started-caring	Stopped-caring	Caring	
Numbers	20705	627	648	481	22461
Percentage across patterns	92.2%	2.8%	2.9%	2.1%	

Table 8-5 shows the distribution of partner caregiver roles over two waves, by ELSA waves. The percentages reported suggest that responses in the Started-caring category may be underrepresented in the consecutive waves 3 to 4, and overrepresented in the consecutive waves 4 to 5, however the odds ratios, which compared the odds of consecutive responses being in the Started-caring category, compared to being in the Non-caring category were not significantly different between waves.

Table 8-5: Number and percentage of responses, by partner caregiver status and wave, over two consecutive waves

Waves	Partner carer role two waves Non-caring	Started-caring	Stopped-caring	Caring	Total	OR[1§]
Number						
Wave 1 to Wave 2	5364	156	311	154	5985	1
Wave 2 to Wave 3	4620	154	123	98	4995	1.15 NS
Wave 3 to Wave 4	4795	124	95	107	5121	0.89 NS
Wave 4 to Wave 5	5926	193	119	122	6360	1.12 NS
Percentage within carer patterns						
Wave 1 to Wave 2	25.9%	24.9%	48.0%	32.0%		
Wave 2 to Wave 3	22.3%	24.6%	19.0%	20.4%		
Wave 3 to Wave 4	23.2%	19.8%	14.7%	22.2%		
Wave 4 to Wave 5	28.6%	30.8%	18.4%	25.4%		

NS=p≥0.1,OR=Odds ratio Start-caring compared with Non-caring; [$] *Logistic regression using fixed effect only*

8.3.3 Responses over three consecutive ELSA waves

Of the 627 responses over two consecutive waves who were in the Started-caring category, identified in the section above, 319 (50.9 per cent) consecutive responses had a third wave of data available in the study dataset. Of these, 200 reported that they were no longer caring for their partner and were categorised as Short-term caregivers, while 119 reported that they were still caring for their spouse or partner in the next wave and were categorised as Long-term caregivers. The remaining 308 responders did not have a third consecutive wave of data available in the study dataset (See Table 8-6).

Table 8-6: Number of percentage of responses, by partner caring over three consecutive waves

Variable	Partner carer role three waves Short-term	Long-term	Missing wave	Total
Numbers	200	119	308	627
Percentage across carer patterns	31.9%	19.0%	49.1%	100.0%

The 319 responses with three consecutive waves available constitute 316 participants. As this number means that only three participants are represented twice, and no participant can be represented twice in the Long-term caregiver group, as only five ELSA waves are available, the following analysis was based only on fixed effects.

Table 8-7 presents the logistic regression analysis comparing the likelihood of being a Long-term caregiver compared to a Short-term caregiver, by consecutive wave patterns. The results suggest that participants who started caring for their partner in wave 3 (wave pattern 2 to 4) were significantly more likely to report that they were a Long-term caregiver, compared to participants who started caring in wave 2 (wave pattern 1 to 3).

Table 8-7: Number and percentage of responses, by partner caregiver status and wave, over three consecutive waves

	Partner carer role three waves					
Variable	**Short-term**	**Long-term**	**Missing wave**	**Total**	**OR**	
Number						
Wave 1 to Wave 3	81	32	43	156	1	
Wave 2 to Wave 4	60	51	43	154	2.15	*
Wave 3 to Wave 5	59	36	29	124	1.54	NS
Wave 4 to Wave 5	0	0	193	193		
Percentage within waves						
Wave 1 to Wave 3	51.9%	20.5%	27.6%	100.0%		
Wave 2 to Wave 4	39.0%	33.1%	27.9%	100.0%		
Wave 3 to Wave 5	47.6%	29.0%	23.4%	100.0%		
Wave 4 to Wave 5	0.0%	0.0%	100.0%	100.0%		

*NS = p≥0.1, *p<0.05; OR=Odds Ratio Long-term caregiver compared to Short-term caregiver (reference)*

8.3.4 Summary of findings

The likelihood of reporting caring for a partner was significantly different between waves, with significantly more participant responses reporting caring for a partner in wave 1 compared to waves 2 to 5. The likelihood of becoming a Long-term caregiver compared to a short-term caregiver also varied by wave.

8.4 Demographic and social factors

This section considers the association between partner caregiver status and other demographic and social factors, over one, two and three consecutive waves.

As with section 8-3, participant responses reporting being a partner caregiver were compared with responses not reporting being a partner caregiver for one time point. For two consecutive waves, time varying demographic factors reported at the first wave were compared between Started-caring and Non-caring groups.

For the analysis based on three consecutive waves comparisons were made between Long-term caregiver and Short-term caregiver for the following:

- Time variant and time invariant demographic factors in the wave before reporting caring for a partner.

- Time variant demographic factors in the wave when caring for a partner was first reported.

8.4.1 Responses at one time point

Table 8-8 compares participant responses reporting caring for their partner with participant responses not reporting caring for a partner, for a range of demographic factors. The univariable and multivariable odds ratios of reporting being a partner caregiver for each of these factors are presented; the multivariable results were based on fixed effects only due to non-convergence. The results from the univariable and multivariable modelling, however, were fairly consistent.

The odds of participant responses reporting that they were a caregiver for their partner was not statistically significantly different between ethnic groups. The difference between males and females was not significant after controlling for other demographic factors.

Participant responses were significantly more likely to report caring for their partner if they were older, not working or retired, did not consider themselves to be getting along quite or very well financially, were not a member of an organisation, and were caring for others in addition to their spouse or partner. Participant responses reporting that their highest qualification was less than A level, or foreign, were more likely to report caring for their partner, compared to participants who held at least A level qualifications .

Table 8-8: Comparison of demographic factors by partner caregiver status

Demographic variables	Reported caring for partner			Odds Ratio	
	Yes	No	% Yes	Uni	Multi§
Sex					
Male	928	17072	5.20%	1	1
Female	1082	16334	6.20%	1.34 •	1.07 NS
Age band (years)					
50-59	517	12841	3.90%	1	1
60-69	664	11874	5.30%	1.31 *	1.17 *
70-79	618	6822	8.30%	2.22 **	1.73 **
80+	211	1869	10.10%	1.82 *	2.22 **
Ethnic origin					
White	1960	32352	5.70%	1	1
Not white	47	967	4.60%	0.69 NS	0.8 NS
Information not available	3	87	3.30%	0.16 NS	0.71 NS
Economic activity					
Working	431	14775	2.80%	1	1
Not working	498	4201	10.60%	2.97 **	3.01 **
Retired	1081	14430	7.00%	1.86 **	1.83 **
Highest qualification					
A' level/higher	543	12917	4.00%	1	1
NVQ 1-2/O level	477	7789	5.80%	1.48 *	1.23 **
Foreign/other	195	2941	6.20%	2.37 **	1.19 *
No qualifications	788	9441	7.70%	2.29 **	1.28 **
Information not available	7	318	2.20%	0.22 NS	0.43 *
How is respondent (and partner) getting along financially these days					
Manage very/quite well	1183	23617	4.80%	1	1
Get by alright	704	8318	7.80%	1.46 **	1.54 **
Not manage very well	38	367	9.40%	2.25 *	2 **
Some/severe difficulties	70	757	8.50%	2.71 **	1.83 **
Information not available	15	347	4.10%	0.43 NS	0.86 NS
Member of an organisation					
No	641	7553	7.80%	1	1
Yes	1077	20904	4.90%	0.66 **	0.71 **
Missing values	292	4949	5.60%	0.47 **	0.68 **
Reported caring for someone who was not their spouse or partner in the last week					
No	30540	1752	94.60%	1	1
Yes	2866	258	91.70%	2.46 **	1.75 **

*NS = p≥0.1, •p<0.1*p<0.05, **p<0.005; Uni=Univariable odds ratio of caring for a partner compared to not reporting caring for a partner; Multi=Multivariable odds ratio including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment, membership to an organisation and caring for others; OR=1:Reference category, § using fixed effects only*

8.4.2 Responses over two consecutive ELSA waves

The demographic factors included in this section are only those characteristics which are not fixed, but can change over time.

Table 8-9 shows that being in the Started-caring category was associated with reporting not working or being retired in the wave before caring, compared to the Non-caring category. This finding remained significant after controlling for other factors including age and sex, however the multivariable analysis was based on fixed effects only. This result reflects the results over one time point and suggests that participants who are not working or retired may be in a better position to take on a caring role for their spouse or partner, compared to responders who still work.

In terms of how well participants are getting on financially, these results provide some evidence that those who started caring for their partner were financially less well off before starting caring, than responders who were Non-caring, however this evidence is weaker compared to the analysis over one time point and based on fixed effects only.

Table 8-9: Comparison of demographic factors by partner caring status at two consecutive waves

Time varying demographic factors	Partner carer role two waves			Odds Ratio	
at first consecutive wave (time 0)	Non-caring	Started	% Started	Uni	Multi§
Economic activity					
Working	9792	164	1.6%	1	1
Not working	2530	118	4.5%	3.51 **	2.23 **
Retired	8383	345	4.0%	2.93 **	1.73 **
Response to: How is respondent (and partner) getting along financially these days?					
Manage very/quite well	14860	405	2.7%	§1	1
Get by alright	4980	189	3.7%	§1.39 **	1.33 **
Not manage very well	226	7	3.0%	§1.14 NS	1.19 NS
Some/severe difficulties	444	18	3.9%	§1.49 NS	1.7 *
Information not available	195	8	3.9%	§1.51 NS	1.48 NS
Response to being a member of an organisation§					
No	4480	153	3.3%	§1	1
Yes	13721	408	2.9%	§0.87 NS	0.96 NS
Information not available	2504	66	2.6%	§0.77 •	0.73 *
Response to caring for someone who was not their spouse or partner in the last week					
No	18783	558	2.9%	§1	1
Yes	1922	69	3.5%	§1.21 NS	1.31 *

*NS = p≥0.1, •p<0.1, *p<0.05, **p<0.005; Uni= Odds ratio Started_caring compared with Non-caring; Multi=Multivariable odds ratio also including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment at time 0; OR=1:Reference category; §Fixed effects only*

No significant difference was found between Started-caring and Non-caring, with respect to being a member of an organisation in the first of the two consecutive waves. This contrasts with the results from one time point which suggested that participant responses who reported caring for their partner were significantly less likely to be a member of an organisation compared with responses reporting not caring for a partner. This suggests that those who started caring for their partner may have been more likely to stop their membership of an organisation. This is supported by the results presented in Table 8-10 below, which show that the likelihood of being in the Started-caring category, compared to the Non-caring category, is significantly higher for those who stopped being a member of an organisation, though this was based on fixed effects only.

Focusing on the likelihood of responders caring for others, Table 8-9 above also shows that the odds of being in the Started-caring category was greater for those who were also caring for someone else in the first of the consecutive waves. Table 8-10 below suggests that they were also less likely to stop this role after starting looking after their partner. This is consistent with the results for one time point.

Table 8-10: Comparison of change in demographic factors by partner caring status at two consecutive waves

Change in time varying factors	Partner carer role two waves			Odds Ratio	
(time 0 to time 1)	Non-caring	Started	% Started	Uni	Multi§
Member of an organisation					
Member both time points	11379	317	2.70%	§1	1
Stopped being a member	1208	48	3.80%	§1.43 *	1.45 *
Started being a member	1084	32	2.90%	§1.06 NS	1.06 NS
Remained not a member	2643	90	3.30%	§1.22 •	1.12 NS
Incomplete information	4391	140	3.10%	§1.14 NS	0.99 NS
Reported caring for someone who was not their spouse or partner in the last week					
Caring both time points	616	32	4.90%	§1	1
Stopped caring	1306	37	2.80%	§0.55 *	0.55 *
Started caring	906	59	6.10%	§1.25 NS	1.32 NS
Remained not caring	17877	499	2.70%	§0.54 **	0.48 **

NS = $p \geq 0.1$, •$p > .0.1$, *$p < 0.05$, **$p < 0.005$; Uni=Odds ratio of starting caring for a partner compared to not reporting caring for a partner both time points; Multi=Multivariable odds ratio also including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment; OR=1:Reference category; §Fixed effects only

8.4.3 Responses over three consecutive ELSA waves

Table 8-11 compares the demographic characteristics before caring between Long-term and Short-term partner caregivers. This table suggests that males were more likely to report becoming Long-term caregivers for their partner compared to females. There was no significant difference between Long-term and Short-term caregiver groups for any other demographic characteristic before taking on a caring role for a partner.

Table 8-11: Comparison of demographic factors between Short-term and Long-term partner caregivers over three consecutive waves

Demographic variables at first consecutive wave (time 0)	Partner carer role three waves			Odds Ratio	
	Short-term	Long-term	% Long-term	Uni§	Multi§
Sex					
Male	89	64	41.8%	1	1
Female	111	55	33.1%	0.69 NS	0.59 *
Age band (years)					
50-59	61	38	38.4%	1	1
60-69	68	36	34.6%	0.84 NS	0.74 NS
70-79	57	37	39.4%	1.04 NS	0.81 NS
80+	14	8	36.4%	0.91 NS	0.62 NS
Ethnic origin					
White	197	117	37.3%	1	1
Not white	2	2	50.0%	1.68 NS	1.27 NS
Information not available	1	0	0.0%	-	
Economic activity					
Working	61	30	33.0%	1	1
Not working	33	25	43.1%	1.54 NS	1.76 NS
Retired	106	64	37.6%	1.23 NS	1.43 NS
Highest qualification					
A' level/higher	68	34	33.3%	1	1
NVQ 1-2/O level	43	33	43.4%	1.53 NS	1.56 NS
Foreign/other	14	9	39.1%	1.29 NS	1.42 NS
No qualifications	73	43	37.1%	1.18 NS	1.16 NS
Information not available	2	0	0.0%	-	-
How is respondent (and partner) getting along financially these days					
Manage very/quite well	133	74	35.7%	1	1
Get by alright	57	40	41.2%	1.26 NS	1.22 NS
Not manage very well	2	1	33.3%	0.9 NS	1.04 NS
Some/severe difficulties	6	3	33.3%	0.9 NS	1.02 NS
Information not available	2	1	33.3%	-	-
Member of an organisation					
No	44	27	38.0%	1	1
Yes	142	79	35.7%	0.91 NS	0.85 NS
Missing values	14	13	48.1%	1.51 NS	1.59 NS
Reported caring for someone who was not their spouse or partner in the last week					
No	171	103	37.6%	1	1
Yes	29	16	35.6%	0.92 NS	0.97 NS

*NS = p≥0.1, *p<0.05; OR=Odds Ratio Long-term caring compared to short-term caring (reference), Uni=univariable odds ratio, Multi=Multivariable odds ration also including sex, age band, ethnic origin, economic activity, highest qualification, financial self-assessment at time 0*

Table 8-12 compares time variant demographic characteristics between Short-term and Long-term partner caregiver groups in the wave they reported moving into the caring role. The results suggest that those who reported not working when they first reported starting caring for their partner were more likely to become a Long-term caregiver for their partner. The results also suggest that those who were caring for someone in addition to caring for their partner were significantly less likely to become long-term caregivers.

Table 8-12: Comparison of time variant demographic factors between Short-term and Long-term caregivers over three consecutive waves

Demographic variables at second consecutive wave (time 1)	Partner carer role three waves			Odds Ratio	
	Short-term	Long-term	% Long-term	Uni§	Multi§
Economic activity					
Working	62	20	24.4%	1	1
Not working	33	23	41.1%	2.13 *	6.82 **
Retired	105	76	42.0%	2.24 *	9.03 **
How is respondent (and partner) getting along financially these days					
Manage very/quite well	130	77	37.2%	1	1
Get by alright	60	31	34.1%	0.87 NS	0.78 NS
Not manage very well	3	4	57.1%	2.25 NS	2.71 NS
Some/severe difficulties	7	6	46.2%	1.45 NS	1.21 NS
Information not available	0	1	100.0%	-	
Member of an organisation					
No	53	32	37.6%	1	1
Yes	124	67	35.1%	0.89 NS	0.94 NS
Missing values	23	20	46.5%	1.44 NS	1.38 NS
Reported caring for someone who was not their spouse or partner in the last week					
No	157	104	39.8%	1	1
Yes	43	15	25.9%	0.53 *	0.52 •

NS = p≥0.1, •p<0.1, *p<0.05, **p<0.005; OR=Odds Ratio Long-term caring compared to short-term caring (reference), Uni=univariable odds ratio, Multi=Multivariable odds ration also including sex, age band, ethnic origin, economic activity, highest qualification, financial self-assessment at time 0

Table 8-13 compares the health of the partner in the wave when Short-term and Long-term caregivers first reported caring for their partner. The results show that having a heart condition was the most common health problem reported. These results suggest that those caring for a partner who had had a stroke, a psychological or emotional disorder, were diagnosed with dementia or depression, or had difficulty in at least one ADL were significantly more likely to become Long-term caregivers.

Table 8-13: Comparison of partner health between short-term and long-term caregivers over three consecutive waves

Partner health at second wave (time 1)	Partner carer role three waves			Odds Ratio	
	Short-term	Long-term	% Long-term	Uni§	Multi§
Activities of daily living (ADL)					
No difficulty with any ADL	103	26	20.20%	1	1
Difficulty with at least one ADL	92	90	49.50%	3.88 **	4.06 **
Information not available	5	3	37.50%	2.38 NS	2.53 NS
Partner has had a stroke					
No	186	93	33.30%	1	1
Yes	9	23	71.90%	5.11 **	6.78 **
Information not available	5	3	37.50%	1.2 NS	1.3 NS
Partner has a heart condition					
No	74	41	35.70%	1	1
Yes	121	75	38.30%	1.12 NS	1.1 NS
Information not available	5	3	37.50%	1.08 NS	1.11 NS
Spouse/partner has been diagnosed with cancer in the last two years					
No	186	106	36.30%	1	1
Yes	9	10	52.60%	1.95 NS	1.65 NS
Information not available	5	3	37.50%	1.05 NS	1.07 NS
Spouse/partner has a psychological or emotional disorder					
No	186	106	36.30%	1	1
Yes	9	10	52.60%	2.42 *	2.74 *
Information not available	5	3	37.50%	1.15	1.18 NS
Spouse/Partner has been diagnosed with dementia or Alzheimers					
No	188	103	35.40%	1	1
Yes	7	13	65.00%	3.39 *	4.1 *
Information not available	5	3	37.50%	1.1	1.16 NS

*NS = p≥0.1, *p<0.05; OR=Odds Ratio Long-term caring compared to short-term caring (reference), Uni=univariable odds ratio, Multi=Multivariable odds ratio also including sex, age band, ethnic origin, economic activity, highest qualification, financial self-assessment at time 0, §Fixed effects only*

8.4.4 Summary of key findings for demographic and social factors

Cross-sectional

- Demographic factors associated with an increased likelihood of reporting caring for a partner, were: being older, possessing qualifications lower than A level or equivalent, not working, not getting along well financially, not being a member of an organisation, and caring for others in addition to their spouse or partner.

Longitudinal

- Starting caring for a partner was associated with not working or being retired, caring for someone else, and being less well off financially in the wave before starting caring for a partner.

- Starting caring for a partner was also associated with an increased likelihood of stopping being a member of an organisation
- Males were more likely to report being long term partner caregivers compared to females.
- Participants who were caring for a partner who needed help with daily activities, or who had been diagnosed with a stroke, psychological or emotional disorders, or Alzheimer's were more likely to still report caring for their partner in the next wave.

8.5 Health comparisons between partner caregivers and non-caregivers

This section compares health outcomes by partner caregiver status over one, two and three consecutive waves; for self-rated health, symptoms of depression (CES-D8) and quality of life (CASP-19). For two consecutive waves, health outcomes reported at the first of the consecutive wave, and change in health outcomes between consecutive waves were compared between Started-caring and Non-caring groups. For three consecutive waves change in health outcomes between the first and second consecutive waves were compared between Long-term and Short-term partner caregivers.

8.5.1 Responses at one time point

Self-rated health

Overall 90.7 per cent of all participant responses rated their self-rated health as fair or better.

Table 8-14 compares the odds of being a partner caregiver by self-rated health. Two multivariable models are included: Model 1 includes the self-rated health flag as an extraneous variable, while Model 2 also controls for other demographic factors. Both models are based on fixed effects only. The results show that participant responses who rated their health as poor, bad, or very bad were more likely to report being partner caregivers, compared to those who rated their health as fair or better, however when other factors were taken into account there was no difference in the likelihood of being a partner caregiver. This suggests that other factors account for these differences between the groups.

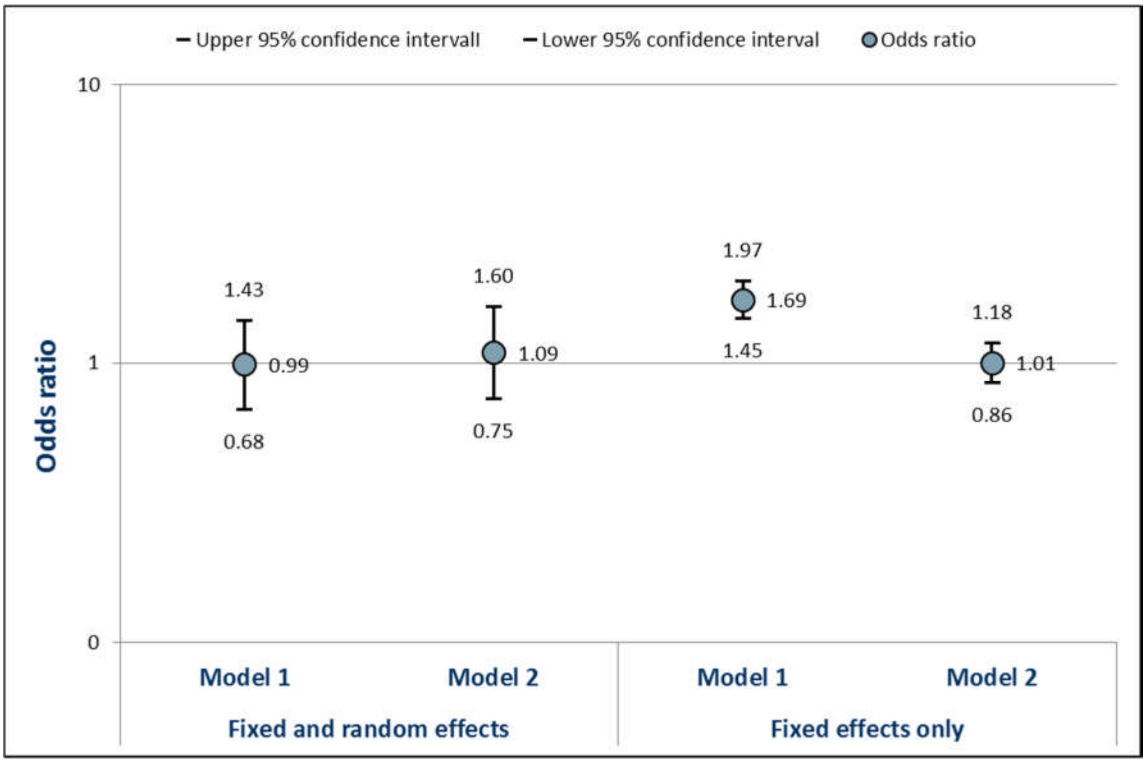
Table 8-14: Self-rated health by partner caregiver status

Health measure	Reported caring for partner			Odds Ratio	
	Yes	No	% Yes	Model 1§	Model 2§
Self-rated health response					
Fair or better	1808	30338	5.60%	1	1
Poor/bad/very bad	201	1996	9.10%	1.69 **	1.01 NS
Information not available	1	1072	0.10%	0.01 **	0.85 *
Self-rated health based on excellent to poor scale?					
Yes	644	9634	6.30%	1	1
No	1365	22700	5.70%	0.9 **	0.88 **

*NS = p≥0.1, *p<0.05, **p<0.005; Model 1:Odds ratio of caring for a partner compared to not reporting caring for a partner, including self-rated health and self-rated health flag only; Model 2: Odds ratio also including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment; OR=1:Reference category, § using fixed effects only*

The odds ratios for both fixed and mixed effects are presented in Figure 8-2. The results from the random effects model suggest that the difference in the odds of reporting being a partner caregiver by self-rated health can be almost wholly explained by the random variation within participants.

Figure 8-2: Odds ratios of reporting being a partner caregiver, for poor/bad/very bad compared to fair or better (reference) self-rated health



Model 1: Odds ratio of caring for a partner compared to not reporting caring for a partner, including self-rated health and self-rated health flag only; Model 2: Odds ratio also including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment

Symptoms of depression (CES-D8)

Just over 95 per cent of responses included full information to enable the calculation of a CES-D8 score.

Approximately 45 per cent of participant responses reported no depressive symptoms, based on the CES-D8 scale; of these 4.2 per cent reported looking after their partner, compared to between 7.5 per cent and 11.7 per cent for responses reporting two or more CES-D8 symptoms.

Table 8-15 presents the percentage and odds ratio of responses reporting being a partner caregiver, for each of the full range of possible total CES-D8 scores. Participant responders who reported two to seven CES-D8 depressive symptoms were significantly more likely to report looking after their partner, compared with responses reporting no CES-D8 symptoms. The results suggest that the odds ratios increase with each additional depressive symptom, up to seven symptoms, however these were based on fixed effects only due to non-convergence and small numbers for five or more symptoms of depression.

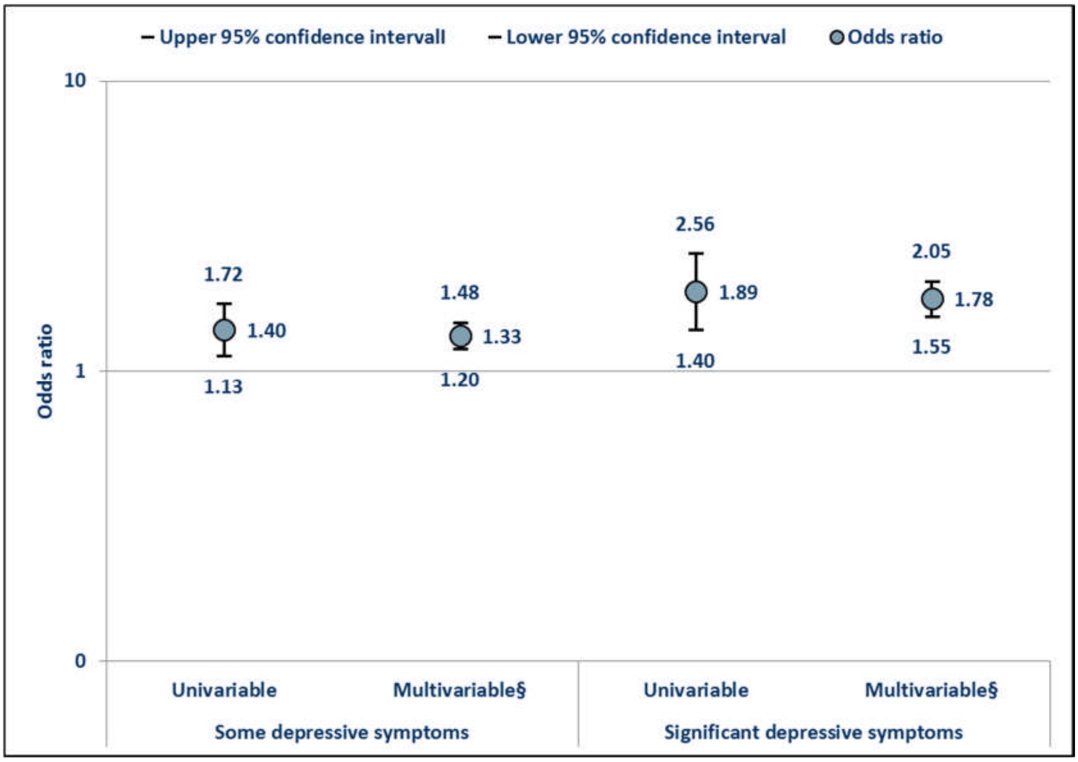
Table 8-15: CES-D8 score by partner caregiver status

Health measure CES-D	Reported caring for partner			Odds Ratio	
	Yes	No	% Yes	Uni	Multi§
0	680	15362	4.20%	1	1
1	456	7981	5.40%	1.13 NS	1.17 **
2	256	3167	7.50%	1.51 **	1.46 **
3	204	2002	9.20%	2.65 **	1.71 **
4	128	1213	9.50%	2.06 **	1.71 **
5	97	854	10.20%	2.04 **	1.83 **
6	83	624	11.70%	1.99 **	2.1 **
7	50	441	10.20%	2.83 **	1.85 **
8	20	230	8.00%	0.97 NS	1.3 NS
Information not available	36	1532	2.30%	0.36 **	0.43 **

NS = p≥0.1,**0<0.005; Uni=Odds ratio of caring for a partner compared to not reporting caring for a partner;Multi=Multivariable odds ratio also including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment; OR=1:Reference category, § using fixed effects only

Figure 8-3 presents the odds ratios for the CES-D8 score categories Some depressive symptoms (scores 1 to 3) and Significant depressive symptoms (score 4 or more), compared with No depressive symptoms, and shows that participant responses reporting some or significant depressive symptoms were significantly more likely to also report looking after their partner, compared to responses reporting No depressive symptoms. There was little change in the odds ratios when demographic variables were also included in the model, however as the multivariable analysis was based on a fixed effects model the confidence intervals are smaller.

Figure 8-3: Odds ratios of reporting being a partner caregiver for participant responses reporting some or significant CES-D8 depressive symptoms (Reference: No depressive symptoms)



Multivariable odds ratio also including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment; § using fixed effects only

Quality of life (CASP-19)

A total of 84 per cent of participant responses included complete information to enable the calculation of a total CASP-19 score.

Figure 8-4 shows that although the distribution of CASP-19 scores are positively skewed, represented by the maximum and minimum values, the inter quartile ranges around the medians are both fairly symmetrical, suggesting that removing outlier CASP-19 scores results in a fairly normal distribution. This is backed up by mean values (presented in Table 8-16) which are similar to the median scores.

Figure 8-4: Box and whisker plot showing distribution of CASP-19 scores by partner caregiver status

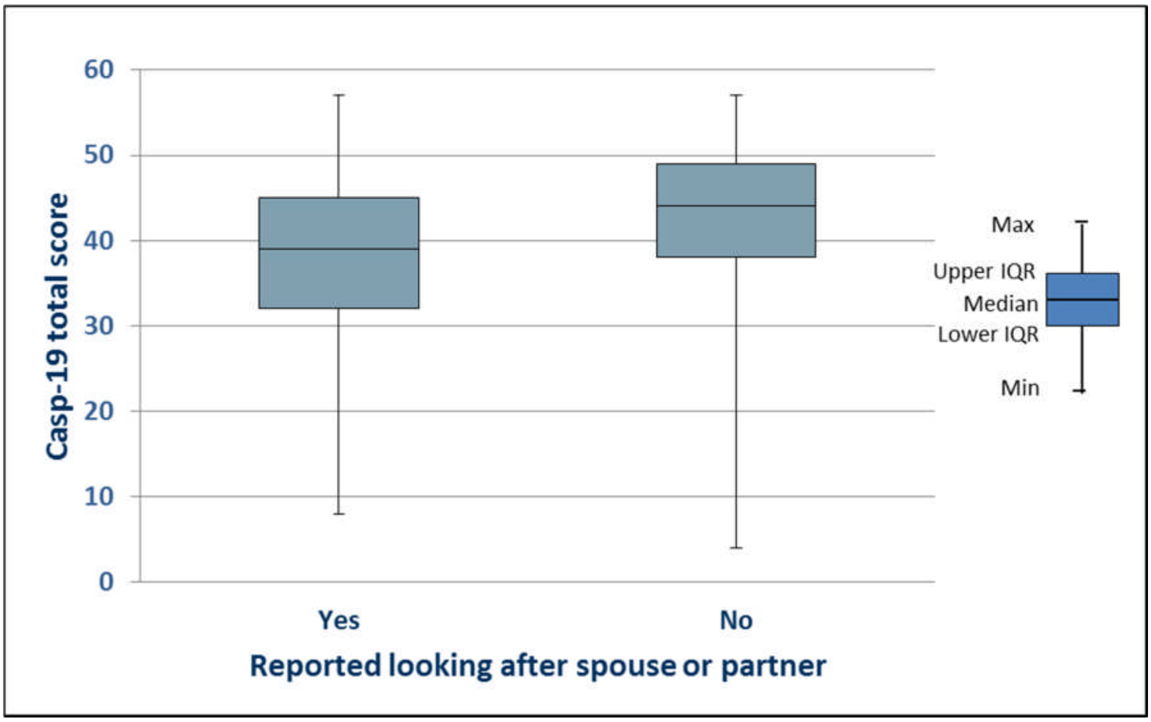


Table 8-16 presents the odds of reporting being a partner caregiver, per point of CASP-19, and shows being a partner caregiver was significantly associated with CASP-19 scores, with participant responses with higher CASP-19 scores being significantly less likely to report being a partner caregiver. These results suggest that reporting caring for a partner was associated with a lower quality of life.

Table 8-16: CASP-19 score by partner caring status

CASP-19	Reported caring for partner		Odds Ratio	
	Yes	No	Uni	Multi
Mean	40.12	42.23	0.94 **	0.96 **
Lower 95% confidence interval	39.79	42.08		
Upper 95% confidence interval	40.44	42.38		

***p<0.005; Univariable odds ratio of caring for a partner compared to not reporting caring for a partner; Multivariable odds ratio also including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment*

8.5.2 Responses over two consecutive ELSA waves

The results presented in Table 8-17 suggest that there was no significant difference in the likelihood of being in the Started-caring group, whether self-rated health responses in the first of the two consecutive waves were poor, bad, or very bad; or fair or better. The results also suggest that there was no significant difference in the likelihood of starting to care for a partner, between participant responses in the first wave with some or significant depressive symptoms, compared to responses with no depressive symptoms. Quality of life, measured using the CASP-19, was significantly lower in the first of the two consecutive waves for those who went on to report caring for their partner in the next wave.

Comparing these results with the results for one time point, which showed that partner caregivers reported more depressive symptoms, suggest that taking on a caregiver role is associated with an increase in depressive symptoms.

Table 8-17: Odds of starting caring for a partner by health measures at first consecutive wave

Health measure at first consecutive wave (time 0)	Partner carer role two waves			Odds Ratio	
	Non-caring	Started	% Started	Uni§	Multi§
Self-rated health response					
Fair or better	19270	582	2.90%	1	1
Poor/bad/very bad	1056	37	3.40%	1.16 NS	0.8 NS
Information not available	379	8	2.10%	0.7 NS	0.58 NS
CESD score					
No depressive symptoms	9946	272	2.70%	1	1
Some depressive symptoms	8222	270	3.20%	1.2 *	1.08 NS
Significant depressive symptoms	1955	75	3.70%	1.4 *	1.13 NS
Information not available	582	10	1.70%	0.63 NS	0.47 *
CASP-19 score					
Mean CASP-19	42.9	41.48		0.94 **	0.98 **
Lower 95% confidence interval	42.73	40.96			
Upper 95% confidence interval	43.07	42.01			
Valid CASP-19 scores	17944	535	2.90%		
Information not available	2761	92	3.20%		

*NS = p≥0.1, *p<0.05, **p<0.005; Uni=Odds ratio of starting caring for a partner compared to not reporting caring for a partner both time points; Multi=Multivariable odds ratio also including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment; OR=1:Reference category; §Fixed effects only*

Table 8-18 presents the results from the analysis assessing change in health outcomes between the two consecutive waves, by partner carer group. These results suggest that participant responses who reported starting caring for their partner were more likely to experience an increase in depression scores, based on CES-D8, and a reduction in their quality of life, based on CASP-19, after taking on the caregiver role, compared to consecutive participant responses reporting that they did not start caring for their partner. This is consistent with the results above and across one time point, which showed a significant association between these health outcomes and the likelihood of responses reporting caring for their spouse or partner.

Table 8-18: Odds of starting caring for a partner by change in health over two consecutive waves

Change between consecutive waves (time 0 to time 1)	Partner carer role two waves			Odds Ratio	
	Non-caring	Started	% Started	Uni	Multi§
Self-rated health (based on binary responses)					
Worse self-rated health	585	24	3.9%	1	1
Same self-rated health	18946	581	3.0%	0.75 NS	1 NS
Better self-rated health	511	14	2.7%	0.67 NS	0.65 NS
Incomplete information	663	8	1.2%	0.29 NS	0.31 *
CESD (based on scores 0 to 8)					
Worse CESD score (higher)	5299	205	3.7%	1	1
Same CESD score	9201	254	2.7%	0.71 **	0.79 *
Better CESD score (Lower)	5213	150	2.8%	0.74 *	0.77 *
Incomplete information	992	18	1.8%	0.47 **	0.39 **
CASP-19					
Worse CASP-19 (Lower)	7960	278	3.4%	§1	1
Same CASP-19	1475	32	2.1%	§0.62 *	0.67 *
Better CASP-19 (Higher)	6660	163	2.4%	§0.70 **	0.74 **
Incomplete information	4610	154	3.2%	§0.96 NS	0.82 •

*NS = p≥0.1, •p<0.1, *p<0.05, **p<0.005; Uni=Odds ratio of starting caring for a partner compared to not reporting caring for a partner both time points; Multi=Multivariable odds ratio also including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment; OR=1:Reference category; §Fixed effects only*

8.5.3 Responses over three consecutive ELSA waves

Results on change in health between Short-term and Long-term caregivers are reported in Table 8-19.

The odds ratios showed no significant difference in the changes experienced in self-rated health, symptoms of depression, or quality of life between Short-term and Long-term caregivers, however this analysis was based on a small number of responders which may be underpowered.

Table 8-19: Odds of caring for a partner long-term by change in health measures from time 0 to time 1

Change between first two consecutive waves	Partner carer role three waves			Odds Ratio	
	Short-term	Long-term	% Long-	Uni§	Multi§
Change in Self Rated Health (based on binary responses)					
Worse (Fair to poor_)SRH	7	6	46.2%	1	1
Same SRH	190	109	36.5%	0.67 NS	0.85 NS
Better (Poor to fair) SRH	1	4	80.0%	4.67 NS	5.96 NS
Incomplete information	2	0	46.2%	-	
Change in CESD (based on scores 0 to 8)					
Worse (Higher) CESD	55	37	40.2%	1	1
Same CESD	80	51	38.9%	0.95 NS	0.93 NS
Better (Lower)CESD	59	28	32.2%	0.71 NS	0.67 NS
Incomplete information	6	3	33.3%	-	
Change in CASP19					
Worse (lower) CASP19	93	53	36.3%	1	1
Same CASP19	15	4	21.1%	0.47 NS	0.55 NS
Better (Higher) CASP19	47	33	41.3%	1.23 NS	1.31 NS
Incomplete information	45	29	39.2%	-	-

*NS = $p \geq 0.1$, *$p < 0.05$; OR=Odds Ratio Long-term caring compared to short-term caring (reference), Uni=univariable odds ratio, Multi=Multivariable odds ration also including sex, age band, ethnic origin, economic activity, highest qualification, financial self-assessment at time 0*

8.5.4 Summary of key findings for health comparisons

Cross-sectional

- Caring for a partner was associated with more symptoms of depression and poorer quality of life.

Longitudinal

- Participants who went on to care for their spouse or partner in the next wave were more likely to report lower quality of life even before caring for their spouse or partner

- Participants who started caring for their partner were more likely to report an increase in their symptoms of depression and a reduction in their quality of life compared to participants who did not start caring for their partner.

- There was no significant difference in the likelihood of becoming a long-term carer, compared to a short-term caregiver, between health outcomes, however these were based on small numbers.

8.6 Associations between health and other demographic and social factors for partner caregivers

Associations between demographic and social factors and the health outcomes self-rated health, CED-D, and CASP-19 were compared for participants who reported caring for their partner. Comparisons over one time point assess associations for participant responses reporting that they care for their partner. Comparisons over two consecutive waves assess the associations between demographic factors, reported at the first of the two consecutive waves, and change in health outcomes when taking on a partner caregiver role.

8.6.1 Responses at one time point

Table 8-20 presents the results from the multivariable analysis which explored the demographic factors associated with self-rated health, CES-D8 and CASP-19 for responses reporting caring for their partner.

Due to non-convergence the odds ratios for self-rated health and CES-D8, from the multivariable analysis, were based on fixed effects only models. Each health outcome was analysed separately and only responses with valid health outcome values were included in the analysis.

Participant responses from partner caregivers were more likely to report poor, bad, or very bad health if they were male, not working or retired, reported having no qualifications, not managing very or quite well financially, not a member of an organisations, and were not caring for someone else as well as their partner.

Participant responses from partner caregivers were more likely to report some or significant depressive symptoms if they were female, not working or retired, not managing very or quite well financially, not a member of an organisation, and not also caring for someone else. Responses from relatively younger partner caregivers were more likely to report some depressive symptoms, compared to partner caregivers ages 60 to 80 years. Responses from partner caregivers who were recorded as ‘Not white’ were more likely to report significant depressive symptoms compared to ‘White’ partner caregivers.

Lower quality of life, measured using the CASP-19, was associated with responses from partner caregivers who were older (aged 80 and over), not working or retired, had lower or no qualifications, not managing very or quite well financially, and not a member of an organisation.

Table 8-20: Odds Ratios and β coefficients from multivariable modelling of health outcomes by demographic characteristics, for responses reporting caring for their partner

Demographic variables	**Self-rated OR §**	**CES-D:Some^2 OR §**	**CES-D:Sig^3 OR §**	**CASP-19 β**
Responses included (No.s)	2009	1974	1974	1689
Sex				
Male	1	1	1	0
Female	0.58 **	2.66 **	1.79 **	0.2 NS
Age band (years)				
50-59	1	1	1	0
60-69	0.7 NS	0.58 *	0.91 NS	1.11 †
70-79	0.76 NS	0.63 *	0.8 NS	-0.08 NS
80+	0.93 NS	0.93 NS	1.04 NS	-4.13 **
Ethnic origin				
White	1	1	1	0
Not white	1.11 NS	1.37 NS	3.02 **	-1.28 NS
Information not available	-	-	-	-
Economic activity				
Working	1	1	1	0
Not working	4.3 **	2.15 **	2.08 **	-3.2 **
Retired	3.61 **	1.68 *	1.56 *	-1.53 *
Highest qualification				
A level/higher	1	1	1	0
NVQ 1-2/O level	1.4 NS	1.14 NS	1.18 NS	-1.89 **
Foreign/other	2.29 NS	1.16 NS	1 NS	-0.74 NS
No qualifications	2.59 **	1.34 NS	1.18 NS	-1.3 *
Information not available	-	-	-	-
How is respondent (and partner) getting along financially these days				
Manage very/quite well	1	1	1	0
Get by alright	1.73 **	1.69 **	1.68 **	-3.24 **
Not manage very well	4.8 **	2.08 NS	2.43 *	-5.39 **
Some/severe difficulties	2.39 *	3.06 *	3.56 **	-8.11 **
Information not available	-	-	-	-
Member of an organisation				
No	1	1	1	0
Yes	0.7 *	0.62 **	0.67 **	2.57 **
Missing values	0.89 NS	1.19 NS	1.13 NS	0.04 NS
Reported caring for someone who was not their spouse or partner in the last week				
No	1	1	1	0
Yes	0.51 *	0.6 *	0.66 *	0.36 NS

*NS = p≥0.1, †p<0.1, **p<0.005; ^{1} Poor/Bad/Vey bad vs. Fair or better (reference); ^{2} Some vs, None (Reference); ^{3} Significant vs. Not significant (reference); Multivariable included sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment, membership to an organisation and caring for others; OR=Odds ratio; OR 1:Reference category; β=Beta coefficient from linear models, β=0: Reference category; § Fixed effects only; '-' = not reported due to low numbers.*

Table 8-21 presents the results comparing partner ADL scores by each of the health outcomes.

The participant responses from partner caregivers looking after partners who required help with five or more ADL were more likely to report their health as poor, bad, or very bad; experience some or significant symptoms of depression; and experience lower quality of life; compared to partner responses looking after partners who required no assistance with any ADL. These results suggest that poorer health outcomes, in terms of self-reported health, depressive symptoms, and quality of life, were positively associated with the amount of assistance that was required by the partners.

Table 8-21: Odds Ratios and β coefficients for health outcomes by ADL scores from multivariable modelling, for responders who reported caring for their partner

Partner ADL score (difficulty with)	Self-rated OR §	CES-D:Some[2] OR §	CES-D:Sig[3] OR §	CASP-19 β
Responses included (No.s)	2009	1974	1974	1689
No ADL	1	1	1	0
One ADL	0.99 NS	1.03 NS	1.44 •	-0.2 NS
Two to four ADL	1.26 NS	1.34 •	1.4 *	-1.77 **
Five or six ADL	1.73 *	2.13 **	1.9 **	-3.68 **

*NS = p≥0.1, •p<0.1, **P<0.005; ADL=Activities of Daily Living; [1] Poor/Bad/Vey bad vs. Fair or better (reference); [2] Some vs, None (Reference); [3] Significant vs. Not significant (reference); Multivariable included sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment; OR=Odds ratio; OR 1:Reference category; β=Beta coefficient from linear models, β=0: Reference category; § Fixed effects only.*

8.6.2 Responses over two consecutive ELSA waves

Table 8-22 presents the results from the multivariable analysis exploring the demographic characteristics associated with change in self-rated health, symptoms of (CES-D8), and quality of life (CASP-19) for consecutive participant responses indicating that participants Started-caring. The separate analyses undertaken for the three health outcomes included only consecutive responses where valid responses to self-rated health, CES-D8, and CASP-19 were available for both consecutive waves. The results from the self-rated health and CES-D8 analyses were based on fixed effects only, due to non-convergence.

The results suggest that no demographic factors, measured at the first of the consecutive waves before starting partner caring, were associated with change in self-rated health after taking on a caregiver role, after controlling for all other demographic factors.

In terms of change in symptoms of depression, women and participant responses from those who were not working appear to have been more likely to change from no depressive symptoms to one or more depressive symptom, based on CES-D8, when taking on a caring role for their partner.

Table 8-22: Odds ratios and β coefficients from ANCOVA multivariable modelling of change in health outcomes by demographic characteristics at time 0, for consecutive participant responses who Started-caring for their partner at time 1

Variables at first consectutive wave (time 0)	Self-rated OR §	CES-D:Some[2] OR §	CES-D:Sig[3] OR §	CASP-19 β
Responses included (No.s)	627	617	617	473
Sex				
Male	1	1	1	0
Female	0.56 NS	1.65 *	1.25 NS	-0.29 NS
Age band (years)				
50-59	1	1	1	0
60-69	0.42 NS	0.72 NS	1.17 NS	0.57 NS
70-79	0.78 NS	0.69 NS	1.22 NS	-1.22 NS
80+	0.67 NS	1.89 NS	2.79 •	-3.74 *
Ethnic origin				
White	1	1	1	0
Not white	5.87 •	0.84 NS	4.77 •	3.22 NS
Information not available	-	-	-	-
Economic activity				
Working	1	1	1	0
Not working	1.76 NS	2.07 *	1.4 NS	0 NS
Retired	2.8 NS	1.71 •	1.2 NS	0.19 NS
Highest qualification				
A level/higher	1	1	1	0
NVQ 1-2/O level	1.92 NS	1.04 NS	0.91 NS	-1.51 NS
Foreign/other	3.56 •	0.91 NS	0.53 NS	0.15 NS
No qualifications	2.21 NS	1 NS	0.89 NS	-0.96 NS
Information not available	-	-	-	-
How is respondent (and partner) getting along financially these days				
Manage very/quite well	1	1	1	0
Get by alright	1.53 NS	1.03 NS	1.64 •	-1.07 NS
Not manage very well	1.68 NS	0.43 NS	0 NS	3.72 NS
Some/severe difficulties	0 NS	1.31 NS	4.63 *	-1.92 NS
Information not available	-	-	-	-
Member of an organisation				
No	1	1	1	0
Yes	0.98 NS	0.79 NS	0.53 *	0.78 NS
Missing values	0.57 NS	1.66 NS	0.56 NS	0.26 NS
Reported caring for someone who was not their spouse or partner in the last week				
No	1	1	1	0
Yes	1.09 NS	0.92 NS	1.79 NS	-0.24 NS

*NS = p≥0.1, •p<0.1, *p<0.05, **P<0.005; [1] Odds ratio of poor, bad or very bad self-rated health at time 1, with self-rated health, sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment at time 0 included as covariates; [2] Odds ratio of 1 or more, compared to no, depressive symptoms at time 1, with CES-D score, sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment at time 0 included as covariates; [3] Odds ratio of 4 or more, compared to 3 or less, depressive symptoms at time 1, with CES-D score, sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment at time 0 included as covariates; OR=1:Reference category; §Fixed effects only*

Partner caregiver's who reported experiencing some or severe financial difficulties and partner caregiver's who reported not being a member of an organisation in the first of the consecutive waves before caring, were more likely to observe an increase in their symptoms of depression, when taking on a caring role for their partner, to the extent that they were considered to have significant depressive symptoms.

Participant responses from older participants (aged 80 years plus), experienced a significantly worse change in their quality of life when taking on a caring role for their spouse or partner, compared to those aged 50 to 59 years.

8.6.3 Summary of key findings for health outcomes and demographic and social factors

Cross-sectional

- Demographic factors associated with poorer self-rated health, more symptoms of depression, and lower quality of life, for participant responses who reported caring for their partner, were: being retired or not working, not managing well financially, not being a member of an organisation, not caring for others, and looking after a partner who required help with a lot of activities (at least five ADL).

- Male caregivers reported fewer symptoms of depression compared to female caregivers, but were more likely to rate their health as poor.

Longitudinal

- Females, and those who were retired or not working before looking after their partner, were more likely to report a change from no depressive symptoms to some depressive symptoms after starting caring for their partner.

- Those experiencing some or severe financial difficulties, or who were not a member of an organisation, before looking after their partner were more likely to report a change from some to significant depressive symptoms after starting caring for their spouse or partner.

- Starting caring for a partner was more detrimental to quality of life for older responders compared to those aged 50 to 59 years.

8.7 Personal relationship comparisons between partner caregivers and non-caregivers

This section compares the scores for the latent variables reflecting the quality and level of contact for each personal relationship type, by partner caregiver status; over one, two and three consecutive waves. For two consecutive waves, the latent variables representing the quality of, and level of contact with, different personal relationship types at the first of the consecutive wave (time 0), and change in the latent variable scores between consecutive waves, were compared between Started-caring and Non-caring groups. Change in personal relationship latent variable scores between the first and second consecutive waves were compared between Long-term and Short-term partner caregivers in the analysis based on three consecutive waves.

8.7.1 Responses at one time point

Spouse or partner relationship

Overall 86.9 per cent of participant responses included complete information to the partner questions within the self-rated health questionnaire.

Table 8-23 shows that there was a significant relationship between the quality of the partner relationship and the odds of caring for their partner, with responses who reported that they cared for their partner experiencing a significantly lower quality of relationship with their partner.

Table 8-23: Quality of partner relationship by partner caregiver status

Partner relationship	**Reported caring for a partner**			**Odds Ratio**	
	Yes	**No**	**% Yes**	**Model 1**	**Model 2**
Quality of partner relationship (all responses)					
Mean latent variable score	-0.165	-0.067		0.73 **	0.77 **
Lower 95% confidence interval	-0.194	-0.08			
Upper 95% confidence interval	-0.136	-0.055			
Do you have a partner?					
No	3	26	10.3%	1	1
Yes	1826	29646	5.8%	0.72 NS	0.71 NS
Information not available	181	3734	4.6%	0.23 NS	0.25 NS
Number of valid variables					
Incomplete responses	252	4399	5.4%	1	1
Complete responses	1758	29007	5.7%	0.51 *	0.57 *

*NS = p≥0.1, *p<0.05, **p<0.005; Model1=Odds ratio of caring for a partner compared to not reporting caring for a partner, taking into account only the three partner quality variables; Model2=Multivariable odds ratio also including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment; OR=1:Reference category*

Relationship with children

Most responders (91.2 per cent) who provided a valid response to the question regarding whether they had any children reported that they did have children. Of these 94.0 per cent provided complete information for the quality of relationship with children questions.

The odds ratio and level of statistical significance reported in Table 8-24 suggest that there was no significant difference between the quality of the relationship responses reported having with their children and the likelihood of caring for their partner.

Table 8-24: Quality of children relationships by partner caregiver status

Children relationship	Reported caring for a partner			Odds Ratio	
	Yes	No	% Yes	Model 1	Model 2
Quality of children relationship (all responses)					
Mean latent variable score	-0.051	-0.048		0.97 NS	0.94 NS
Lower 95% confidence interval	-0.081	-0.06			
Upper 95% confidence interval	-0.022	-0.036			
Do you have any children?					
No	185	2592	6.7%	1	1
Yes	1638	27030	5.7%	0.71 NS	0.57 •
Information not available	187	3784	4.7%	0.43 **	0.38 **
Number of valid variables					
Incomplete responses	493	7981	5.8%	1	1
Complete responses	1517	25425	5.6%	0.96 NS	1.06 NS

*NS = p≥0.1, •p<0.1, **p<0.005; Model1=Odds ratio of caring for a partner compared to not reporting caring for a partner, taking into account only the three partner quality variables; Model2=Multivariable odds ratio also including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment; OR=1:Reference category*

Complete information for the level of contact with children was provided by 93.3 per cent of responses who reported having children.

In contrast to the results for quality of relationship with children, presented above, Table 8-25 suggests that participant responses who reported caring for their partner had significantly more contact with their children than responses who did not report looking after their partner.

Table 8-25: Level of contact with children by partner caregiver status

Children relationship	Reported caring for a partner			Odds Ratio	
	Yes	No	% Yes	Model 1	Model 2
Contact with children					
Mean latent variable score	0.049	0.025		1.21 *	1.22 *
Lower 95% confidence interval	0.024	0.014			
Upper 95% confidence interval	0.075	0.036			
Do you have any children?					
No	185	2592	6.7%	1	1
Yes	1638	27030	5.7%	0.4 **	0.37 **
Information not available	187	3784	4.7%	0.42 **	0.37 **
Number of valid variables					
Incomplete responses	460	8222	5.3%	1	1
Complete responses	1550	25184	5.8%	1.72 *	1.65 *

**=p<0.05, **p<0.005; Model1=Odds ratio of caring for a partner compared to not reporting caring for a partner, taking into account only the three partner quality variables; Model2=Multivariable odds ratio also including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment; OR=1:Reference category*

These results also suggest that when the level of contact with children is taken into account participant responses from participants who have children were significantly less likely to report being a carer for their partner.

Relationship with family

The percentage of participant responses providing complete information to enable the calculation of valid family quality and level of contact latent variables were 72.8 per cent and 70.1 per cent respectively. Based on valid responses to the question ascertaining if responders had any other family, the majority (93.3 per cent) of responses reported that they did have other family members.

Results presented in Table 8-26 and Table 8-27 suggest that there was no significant difference in the quality of family relationships or level of contact with family members between responses reporting they cared for their partner and responses not reporting that they cared for their partner.

Table 8-26: Quality of family relationships by partner caregiver status

Family relationship	Reported caring for a partner			Odds Ratio	
	Yes	No	% Yes	Model 1	Model 2
Quality of family relationship					
Mean latent variable score	-0.01	-0.013		1.02 NS	1.01 NS
Lower 95% confidence interval	-0.042	-0.025			
Upper 95% confidence interval	0.022	-0.001			
Do you have any family?					
No	149	1941	7.1%	1	1
Yes	1665	27593	5.7%	0.81 NS	0.8 NS
Information not available	196	3872	4.8%	0.6 *	0.62 *
Number of valid variables					
Incomplete responses	571	9064	5.9%	1	1
Complete responses	1439	24342	5.6%	1.19 NS	1.28 •

*NS = $p \geq 0.1$, •$p < 0.1$, *$p < 0.05$; Model1=Odds ratio of caring for a partner compared to not reporting caring for a partner, taking into account only the three partner quality variables; Model2=Multivariable odds ratio also including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment; OR=1:Reference category*

Table 8-27: Level of contact with family by partner caring status

Family relationship	Reported caring for a partner			Odds Ratio	
	Yes	No	% Yes	Model 1	Model 2
Contact with family					
Mean latent variable score	0.024	0.018		0.96 NS	0.96 NS
Lower 95% confidence interval	-0.008	0.007			
Upper 95% confidence interval	0.056	0.028			
Do you have any family?					
No	149	1941	7.1%	1	1
Yes	1665	27593	5.7%	1.18 NS	1.14 NS
Information not available	196	3872	4.8%	0.6 *	0.61 *
Number of valid variables					
Incomplete responses	679	9681	6.6%	1	1
Complete responses	1331	23725	5.3%	0.74 *	0.81 NS

*NS = p≥0.1, *p<0.05; Model1=Odds ratio of caring for a partner compared to not reporting caring for a partner, taking into account only the three partner quality variables; Model2=Multivariable odds ratio also including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment; OR=1:Reference category*

Relationship with friends

Complete information on the quality of, and the level of contact with, friends was provided by 76.9 per cent and 70.7 per cent of responses respectively. Overall, 95.1 per cent of valid responses to the question ‘Do you have any friends?’ reported having friends.

There is no significant difference in the quality of friendships, or the level of contact, between responses reporting caring for their partner and responses not reporting caring partner (Table 8-28 and Table 8-29).

Table 8-28: Quality of friendships by partner caring status

Friend relationship	Reported caring for a partner			Odds Ratio	
	Yes	No	% Yes	Model 1	Model 2
Quality of friend relationships					
Mean latent variable score	-0.052	-0.038		0.99 NS	1 NS
Lower 95% confidence interval	-0.085	-0.05			
Upper 95% confidence interval	-0.02	-0.026			
Do you have any friends?					
No	154	1384	10.0%	1	1
Yes	1651	28107	5.5%	0.82 NS	0.81 NS
Information not available	205	3915	5.0%	0.46 **	0.48 **
Number of valid variables					
Incomplete responses	533	7649	6.5%	1	1
Complete responses	1477	25757	5.4%	0.76 •	0.84 NS

*NS = p≥0.1, •p<0.1, **p<0.005; Model1=Odds ratio of caring for a partner compared to not reporting caring for a partner, taking into account only the three partner quality variables; Model2=Multivariable odds ratio also including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment; OR=1:Reference category*

Table 8-29: Level of contact with friends by partner caring status

Friend relationship	Reported caring for a partner			Odds Ratio	
	Yes	No	% Yes	Model 1[1]	Model 2[2]
Contact with friends					
Mean latent variable score	0.021	0.003		1.12 NS	1.14 •
Lower 95% confidence interval	-0.01	-0.008			
Upper 95% confidence interval	0.051	0.013			
Do you have any friends?					
No	154	1384	10.0%	1	1
Yes	1651	28107	5.5%	0.76 NS	0.75 NS
Information not available	205	3915	5.0%	0.47 **	0.5 **
Number of valid variables					
Incomplete responses	679	9681	6.6%	1	1
Complete responses	1331	23725	5.3%	0.85 NS	0.96 NS

*NS = p≥0.1, •p<0.1, **P<0.005; Model1=Odds ratio of caring for a partner compared to not reporting caring for a partner, taking into account only the three partner quality variables; Model2=Multivariable odds ratio also including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment; OR=1:Reference category*

8.7.2 Responses over two consecutive ELSA waves

Comparisons with personal relationships at time 0

Spouse or Partner

Table 8-30 suggests that there was no difference in the likelihood of starting caring based on the quality of the partner relationship reported in the first wave (time 0).

Table 8-30: Partner quality at first consecutive wave by partner caregiver status over two consecutive waves

Partner relationship at first consecutive wave (time 0)	Partner caregiver role two waves			Odds Ratio	
	Non-caring	Started	% Started	Model 1§	Model 2§
Quality of spouse or partner relationship					
Mean latent variable score	-0.039	-0.044		0.95 NS	0.96 NS
Lower 95% confidence interval	-0.054	-0.092			
Upper 95% confidence interval	-0.023	0.003			
Do you have a partner?					
No	10	0		1	1
Yes	18910	580	3.1%	Large NS	Large NS
Information not available	1785	47	2.6%	Large NS	Large NS
Number of valid variables					
Incomplete responses	2180	59	2.7%	1	1
Complete responses	18525	568	3.1%	0.99 NS	1.25 NS

*NS = p≥0.1, *p<0.05, **P<0.005; Model1=Odds ratio of starting caring for a partner compared to not reporting caring for a partner both time points, taking into account only the three partner quality variables; Model2=Multivariable odds ratio also including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment; OR=1:Reference category; §Fixed effects only*

Children

Table 8-31 suggests that there were no significant associations between the likelihood of starting caring for a partner and relationship with children, for either the quality of the relationship with children or the level of contact with children reported at time 0. These results do suggest that participants who have children were less likely to take on a caregiver role for their partner, which lends further support to the results presented in Table 8.25.

Table 8-31: Children quality and level of contact at first consecutive wave by partner caregiver status over two consecutive waves

Children relationship at first consecutive wave (time 0)	Partner caregiver role two waves			Odds Ratio	
	Non-caring	Started	% Started	Model 1§	Model 2§
Quality of children relationship					
Mean latent variable score	-0.045	-0.017		1 NS	0.91 NS
Lower 95% confidence interval	-0.06	-0.066			
Upper 95% confidence interval	-0.031	0.032			
Do you have any children?					
No	1618	64	3.8%	1	1
Yes	17298	515	2.9%	0.91 NS	0.64 *
Information not available	1789	48	2.6%	0.68 *	0.56 **
Number of valid variables					
Incomplete responses	4323	145	3.2%	1	1
Complete responses	16382	482	2.9%	0.82 NS	1.03 NS
Contact with children					
Mean latent variable score	0.025	-0.023		0.9 •	0.97 NS
Lower 95% confidence interval	0.012	-0.066			
Upper 95% confidence interval	0.038	0.019			
Do you have any children?					
No	1618	64	3.8%	1	1
Yes	17298	515	2.9%	0.74 NS	0.74 NS
Information not available	1789	48	2.6%	0.7 †	0.57 **
Number of valid variables					
Incomplete responses	4630	145	3.0%	1	1
Complete responses	16075	482	2.9%	1.03 NS	0.9 NS

*NS = p≥0.1, •p<0.1, *p<0.05, **P<0.005; Model1=Odds ratio of starting caring for a partner compared to not reporting caring for a partner both time points, taking into account having any children and responding to all questions, analysing quality and contact separately; Model2=Multivariable odds ratio also including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment; OR=1:Reference category; §Fixed effects only*

Family

Table 8-32 suggests that there was no difference in the likelihood of starting caring for a partner, based on the quality of the relationship with family, or the level of contact with family, reported in the first consecutive wave (time 0).

Table 8-32: Family quality and level of contact at time 0 by partner status over two consecutive waves

Family relationship at first consecutive wave (time 0)	Partner caregiver role two waves Non-caring	Started	% Started	Odds Ratio Model 1§	Model 2§
Quality of family relationships					
Mean latent variable score	-0.008	-0.04		0.94 NS	0.92 NS
Lower 95% confidence interval	-0.023	-0.093			
Upper 95% confidence interval	0.007	0.014			
Do you have other family?					
No	1200	38	3.1%	1	1
Yes	17659	543	3.0%	1.08 NS	1.03 NS
Information not available	1846	46	2.4%	0.79 NS	0.83 NS
Number of valid variables					
Incomplete responses	5171	157	2.9%	1	1
Complete responses	15534	470	2.9%	0.89 NS	1.09 NS
Contact with family members					
Mean latent variable score	0.011	0.043		1.08 NS	1.09 NS
Lower 95% confidence interval	-0.002	-0.01			
Upper 95% confidence interval	0.025	0.096			
Do you have other family?					
No	1200	38	3.1%	1	1
Yes	17659	543	3.0%	1.08 NS	1.06 NS
Information not available	1846	46	2.4%	0.78 NS	0.83 NS
Number of valid variables					
Incomplete responses	5540	171	3.0%	1	1
Complete responses	15165	456	2.9%	0.88 NS	1.07 NS

*NS = p≥0.1, *p<0.05, **P<0.005; Model1=Odds ratio of starting caring for a partner compared to not reporting caring for a partner both time points, taking into account having any family and responding to all questions, analysing quality and contact separately; Model2=Multivariable odds ratio also including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment; OR=1:Reference category; §Fixed effects only*

Friends

Table 8-33 suggests that there was no difference in the likelihood of starting caring based on the quality of the relationship, or the level of contact, responses reported having with their friends at time 0.

Table 8-33: Friendship quality and level of contact at time 0 by partner status over two consecutive waves

Friend relationship at first	Partner caregiver role two waves			Odds Ratio	
consecutive wave (time 0)	Non-caring	Started	% Started	Model 1§	Model 2§
Quality of friend relationships					
Mean latent variable score	-0.035	-0.053		0.94 NS	0.94 NS
Lower 95% confidence interval	-0.049	-0.108			
Upper 95% confidence interval	-0.02	0.002			
Do you have any friends?					
No	787	28	3.4%	1	1
Yes	18048	553	3.0%	0.93 NS	0.86 NS
Information not available	1870	46	2.4%	0.69 NS	0.73 NS
Number of valid variables					
Incomplete responses	3992	119	2.9%	1	1
Complete responses	16713	508	2.9%	0.92 NS	1.17 NS
Contact with friends					
Mean latent variable score	-0.007	-0.019		0.94 NS	0.97 NS
Lower 95% confidence interval	-0.02	-0.07			
Upper 95% confidence interval	0.007	0.031			
Do you have any friends?					
No	787	28	3.4%	1	1
Yes	18048	553	3.0%	1 NS	0.98 NS
Information not available	1870	46	2.4%	0.69 NS	0.73 NS
Number of valid variables					
Incomplete responses	5386	171	3.1%	1	1
Complete responses	15319	456	2.9%	0.83 NS	1.03 NS

*NS = p≥0.1, *p<0.05, **P<0.005; Model1=Odds ratio of starting caring for partner compared to not reporting caring for a partner both time points, taking into account having any friends and responding to all questions, analysing quality and contact separately; Model2=Multivariable odds ratio also including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment; OR=1:Reference category; §Fixed effects only*

The results presented in the above tables show that in the wave before consecutive responses reported caring for their partner there was no difference in the relationships responders had with their partner, children, family, or friends, between those who subsequently went on to care for their partner and those who did not.

Comparing change in latent scores between consecutive waves

The following table will present analyses which explored if those who Started-caregiving experienced different changes in their relationships compared to Non-carers.

Although the results presented in Table 8-34 are based on fixed effects due to non-convergence, so are indicative only, they suggest that taking on a caregiver role for a partner is associated with a subsequent reduction in the quality of the relationship with the partner and an increase in contact with children.

Table 8-34: Change in personal relationships characteristics by partner status over two consecutive waves

Change between consecutive waves (time 0 and time 1)	Partner caregiver role two waves			Odds Ratio	
	Non-caring	Started	% Started	Uni§	Multi§
Change in quality of partner					
Worse quality score	7376	258	3.4%	1	1
Same quality score	3045	70	2.2%	0.66 **	0.68 *
Better quality score	6499	178	2.7%	0.78 *	0.79 *
Incomplete information	3785	121	3.1%	0.91 NS	0.82 •
Children					
Change in quality of relationship					
Worse quality score	6405	205	3.1%	1	1
Same quality score	1655	46	2.7%	0.87 NS	0.82 NS
Better quality score	6417	172	2.6%	0.84 •	0.85 NS
Incomplete information	6228	204	3.2%	1.02 NS	0.94 NS
Change in level of contact					
Less contact score	4742	108	2.2%	1	1
Same contact score	5779	182	3.1%	1.38 *	1.29 *
Better contact score	3980	140	3.4%	1.54 **	1.5 **
Incomplete information	6204	197	3.1%	1.39 *	1.38 *
Family					
Change quality of relationship					
Worse quality score	6164	192	3.0%	1	1
Same quality score	589	12	2.0%	0.65 NS	0.7 NS
Better quality score	6076	179	2.9%	0.95 NS	0.95 NS
Incomplete information	7876	244	3.0%	0.99 NS	0.83 •
Change in level of contact					
Less contact score	5159	164	3.1%	1	1
Same contact score	2160	52	2.4%	0.76 •	0.82 NS
Better contact score	5272	148	2.7%	0.88 NS	0.89 NS
Incomplete information	8114	263	3.1%	1.01 NS	0.86 NS
Friends					
Change quality of relationship					
Worse quality score	6774	210	3.0%	1	1
Same quality score	659	23	3.4%	1.12 NS	1.11 NS
Better quality score	6833	188	2.7%	0.89 NS	0.9 NS
Incomplete information	6439	206	3.1%	1.03 NS	0.87 NS
Change in level of contact					
Less contact score	5229	161	3.0%	1	1
Same contact score	2127	54	2.5%	0.82 NS	0.83 NS
Better contact score	5407	156	2.8%	0.94 NS	0.96 NS
Incomplete information	7942	256	3.1%	1.05 NS	0.87 NS

*NS = p≥0.1, •p<0.1*p<0.05, **P<0.005; Uni=Odds ratio of starting caring for a partner compared to not reporting caring for a partner both time points; Multi=Multivariable odds ratio also including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment; OR=1:Reference category; §Fixed effects only*

These results are consistent with the results presented earlier, which compared partner caregivers with non-caregivers over one time point and found that caregivers experienced worse quality of partner relationship and more contact with children compared to non-caregivers, and suggest that taking on a caring role for a partner may contribute to a reduction in the quality of that relationship but an increase in contact with children.

8.7.3 Responses over three consecutive ELSA waves

Results on change in personal relationships between short-term and long-term carers are reported in Table 8-35. They show no significant difference in the changes experienced in any personal relationship characteristics between not caring and starting caring for a spouse or partner, for Short-term and Long-term caregivers. Again this analysis is based on a small number of responders and is likely to be underpowered.

Table 8-35: Odds of caring for a partner long-term by change in personal relationships, from time 0 to time 1

Change between first two consecutive waves	Partner caregiver role three waves			Odds Ratio	
	Short-term	Long-term	% Long-term	Uni§	Multi§
Change in quality of partner relationship					
Worse quality	81	55	40.4%	1	1
Same quality	32	16	33.3%	0.74 NS	0.66 NS
Better quality	55	33	37.5%	0.88 NS	0.74 NS
Incomplete information	32	15	31.9%	-	-
Children					
Change in quality					
Worse quality	70	42	37.5%	1	1
Same quality	17	9	34.6%	0.88 NS	0.88 NS
Better quality	59	36	37.9%	1.02 NS	0.96 NS
Incomplete information	54	32	37.2%	-	-
Change on level of contact					
Less contact	35	24	40.7%	1	1
Same contact	59	34	36.6%	0.84 NS	0.8 NS
More contact	50	29	36.7%	0.85 NS	0.86 NS
Incomplete information	56	32	36.4%	-	-
Family					
Change in quality					
Worse quality	64	41	39.0%	1	1
Same quality	2	2	50.0%	1.56 NS	3.41 NS
Better quality	58	39	40.2%	1.04 NS	0.96 NS
Incomplete information	76	37	32.7%	-	-
Change in level of contact					
Less contact	51	31	37.8%	1	1
Same contact	20	14	41.2%	1.15 NS	1.1 NS
More contact	48	24	33.3%	0.82 NS	0.84 NS
Incomplete information	81	50	38.2%	-	-
Friend					
Change in quality					
Worse quality	75	43	36.4%	1	1
Same quality	9	3	25.0%	0.58 NS	0.52 NS
Better quality	58	40	40.8%	1.2 NS	1.17 NS
Incomplete information	58	33	36.3%	-	-
Change in level of contact					
Less contact	51	33	39.3%	1	1
Same contact	16	7	30.4%	0.67 NS	0.65 NS
More contact	58	28	32.6%	0.75 NS	0.8 NS
Incomplete information	75	51	40.5%	-	-

*NS = p≥0.1, *p<0.05; OR=Odds Ratio Long-term caring compared to short-term caring (reference), Uni=univariable odds ratio, Multi=Multivariable odds ration also including sex, age band, ethnic origin, economic activity, highest qualification, financial self-assessment at time 0*

8.7.4 Summary of key findings for personal relationships

Cross-sectional

- Older adults without children were more likely to report caring for their partner.

- Partner caregivers were more likely to report poorer quality of relationship with their partner, compared to older adults who did not report caring for their partner.

- The quality and level of contact with other family members and with friends was not associated with partner caregiver status.

Longitudinal

- Comparing personal relationships between those who went on to care for their partner and those who did not, in the wave before becoming a caregiver, there was no difference in the quality or level of contact in any personal relationships.

- Those who went on to care for their partner were more likely to report that the quality of their relationship with their partner had deteriorated but they had more contact with children, compared to those who did not start caring for their partner.

8.8 Associations between personal relationships and other demographic and social factors for partner caregivers

Associations between demographic and social factors and personal relationship latent variable scores will be compared for participants who report caring for their partner. Comparisons over one time point will assess associations for participant responses reporting that they care for their partner. Comparisons over two consecutive waves will assess the associations between demographic factors, reported at the first of the two consecutive waves, and change in personal relationship latent trait scores when taking on a partner caregiver role.

8.8.1 Responses at one time point

Table 8-36 presents the results from the multivariable analyses exploring the demographic factors associated with personal relationship characteristics for responses from partner caregivers. Only the multivariable β coefficient values have been presented as the findings, using results from the univariable and multivariable models, were fairly consistent. Positive β coefficients represent better outcomes, either in terms of higher personal relationship quality, or more personal relationship contact, while negative β coefficients represent lower quality or level of contact

Table 8-36: β coefficients from multivariable modelling of personal relationship quality and level of contact latent variables and demographic factors, for responses reporting caring for their partner

	Dependent variables						
Demographic variables	**Partner**	**Children**		**Family**		**Friend**	
	Quality	**Quality**	**Contact**	**Quality**	**Contact**	**Quality**	**Contact**
Responses included (No.s)	1758	1517	1550	1439	1331	1477	1313
Sex							
Male	0	0	0	0	0	0	0
Female	-0.4 **	0.19 **	0.09 *	0.26 **	0.34 **	0.43 **	0.26 **
Age band (years)							
50-59	0	0	0	0	0	0	0
60-69	0.01 NS	0.24 **	-0.05 NS	0.13 *	-0.04 NS	0.2 NS	-0.07 NS
70-79	0.03 NS	0.43 **	-0.11 ˙	0.18 *	-0.02 NS	0.05 NS	-0.1 NS
80+	-0.07 NS	0.48 **	-0.16 *	0.25 *	0.11 NS	0.02 NS	-0.31 **
Ethnic origin							
White	0	0	0	0	0	0	0
Not white	-0.4 *	0.02 NS	0.26 NS	0.27 NS	0.02 NS	-0.11 NS	0.23 NS
Information not available	-	-	-	-	-	-	-
Economic activity							
Working	0	0	0	0	0	0	0
Not working	0.01 NS	-0.04 NS	0 NS	-0.13 †	-0.09 NS	-0.06 NS	-0.03 NS
Retired	0.08 NS	0.05 NS	-0.06 NS	-0.05 NS	0 NS	0.02 NS	0.04 NS
Highest qualification							
A level/higher	0	0	0	0	0	0	0
NVQ 1-2/O level	0 NS	-0.1 NS	0.1 ˙	-0.04 NS	-0.04 NS	-0.06 NS	-0.17 *
Foreign/other	0 NS	-0.01 NS	0.12 ˙	0.12 NS	-0.01 NS	-0.33 **	-0.29 **
No qualifications	0 NS	0.06 NS	0.18 **	0.14 *	-0.05 NS	-0.06 NS	-0.2 **
Information not available	-	-	-	-	-	-	-
How is respondent (and partner) getting along financially these days							
Manage very/quite well	0	0	0	0	0	0	0
Get by alright	-0.08 *	-0.08 *	0.01 NS	-0.04 NS	-0.02 NS	0.05 NS	-0.03 NS
Not manage very well	-0.37 *	-0.12 NS	0.2 ˙	-0.02 NS	0.03 NS	-0.15 NS	-0.23 NS
Some/severe difficulties	-0.29 **	-0.11 NS	-0.03 NS	-0.33 **	-0.27 *	-0.11 NS	-0.27 *
Information not available	-	-	-	-	-	-	-
Member of an organisation							
No	0	0	0	0	0	0	0
Yes	0.1 *	-0.04 NS	-0.08 *	0.05 NS	0.01 NS	0.09 †	0.21 **
Missing values	5 •	0.03 NS	-0.04 NS	0.13 NS	0.02 NS	0.09 NS	0.11 NS
Reported caring for someone who was not their spouse or partner in the last week							
No	0	0	0	0	0	0	0
Yes	0.04 NS	-0.04 NS	0.12 *	0.07 NS	0.19 **	0.02 NS	0 NS

*NS = p≥0.1, ˙p<0.1, *p<0.05, **p<0.005; β=Beta coefficient from linear mixed effects models; Multivariable including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment, membership to an organization and caring for others; 0:Reference category,‘-‘ = not reported due to low numbers.*

The results show that there were significant differences in the reporting of personal relationships between male and female participant responses; with female responses reporting significantly worse quality of relationship with their partner, but significantly better quality of relationship, and more contact with, children, family and friends than male responses.

Compared to responders aged 50 to 59 years, responders ages 60 years and over reported significantly better quality of relationships with children and family, but responders ages 80 and over reported significantly less contact with children and friends.

Responses from participants who were classified as ’Not white’ within ELSA had significantly lower quality of relationship with their partner compared to responders categorised as ‘White’.

Responses who reported having qualifications to at least A level experienced significantly more contact with, and significantly better quality of relationships with, friends compared to responders with foreign or other qualifications, however responses from participants with no qualification reported better quality of relationships with family and more contact with children compared to responders reporting having at least A levels.

Responses from participants who felt they were getting along very or quite well financially had better quality of relationship with their partner. Family relationships and contact with friends was negatively associated with experiencing some or severe financial difficulties.

Responses from participants who reported being a member of an organisation also reported significantly better quality of relationship with their partner and more contact with friends, but less contact with children. It is likely that some of these friendships were with people who were also involved in the organisation in which they were a member, and so being an active member of an organisation enabled regular contact with friends.

Responses from participants who were also looking after someone in addition to their spouse or partner experienced significantly more contact with family, quite possibly reflecting that these participants were looking after another family member.

Table 8-37 presents the results comparing partner ADL scores by personal relationship characteristics. The results suggest that the quality of the partner relationship is negatively associated with the level of care partner require, but the level of partner care required does not seem to be detrimental to other personal relationships.

Table 8-37: β coefficients from multivariable modelling of personal relationship quality and level of contact by partner ADL, for responses reporting caring for a partner

Partner ADL score (difficulty with)	Dependent variables						
	Partner	Children		Family		Friend	
	Quality	Quality	Contact	Quality	Contact	Quality	Contact
Responses included (No.s)	1758	1517	1550	1439	1331	1477	1313
No ADL	0	0	0	0	0	0	0
One ADL	0 NS	0.03 NS	0.01 NS	0.01 NS	0.04 NS	0.04 NS	0.05 NS
Two to four ADL	-0.08 •	-0.03 NS	0.07 NS	0.04 NS	0.04 NS	0.01 NS	-0.02 NS
Five or six ADL	-0.22 **	-0.01 NS	0.07 NS	-0.08 NS	-0.01 NS	0 NS	0.05 NS

*NS = p≥0.1, •p<0.1, *p<0.05, **p<0.005; ADL=Activities of daily living; β=Beta coefficient from linear mixed effects models; Multivariable including sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment; 0:Reference category,‘-‘ = not reported due to low numbers.*

8.8.2 Responses over two consecutive ELSA waves

The results presented in Table 8-38 compare the likelihood of a change in different personal relationship characteristics, after taking on a caring role for a spouse or partner, by different demographic characteristics at time 0. The results are from the multivariable analyses, using mixed effects, and each analysis included only consecutive responses where complete information for the personal relationship latent variable scores were available at both time points.

Table 8-38: β coefficients from ANCOVA multivariable modelling of change in personal relationships and demographic characteristics at time 0, for consecutive participant responses who Started-caring for their partner at time 1

Variable at first consecutive wave (time 0)	Change in personal relationships						
	Partner	Children		Family		Friend	
	Quality	Quality	Contact	Quality	Contact	Quality	Contact
Responses included (No.s)	506	523	430	383	364	421	371
Sex							
Male	0	0	0	0	0	0	0
Female	-0.2 **	-0.03 NS	0.04 NS	0.09 NS	0.19 *	0.18 *	0.14 *
Age band (years)							
50-59	0	0	0	0	0	0	0
60-69	-0.03 NS	0.07 NS	0.06 NS	0.11 NS	-0.02 NS	0.07 NS	-0.03 NS
70-79	-0.02 NS	0.15 NS	0.06 NS	0.14 NS	0.05 NS	0.12 NS	-0.06 NS
80+	-0.05 NS	0.19 NS	0.08 NS	0.06 NS	0.16 NS	0.04 NS	-0.44 **
Ethnic origin							
White	0	0	0	0	0	0	0
Not white	0.15 NS	0.25 NS	-0.05 NS	0.03 NS	0.19 NS	-0.07 NS	0.79 *
Information not available	-	-	-	-	-	-	-
Economic activity							
Working	0	0	0	0	0	0	0
Not working	0.14 NS	-0.01 NS	0.15 •	0.07 NS	0.02 NS	0.07 NS	0.1 NS
Retired	0.02 NS	-0.11 NS	-0.02	0 NS	-0.03 NS	-0.05 NS	0.08 NS
Highest qualification							
A level/higher	0	0	0	0	0	0	0
NVQ 1-2/O level	0 NS	0.18 *	-0.03 NS	-0.16 •	0.04 NS	-0.15 NS	-0.13 NS
Foreign/other	0.05 NS	0 NS	-0.16 •	-0.01 NS	-0.14 NS	-0.23 NS	-0.32 *
No qualifications	-0.01 NS	0.11 NS	-0.02 NS	0.02 NS	-0.09 NS	-0.11 NS	-0.18 *
Information not available	-	-	-	-	-	-	-
How is respondent (and partner) getting along financially these days							
Manage very/quite well	0	0	0	0	0	0	0
Get by alright	0.02 NS	-0.02 NS	0.01 NS	-0.07 NS	-0.04 NS	-0.15 NS	0.06 NS
Not manage very well	0.7 •	-0.19 NS	-0.02 NS	-0.08 NS	-0.33 NS	-0.23 NS	-0.34 NS
Some/severe difficulties	-0.11 NS	-0.33 †	-0.11 NS	-0.2 NS	-0.28 NS	-0.11 NS	0.16 NS
Information not available	-	-	-	-	-	-	-
Member of an organisation							
No	0	0	0	0	0	0	0
Yes	0.04 NS	0.06 NS	-0.1 •	-0.07 NS	-0.21 *	0.16 •	0.11 NS
Missing values	0.06 NS	-0.01 NS	-0.08 NS	-0.27 NS	0.05 NS	-0.04 NS	-0.05 NS
Reported caring for someone who was not their spouse or partner in the last week							
No	0	0	0	0	0	0	0
Yes	-0.09 NS	0.07 NS	0.01 NS	0.08 NS	0.01 NS	-0.02 NS	-0.18 •

NS = p≥0.1, •p<0.1, *p<0.05, **p<0.005; Multivariate included the covariates personal relationship latent score, sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment at time 0; each analysis included only responders with personal relationship latent variable scores based on complete information for both time points

Relative to males, females experienced a significantly worse change in the quality of relationship with their partner after taking on a caring role.

Responses from older participants, aged 80 years plus, at time 0, and responses from participants with foreign or no qualifications experienced a significantly worse change in the amount of contact with friends after taking on a caring role for their partner, compared to younger responders and responders with qualifications to at least A level, respectively. Responses from participants with lower qualifications did, however, report a significantly better change in the quality of the relationship they had with their children compared to responders who were educated to at least A level.

Responses from participants classified as ‘Not white’ within ELSA experienced a significantly better change in the amount of contact with friends, compared to ‘White’ responders. Responses from participant who were a member of an organisation at time 0 reported a significantly worse change in the level of contact with family compared to responders who were not a member of an organisation at time 0.

8.8.3 Summary of key findings for personal relationship and other demographic and social factors

Cross-sectional

- Although responses from female partner caregivers were associated with worse quality of relationship with partners they were associated with better quality, and more contact, with children, family, and friends, compared with male caregivers.

- Older partner caregivers (aged 60 years and over) reported better quality of relationships with children and family, while those ages 80 years and over reported less contact with children and friends, compared with younger partner caregivers (aged 50 to 59 years).

- Caregivers who reported caring for someone else in addition to their spouse or partner reported more contact with children and family.

- Being a member of an organisation was associated with better quality of partner relationship, more contact with friends, but less contact with children.

- Having fewer qualifications was associated with more contact with children and better quality of relationship with family, but less contact with friends.

- Other factors associated with poorer partner relationship quality, for partner caregivers, were being categorised within ELSA as ‘Not white’, not managing very or quite well financially, and caring for a partner with difficulties with five or six ADL.

Longitudinal

- Females who started caring for their partner experienced a worse change in the quality of their relationship with their partner when they took on the caregiver role but a better change in their relationships with friends and amount of contact with family, relative to males.

8.9 Connections between personal relationships and health for partner caregivers

Personal relationship latent variable scores and health outcomes will be compared over one, two and three consecutive waves, for partner caregiver responses, consecutive responses identifying participants moving into the partner caregiver role, and participants who are Long-term partner caregivers.

8.9.1 Responses at one time point

The multivariable results which are included in Table 8.39 are modelling each health outcome (valid responses only) against each type of personal relationship characteristic separately, adjusting for demographic and social factors; for participant responses reporting caring for their partner.

Though the results for self-rated health are based on fixed effects only they are fairly consistent in terms of the association between health and the quality of relationships participant responses reported experiencing with their partner, children and other family members, and suggest that better quality relationships were associated with better quality of life, fewer depressive symptoms, and a lower likelihood of reporting poor, bad, or very bad general health. There was no significant difference in health outcomes in terms of the amount of contact with children, however more contact with family was associated with better quality of life and a lower likelihood of reporting poor, bad, or very bad general health.

In terms of friendships better relationships were associated with better quality of life and fewer depressive symptoms; for both the quality of friendships and the amount of contact with friends. In addition responders who reported having friends experienced significantly better quality of life and were less likely to experience any or significant depressive symptoms compared to responders who reported having no friends.

Table 8-39: Odds ratios and β coefficients from multivariable modelling of health outcomes by personal relationship characteristics, for responders who reported caring for their partner

Personal relationship variables	Dependent variables Self-rated health[1] OR §	CES-D Some[2] OR	CES-D Sig[3] OR	Casp-19 β
Responses included (No.s)	2009.00	1974.00	1974.00	1689.00
Partner Quality				
Mean latent variable score	0.79 *	0.49 **	§ 0.49 **	3.91 **
Do you have a partner?				
Yes (Ref: No)	0.40 NS	0.00 NS	§0.20 NS	4.67 NS
No. of valid variables				
Complete (Ref: Incomplete)	0.70 NS	0.62 NS	§ 0.68 NS	1.16 NS
Children Quality				
Mean latent variable score	0.77 *	0.66 **	0.47 **	2.78 **
Do you have any children?				
Yes (Ref: No)	1.24 NS	0.76 NS	2.79 NS	0.49 NS
Number of valid variables				
Complete (Ref: Incomplete)	0.84 *	0.81 NS	0.10 **	0.65 NS
Children Contact				
Mean latent variable score	0.92 NS	1.13 NS	0.68 NS	0.34 NS
Do you have any children?				
Yes (Ref: No)	1.20 NS	0.64 NS	3.23 NS	-1.72 NS
Number of valid variables				
Complete (Ref: Incomplete)	0.93 NS	1.07 NS	0.94 •	2.53 *
Family Quality				
Mean latent variable score	0.84 •	0.83 *	0.52 **	1.89 **
Do you have any family?				
Yes (Ref: No)	0.88 NS	1.52 NS	0.58 NS	0.04 NS
Number of valid variables				
Complete (Ref: Incomplete)	0.66 •	0.69 NS	0.57 NS	0.38 NS
Family Contact				
Mean latent variable score	0.80 *	0.98 NS	§ 0.88 NS	0.67 *
Do you have any family?				
Yes (Ref: No)	0.87 NS	1.01 NS	§ 1.04 NS	0.52 NS
Number of valid variables				
Complete (Ref: Incomplete)	0.64 *	0.96 NS	§ 0.96 NS	-0.35 NS
Friendship Quality				
Mean latent variable score	1.10 NS	0.94 NS	0.93 NS	2.01 **
Do you have any friends?				
Yes (Ref: No)	0.82 NS	0.54 •	0.38 *	6.68 **
Number of valid variables				
Complete (Ref: Incomplete)	0.81 NS	0.82 NS	0.86 NS	0.34 NS
Friendship Contact				
Mean latent variable score	1.00 NS	0.87 NS	0.87 •	1.17 **
Do you have any friends?				
Yes (Ref:No)	0.79 NS	0.51 *	0.45 **	6.68 **
Number of valid variables				
Complete (Ref: Incomplete)	0.81 NS	0.83 NS	1.02 NS	-0.04 NS

*NS = p≥0.1, •p<0.1, *p<0.05, **p<0.005; [1] Poor/Bad/Vey bad vs. Fair or better (reference); [2] Some vs, None (Reference); [3] Significant vs. Not significant (reference); β=Beta coefficient; Multivariable including individual personal relationship characteristics, sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment, membership to an organisation and caring for others; Ref:Reference*

8.9.2 Responses over two consecutive ELSA waves

Change in health outcomes (time 0 to time 1)

Table 8.40 presents the results from the multivariable ANCOVA analyses comparing the likelihood of change in self-rated health, symptoms of depression, and quality of life by personal relationship characteristics at time 0; for consecutive participant responses showing participants moving into a caring role for their partner.

Only responders who provided valid responses to self-rated health, CES-D8, and CASP-19 at both time 0 and time 1 were included in the analyses. The results from the self-rated health and CES-D8 analyses were based on fixed effects only due to non-convergence.

The results suggest that changes in self-rated health, symptoms of depression and quality of life after taking the partner caregiver was not significantly associated with the relationship quality or level of contact with children, family, or friends before taking on this caring role.

Partner caregivers who reported better quality relationships with their partner before becoming a partner caregiver were less likely to develop some or significant depressive symptoms, and did not experience such a negative impact on their quality of life after moving into the partner caregiver role, relative to poorer partner relationships.

Though Table 8-40 shows no significant associations between changes in health outcomes and the quality of, or amount of contact with, friends, having friends before becoming a partner caregiver was associated with a less negative change in quality of life after starting caring for a partner, compared to responders who reported having no friends at time 0,

Table 8-40: Odds ratio and β coefficients from ANCOVA multivariable modelling of change in health outcomes by personal relationship characteristics at time 0, for consecutive participant responses who Started-caring for their partner at time 1

	Change in health outcomes			
Personal relationship variables at time 0	**Self-rated health^1 OR §**	**CES-D Some^2 OR§**	**CES-D Sig^3 OR§**	**CASP-19 β**
Responses included (No.s)	627.00	617.00	617.00	473.00
Partner Quality				
Mean latent variable score	0.82 NS	0.75 *	0.66 *	0.91 *
Do you have a partner?				
Yes (Ref: No)	Removed			
No. of valid variables				
Complete (Ref: Incomplete)	0.40 NS	0.34 NS	0.51	2.77 NS
Children Quality				
Mean latent variable score	0.87 NS	1.15 NS	0.95 NS	-0.45 NS
Do you have any children?				
Yes (Ref: No)	0.30 NS	1.04 NS	1.65 NS	1.06 NS
Number of valid variables				
Complete (Ref: Incomplete)	2.59 NS	0.89 NS	0.66 NS	-0.59 NS
Children Contact				
Mean latent variable score	1.66 •	1.34 •	0.79 NS	0.10 NS
Do you have any children?				
Yes (Ref: No)	0.84 NS	0.67 NS	1.28 NS	1.61 NS
Number of valid variables				
Complete (Ref: Incomplete)	0.75 NS	1.35 NS	0.90 NS	-1.19 NS
Family Quality				
Mean latent variable score	1.16 NS	0.92 NS	0.99 NS	0.67 •
Do you have any family?				
Yes (Ref: No)	0.79 NS	0.81 NS	0.37 NS	-1.14 NS
Number of valid variables				
Complete (Ref: Incomplete)	0.83 NS	1.11 NS	1.64 NS	-0.34 NS
Family Contact				
Mean latent variable score	0.94 NS	1.07 NS	0.95 NS	0.47 NS
Do you have any family?				
Yes (Ref: No)	0.53 NS	1.02 NS	0.68 NS	-1.69 NS
Number of valid variables				
Complete (Ref: Incomplete)	1.34 NS	0.84 NS	0.83 NS	0.24 NS
Friendship Quality				
Mean latent variable score	1.28 NS	1.07 NS	1.10 NS	0.16 NS
Do you have any friends?				
Yes (Ref: No)	0.46 NS	0.61 NS	0.38 NS	3.68 *
Number of valid variables				
Complete (Ref: Incomplete)	0.64 NS	1.10 NS	1.32 NS	-0.67 NS
Friendship Contact				
Mean latent variable score	0.89 NS	0.92 NS	0.85 NS	0.20 NS
Do you have any friends?				
Yes (Ref:No)	0.21 *	0.77 NS	0.46 NS	3.22 *
Number of valid variables				
Complete (Ref: Incomplete)	1.58 NS	0.80 NS	1.07 NS	1.70 NS

*NS = p≥0.1, •p<0.1, *p<0.05, **P<0.005; 1Odds ratio of poor, bad or very bad self-rated health at time 1, with self-rated health, sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment at time 0 included as covariates; 2Odds ratio of 1 or more, compared to no, depressive symptoms at time 1, with CES-D score, sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment at time 0 included as covariates; 3Odds ratio of 4 or more, compared to 3 or less, depressive symptoms at time 1, with CES-D score, sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment at time 0 included as covariates; OR=1:Reference category; §Fixed effects only*

Change in personal relationship outcomes (time 0 to time 1)

Table 8.41 compares the likelihood of a change in different personal relationship characteristics, after taking on a caring role for a spouse or partner, by health outcomes at time 0. The results are from the multivariable analyses, including mixed effects, where each analysis included only responders who provided complete information for the personal relationship latent dependent variable at both time points.

There were no significant associations between self-rated health before starting to care for a partner and change in personal relationship characteristics after taking of a caring role.

In terms of symptoms of depression, reporting between one to three symptoms of depression was associated with an increased likelihood of reporting less contact with friends after taking on the partner caregiver role, compared to responders who reported no depressive symptoms.

Quality of life at time 0 was positively associated with better quality of relationships with partner, children, and friends after becoming a partner caregiver, compared to responders with lower quality of life scores.

Table 8-41: β coefficients from ANCOVA multivariable modelling of change in personal relationships by health at time 0, for consecutive participant responses who Started-caring for their partner at time 1

	Change in personal relationships						
Health outcomes at time 0	**Partner**	**Children**		**Family**		**Friend**	
	Quality	**Quality**	**Contact**	**Quality**	**Contact**	**Quality**	**Contact**
Responses (No.s)	506	423	430	383	364	421	371
Self-reported health							
Fair or better	1	1	1	1	1	1	1
Poor/bad/very bad	-0.01 NS	-0.07 NS	0.1 NS	-0.04 NS	-0.05 NS	0.14 NS	0.22 NS
Information not available	0.24 NS	0.24 NS	1.62 **	-0.05 NS	-0.24 NS	1.12 NS	-0.79 NS
CES-D score							
None (CES-D=0)	1	1	1	1	1	1	1
Some (CES-D=1-3)	-0.02 NS	-0.12 •	-0.01 NS	0.05 NS	0.05 NS	-0.07 NS	-0.17 *
Significant (CES-D=4+)	-0.06 NS	-0.16 NS	0.03 NS	0.09 NS	0.03 NS	-0.05 NS	-0.15 NS
Information not available	-0.04 NS	-0.28 NS	0.3 NS	-0.56 NS	-0.23 NS	-0.54 NS	-0.28 NS
CASP-19	0.01 *	0.01 **	0 NS	0 NS	0 NS	0.01 **	0.01 NS

*NS = p≥0.1, •p<0.1, *p<0.05, **p<0.005; Multivariate included the covariates personal relationship latent score, sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment at time 0; each analysis included only responders with personal relationship latent variable scores based on complete information for both time points*

8.9.3 Responses over three consecutive ELSA waves

The analyses over three time points compares change in personal relationship outcomes between time 0 and time 1 with changes in health outcomes between time 1 and time 2; and change in health outcomes between time 0 and time 1 with changes in personal relationship outcomes between time 1 and time 2; for participants who moved into a partner caregiver role at time 1 and remained caring for their partner at time 2.

The analyses over three time points is based on small numbers however and is underpowered.

Change in health outcomes time 1 to time 2

The significant results presented in Table 8-42 suggest that participants who experienced a deterioration in the quality of relationships with their family and friends after taking on a caring role for their partner were less likely to experience a worse change in their quality of life when they continued to care for their partner, compared to participants who experienced the same, or better quality of relationship with family and friends respectively when they first started caring for their partner. A deterioration in friendship quality when starting caring for a partner was also associated with a reduced likelihood to go on to report some depressive symptoms when continuing to care, compared to participants who reported an increase in their friendship quality when they first started caring for their partner.

Table 8-42: Odds ratio and β coefficients from ANCOVA multivariable modelling of change in health outcomes following changes in personal relationship characteristics, for responders who continued to care for their partner (Long-term caregivers)

	Change in health outcomes (time 1 to time 2)			
Change in personal relationships (time 0 to time 1)	**Self-rated health[1]**	**CES-D Some[2]**	**CES-D Sig[3]**	**CASP-19**
	OR	**OR**	**OR**	**β**
Responses included (No.s)	117.00	116.00	116.00	90.00
Change in quality of spouse/partner relationship (complete responses = 104)				
Worse quality	1.00	1.00	1.00	0.00
Same quality	3.70 NS	0.70 NS	0.04 NS	-0.54 NS
Better quality	2.57 NS	2.47 NS	1.01 NS	-2.52 •
Change in quality of Children relationships (complete responses = 87)				
Worse quality	1.00	1.00	1.00	0.00
Same quality	1.47 NS	0.59 NS	0.31 NS	0.27 NS
Better quality	5.78 NS	0.79 NS	6.06 NS	0.01 NS
Change on level of contact with children (complete responses = 87)				
Less contact	1.00	1.00	1.00	0.00
Same contact	1.61 NS	2.11 NS	0.89 NS	-0.10 NS
More contact	1.13 NS	5.23 NS	5.92 NS	-0.80 NS
Change in quality of family relationships (complete responses = 82)				
Worse quality	1.00	1.00	1.00	0.00
Same quality	0.00 NS	1.17 NS	999.00 NS	-7.55 *
Better quality	1.46 NS	2.28 NS	0.98 NS	-2.07 NS
Change in level of contact with family (complete responses = 69)				
Less contact	1.00	1.00	1.00	0.00
Same contact	1.27 NS	39.68 •	54.80 •	0.30 NS
More contact	0.00 NS	0.10 NS	0.60 NS	-1.53 NS
Change in quality of friendships (complete responses = 86)				
Worse quality	1.00	1.00	1.00	0.00
Same quality	0.00 NS	999.00 NS	0.00 NS	-1.09 NS
Better quality	0.09 NS	6.21 *	2.71 NS	-4.34 **
Change in level of contact with friends (complete responses = 68)				
Less contact	1.00	1.00	1.00	0.00
Same contact	0.98 NS	2.26 NS	0.00 NS	0.42 NS
More contact	3.37 NS	1.98 NS	2.78 NS	-1.71 NS

*NS = p≥0.1, •p<0.1, *p<0.05, **p<0.005; [1] Odds ratio of poor, bad or very bad self-rated health at time 2, with self-rated health at time 1 included as a covariate; [2] Odds ratio of 1 or more, compared to no, depressive symptoms at time 1, with CES-D score at time included as a covariate; [3] Odds ratio of 4 or more, compared to 3 or less, depressive symptoms at time 2, with CES-D score at time 1 included as a covariate; Multivariable analysis also included sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment at time 0 OR=1:Reference category*

Counter-intuitively these results suggest that experiencing a deterioration in personal relationships with family and friends initially may lead to an improvement in health outcomes in the long run. One possible explanation for this is that, as the quality of family and friend relationships were positively associated with quality of life for partner caregivers (see Table 8-39), the effect of the quality of relationships with family and friends on quality of life in the short-term, when first taking on the partner caregiver role, may be redressed when moving into a long-term partner caregiver role.

Change in personal relationship outcomes time 1 to time 2

Comparing initial change in health status with later changes in personal relationships (Table 8-43) suggest that participants who moved from rating their health as fair or better to rating their health as poor, bad, or very bad after taking on a caring role for their spouse or partner were more likely to report more contact with their children when they continued to care for their spouse or partner, relative to participants who reported their self-rated health changes from poor, bad, or very bad to fair or better initially. This seems reasonable and suggests that children may increase the amount of time they spend or communicate with parents if the health of the partner caregiver deteriorates.

In terms of symptoms of depression, participants who reported more symptoms of depression after taking on a caring role for their partner seemed to be more likely to experience a worse change in the quality of their relationship with their partner, less contact with family members, but better quality of relationship with friends compared to responders who reported less of the same number of depressive symptoms. This may suggest that partner caregivers who experience symptoms of depression may seek support outside of the home.

Participants who experienced a reduction in their quality of life when they started caring for their spouse or partner experienced a subsequent better relationship with their spouse or partner, but less contact with their children, compared to participants who experienced no change in their overall quality of life.

Table 8-43: β coefficients from ANCOVA multivariable modelling of change in personal relationships following changes in health for responders who continued to care for their spouse or partner (long-term caregivers)

Change in health outcomes (time 0 to time 1)	Change in personal relationships (time 1 to time 2)						
	Partner	Children		Family		Friend	
	Quality	Quality	Contact	Quality	Contact	Quality	Contact
Responses (No.s)	97	85	85	78	66	73	70
Change in self-rated health (complete responses = 119)							
Worse (Fair to poor)	0	0	0	0	0	0	0
Same SRH	0.2 NS	0.39 NS	-0.39 NS	0.31 NS	0.26 NS	-0.11 NS	0.1 NS
Better (Poor to fair)	0.03 NS	0.46 NS	-1.01 *	-0.36 NS	-0.06 NS	-0.61 NS	-0.44 NS
Change in CES-D (based on scores 0 to 8) (complete responses = 116)							
Worse (Higher) CES-D	0	0	0	0	0	0	0
Same CES-D	0.19 NS	0.09 NS	0.22 NS	0.07 NS	0.41 *	-0.33 NS	0.03 NS
Better (Lower)CES-D	0.4 *	-0.01 NS	0.1 NS	0.22 NS	0.41 •	-0.64 *	-0.08 NS
Change in CASP19 (complete responses = 90)							
Worse (lower) CASP19	0	0	0	0	0	0	0
Same CASP19	-0.68 *	0.15 NS	1.04 **	-0.47 NS	-1.32 NS	0.01 NS	-0.1 NS
Better (Higher) CASP19	-0.21 NS	0 NS	-0.24 •	-0.03 NS	-0.17 NS	-0.21 NS	-0.1 NS

*NS = p≥0.1, •p<0.1, *p<0.05, **p<0.005; Multivariable covariates = personal relationship latent score at time 1, sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment at time 0; each analysis included only responders with personal relationship latent variable scores based on complete information for both time points*

8.9.4 Summary of key findings for personal relationships and health

Cross-sectional

- The quality of relationships partner caregivers reported having with their partner, children, and family members were positively associated with better health, in terms of fair or better self-reported general health, fewer depressive symptoms, and better quality of life. Better quality of life was also associated with having friends, more contact with family and friends, and better quality of friendship relationships.

Longitudinal

- Having a better quality of partner relationship before taking on a partner caregiver role was associated with a reduced likelihood of experiencing an increase in symptoms of depression when moving into the caregiver role. The level of depressive symptoms before reporting caring for a partner was not, however significantly associated with change in the quality of the partner relationship after becoming a partner caregiver. This suggests that the partner relationship may be influencing the likelihood of experiencing symptoms of depression.

- There was a bi-directional association between quality of life and the quality of the partner relationship over time; with a positive association between quality of life and partner relationship quality measured at time 0 and change in partner relationship and quality of life respectively, between time 0 and time 1, when taking on the caregiver role.

- Symptoms of depression before starting caring for their partner was associated with a worse change in the amount of contact with friends after taking on the caring role, relative to responders who reported having no symptoms of depression. There was no significant difference in the level of contact with friends before becoming a partner caregiver and change in depressive symptoms after taking on the caring role, which suggests that depression before caring may influence the level of contact with friends when responders started caring for their partner.
- Evidence from changes over three time points is limited due to small numbers, however the results provide some evidence that while changes in participants relationships with their partner and children when moving into the caregiver role did not seem to be associated with subsequent changes in any health outcomes; changes in health outcomes when moving into the caregiver role seemed to be associated with subsequent changes in the relationship with partners and contact with children.
- In terms of friendships, evidence from three time points suggests that an increase in symptoms of depression when first moving into the caregiver role, compared to partner caregivers experiencing fewer depressive symptoms, was associated with an increase in the quality of friend relationships in the longer-term; however a reduction in the quality of friendships when first moving into the caregiver role, compared to partner caregivers experiencing better quality friendships, was associated with a reduced likelihood of reporting some symptoms of depression, and an increase in quality of life, subsequently. These results suggest that short-term negative consequences associated with taking on the partner caregiver role may be redressed in the longer-term, though small numbers make the results difficult to interpret.

8.10 Connections between different personal relationships for partner caregivers

In this section different personal relationship latent variable scores will be compared over one, two and three consecutive waves, for partner caregiver responses, consecutive responses identifying participants moving into the partner caregiver role, and participants who became Long-term partner caregivers.

8.10.1 Responses at one time point

Table 8-44 presents the results from the linear mixed effects multivariable models, comparing associations between different personal relationship characteristics for participant responses who reported caring for their partner.

These results clearly show that the personal relationship characteristics experienced were closely connected, with positive associations between the relationships experienced with their partner, children, family and friends.

Table 8-44: β coefficients from multivariable modelling of personal relationship characteristics, for responses reporting caring for their partner

Personal relationship variables (independent variables)	Dependent variables						
	Partner	Children		Family		Friend	
	Quality	Quality	Contact	Quality	Contact	Quality	Contact
Responses (No.s)	1758	1517	1550	1439	1331	1477	1313
Children Quality							
Mean latent variable score	0.29 **						
Do you have children?							
Yes (Ref: No)	0.07 NS						
No. of valid variables							
Complete	0.04 NS						
Children Contact							
Mean latent variable score	0.06 •	0.34 **					
Do you have children?							
Yes (Ref: No)	-0.11 NS	Not included					
No. of valid variables							
Complete	0.18 *						
Family Quality							
Mean latent variable score	0.22 **	0.25 **	0.07 **				
Do you have any family?							
Yes (Ref: No)	0.12 NS	0.32 **	0.13 NS				
No. of valid variables							
Complete	-0.05 NS	-0.11 †	-0.03 NS				
Family Contact							
Mean latent variable score	0.1 **	0.12 **	0.16 **	0.49 **			
Do you have any family?							
Yes (Ref: No)	0.07 NS	0.22 *	0.08 NS	Not included			
No. of valid variables							
Complete	0.01 NS	-0.04 NS	0.01 NS				
Friendship Quality							
Mean latent variable score	0.13 **	0.2 **	0.03 NS	0.24 **	0.07 *		
Do you have any friends?							
Yes (Ref: No)	0.4 **	0.31 **	0.05 NS	0.36 **	-0.07 NS		
No. of valid variables							
Complete	-0.02 NS	-0.04 NS	0.02 NS	-0.07 NS	0.05 NS		
Friendship Contact							
Mean latent variable score	0.06 *	0.07 *	0.09 **	0.09 **	0.19 **	0.39 **	
Do you have any friends?							
Yes (Ref:No)	0.36 **	0.24 **	0.14 *	0.3 **	0.04 NS	Not included	
No. of valid variables							
Complete	-0.01 NS	-0.04 NS	-0.07 NS	-0.06 NS	0.01 NS		

*NS = $p \geq 0.1$, •$p<0.1$, *$p<0.05$, **$p<0.005$; β=Beta coefficient; Multivariable including selected personal relationship latent variable, identifier variables, sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment; Ref:Reference*

Thus participant responses reporting good relationships with partner were more likely to also report good relationships with their children, family and friends. Conversely, however, participant responses reporting poorer quality of relationship were also more likely to report poorer relationships with their partner, children, and family.

8.10.2 Responses over two consecutive ELSA waves

Table 8-45 compares the likelihood of a change in different personal relationship characteristics, after taking on a caring role for a partner, by personal relationship characteristics at time 0, to investigate if some personal relationship characteristics present before becoming a partner caregiver could predict changes in other relationship characteristics. The analyses included only responders who provided complete information for the outcome personal relationship characteristic at both time points.

The partner relationship before taking on the caring role was positively associated with change in the quality of relationship responders experienced with their children after taking on this role.

The relationship with children at time 0 was not associated with any significant change in other relationships after taking on the partner caregiver role, however better quality relationships were associated with more contact with children after starting caring.

The results for family and friends suggest that the quality of relationships partner caregivers had with family and friends before becoming a partner caregiver were important for preserving, or improving, the quality of partner and children relationships when moving into a partner caregiver role; suggesting that good relationships outside of the immediate family before becoming a caregiver may support relationships within the immediate family when taking on this role.

What is of note in these results is that where a significant association has occurred all of the associations are positive, suggesting that good relationships before caring are more likely to lead to benefits in other personal relationship types when taking on the partner caregiver role.

Table 8-45: β coefficients from ANCOVA modelling of change in personal relationships and personal relationships at time 0, for consecutive participant responses who Started-caring for their partner at time 1

Personal relationships (time 0)	Change in personal relationships (time 0 to time 1)						
	Partner	Children		Family		Friend	
	Quality	Quality	Contact	Quality	Contact	Quality	Contact
Responses (No.s)	506	423	430	383	364	421	371
Partner Quality							
Mean latent variable score		0.12 **	-0.01 NS	-0.03 NS	-0.04 NS	0.02 NS	0.07 •
Do you have a partner?							
Yes (Ref: No)		Excl	Excl	-0.60 NS	0.33 NS	0.27 NS	-0.35 NS
No. valid variables							
Complete		0.00 NS	-0.31 †	-0.1 NS	0.08 NS	0.95 *	-0.29 NS
Children Quality							
Mean latent variable score	0.02 NS		0.08 **	0.05 NS	0.09 •	0.06 NS	-0.01 NS
Do you have children?							
Yes (Ref: No)	0.12 NS		Excl	0.12 NS	0.05 NS	0.24 NS	0.12 NS
No. valid variables							
Complete	-0.22 NS		0.10 NS	-0.19 NS	-0.05 NS	-0.21 NS	-0.08 NS
Children Contact							
Mean latent variable score	0.00 NS	0.03 NS		-0.02 NS	0.00 NS	0.00 NS	0.00 NS
Do you have children?							
Yes (Ref: No)	0.13 NS	Excl		0.15 NS	-0.09 NS	0.15 NS	-0.14 NS
No. valid variables							
Complete	-0.23 *	0.29 *		-0.21 NS	0.10 NS	-0.11 NS	0.20 NS
Family Quality							
Mean latent variable score	0.07 *	0.16 **	-0.01 NS		0.20 **	0.13 **	0.01 NS
Do you have family?							
Yes (Ref: No)	0.04 NS	0.10 NS	0.01 NS		Excl	0.05 NS	-0.12 NS
No. valid variables							
Complete	-0.28 NS	-0.04 NS	1.00 NS		0.14 NS	-0.19 NS	0.12 NS
Family Contact							
Mean latent variable score	0.01 NS	0.09 *	0.01 NS	0 NS		0.07 NS	0 NS
Do you have family?							
Yes (Ref: No)	-0.07 NS	0.03 NS	0.08 NS	Excl		-0.01 NS	-0.04 NS
No. valid variables							
Complete	-0.27 NS	0 NS	-0.07 NS	-0.09 NS		-0.13 NS	0.02 NS
Friend Quality							
Mean latent variable score	0.09 **	0.11 **	0.05 NS	0.00 NS	0.02 NS		0.10 *
Do you have friends?							
Yes (Ref: No)	0.23 NS	0.28 NS	0.02 NS	0.07 NS	-0.25 NS		Excl
No. valid variables							
Complete	-0.10 NS	0.06 NS	-0.03 NS	-0.31 NS	-0.23 NS		-0.21 •
Friend Contact							
Mean latent variable score	0.07 •	0.02 NS	0.01 NS	0.03 NS	-0.06 NS	0.12 *	
Do you have friends?							
Yes (Ref: No)	0.10 NS	0.33 *	0.07 NS	-0.13 NS	-0.61 •	Excl	
No. valid variables							
Complete	-0.10 NS	-0.01 NS	-0.09 NS	-0.10 NS	0.14 NS	-0.13 NS	

*NS = p≥0.1, •p<0.1, *p<0.05, **p<0.005; Multivariate included the covariates personal relationship latent score, sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment at time 0; each analysis included only responders with personal relationship latent variable scores based on complete information for both time points, Excl = Excluded*

8.10.3 Responses over three consecutive ELSA waves

Table 8-46 compares initial changes in personal relationships after taking on a caring role for a partner with changes in personal relationships when continuing to care in the next wave. The analyses presented here is underpowered as it is based on very small numbers. The results do, however, provide some insights into how different relationship may affect other relationship over time.

Table 8-46: β coefficients from ANCOVA multivariable modelling of change in personal relationship characteristics following changes in other personal relationship characteristics for participants who continued to care for their partner (Long-term caregiver)

Change in health outcomes (time 0 to time 1)	Change in personal relationships (time 1 to time 2)						
	Partner	Children		Family		Friend	
	Quality	Quality	Contact	Quality	Contact	Quality	Contact
Responses (No.s)	97	85	85	78	66	73	70
Change in quality of partner relationship (complete responses = 104)							
Worse quality		0	0	0	0	0	0
Same quality		0.69 NS	-0.17 NS	0.09 NS	0.17 NS	0.13 NS	0.2 NS
Better quality		0.03 NS	0.04 NS	0.03 NS	-0.03 NS	-0.34 •	0.12 NS
Change in quality of Children relationships (complete responses = 87)							
Worse quality	0		0	0	0	0	0
Same quality	0.25 NS		-0.06 NS	0.43 NS	0.43 NS	0.2 NS	0.07 NS
Better quality	0.25 NS		-0.16 NS	-0.22 NS	-0.22 NS	-0.11 NS	0.01 NS
Change on level of contact with children (complete responses = 87)							
Less contact	0	0		0	0	0	0
Same contact	0.13 NS	-0.07 NS		-0.28 NS	-0.28 NS	0.01 NS	0.25 NS
More contact	0.02 NS	-0.21 NS		-0.32 NS	-0.32 NS	-0.32 NS	0.32 NS
Change in quality of family relationships (complete responses = 82)							
Worse quality	0	0	0		0	0	0
Same quality	-0.72 NS	-1.21 *	-0.9 •		-0.07 NS	0.06 NS	0.56 NS
Better quality	-0.15 NS	-0.18 NS	-0.22 •		-0.6 **	0.08 NS	-0.02 NS
Change in level of contact with family (complete responses = 69)							
Less contact	0	0	0	0		0	0
Same contact	0.1 NS	0.13 NS	0.16 NS	0.29 NS		0.03 NS	0.24 NS
More contact	0.12 NS	0.19 NS	-0.27 NS	-0.12 NS		0.35 NS	0.16 NS
Change in quality of friendships (complete responses = 86)							
Worse quality	0	0	0	0	0		0
Same quality	0.5 NS	0.29 NS	-0.15 NS	0.61 NS	0.62 NS		
Better quality	-0.11 NS	-0.16 NS	0.12 NS	0.07 NS	0.07 NS		-0.22 NS
Change in level of contact with friends (complete responses = 68)							
Less contact	0	0	0	0	0	0	
Same contact	-0.35 NS	0.05 NS	0.03 NS	0.03 NS	0.03 NS	-0.15 NS	
More contact	-0.44 *	-0.32 *	0 NS	-0.14 NS	-0.14 NS	-0.24 NS	

*NS = p≥0.1, •p<0.1, *p<0.05, **p<0.005; Multivariable covariates = personal relationship latent score at time 1, sex, age band, ethnic origin, economic activity, highest qualification and financial self-assessment at time 0; each analysis included only responders with personal relationship latent variable scores based on complete information for both time points*

The results suggest participants who experienced a reduction in the amount of contact with friends initially went on to experience relatively better relationship quality with their partner and children in the longer term. A reduction in the quality of family relationships initially was also associated with better quality of relationship with children in the next wave. One possible explanation for this is that some partner caregivers may reduce their contact with other family and friends to focus on the relationships they have with their immediate family, that is their partner and children.

Finally it is interesting to note that the results also suggest that participants who reported better quality of relationship with their family initially were more likely to report less contact with family in the long term. This may suggest that changes in the relationships with other family members initially, may revert back, in the longer term, to how these relationships were before becoming a partner caregiver.

8.10.4 Summary of key findings for personal relationships

Cross-sectional

- There were positive associations across all personal relationship characteristics, suggesting that participant responses reporting difficulties in one relationship were more likely to also experience difficulties in other relationships.

Longitudinal

- Moving in a partner caregiver role was more positive, in terms of maintaining, or improving the quality of the relationship with partners and children, when participants had good quality family and friendship relationships, and having a good quality of relationship with a partner helped the change in the relationship with children after starting caring.
- Participants may be adapting their relationships over time, rebalancing a negative change in one aspect of a relationship with a positive change in another relationship.

8.11 Chapter discussion

8.11.1 Main findings

While this quantitative study was primarily interested in changes over time in health and personal relationships associated with caring for a partner, other demographic factors were also included so that a richer picture of the possible reasons why these changes may occur would emerge.

The small number of participants in the analyses over three time points limits the ability to infer causal relationships, however the extensive analysis completed using two time points does shed light on possible directional relationships.

A summary of the main results from the analyses are presented below and are ordered into findings for health, findings for personal relationships, connections between health and personal relationships, and connections between different personal relationship types.

As the complex nature of the data and multiple analyses undertaken mean that some of these results are difficult to interpret, to aid understanding this section also provides clarification of what these results may mean for partner caregivers.

Health

Summary of findings

Demographic factors

Cross-sectional analysis found factors commonly associated with poorer health outcomes for partner caregivers were: being female, not working or being retired, not managing so well financially, not being a member of an organisation, and not caring for someone else.

Depressive symptoms (CES-D8)

Cross-sectional analysis suggest being a partner caregiver was associated with more depressive symptoms.

Longitudinal analysis identified females and those who were not working or were retired before they started caring for their partner were more likely to report a change from no depressive symptoms to at least one depressive symptom after starting caring. Experiencing some or severe financial difficulties, and not being a member of an organisation, before they started caring for their partner was associated with an increase in depressive symptoms, from some to significant depressive symptoms.

Quality of life (CASP-19)

Cross-sectional analysis found older adults caring for a partner were more likely to report lower quality of life compared to older adults not reporting caring for their partner.

Longitudinal analysis found that older adults who started caring for their partner were more likely to report lower quality of life in the wave preceding becoming a caregiver, and taking on the partner caregiver role was detrimental to their quality of life. Taking on a caregiving role was more detrimental to quality of life for the oldest adults (aged 80 and over) compared to the youngest (aged 50-59 years).

Self-rated health

Cross-sectional and longitudinal analyses identified no significant associations between caring for a partner and self-rated health, after taking into account other factors.

Longitudinal analysis identified no demographic factors associated with a negative change in self-rated health; from fair or better to poor, bad, or very bad; when taking on the partner caregiver role.

Interpretation of the self-rated health results are difficult however due to the limitations of the self-rated health measure (see section 8.11.4).

Clarification

Becoming a partner caregiver is associated with an increase in depressive symptoms and a deterioration in quality of life. Some older adults, in particular females, older adults, and those who are no longer working, may be particularly vulnerable to a negative change in health outcomes; while being a member of an organisation may protect against negative health changes.

Personal relationships

Findings

Partner

Cross-sectional analysis found that partner caregivers who reporting a better quality of partner relationship overall were male, categorised as white within ELSA, reported getting on well financially, and did not look after a partner who required help with most daily activities.

Longitudinal analysis found taking on a partner caregiver role was associated with a deterioration in the quality of the partner relationship.

Longitudinal analysis identified that female partner caregivers, and caregivers aged 60 or over in the wave before taking on the caregiver role, were more likely to experience a deterioration in the partner relationship after taking on the caregiver role, compared to male caregivers, and caregivers aged 50 to 59 years.

Children and Family

Cross-sectional analysis suggest better quality of relationships with children and family members for partner caregivers were associated with being female and being in the older age groups (aged 60 and over), while more contact with children and family members was associated with being female and taking care of someone in addition to partner caregiving.

Cross-sectional analysis also found that older adults who had children were less likely to report caring for their partner than older adults without children.

Longitudinal analysis found taking on a partner caregiver role was associated an increase in contact with children, however there was no significant association between taking on a partner caregiver role and change in the quality of relationship with children or other family members, or the amount of contact with other family members.

Longitudinal analysis found that male caregivers, and caregivers who were members of an organisation in the wave before taking on the caregiver role, were more likely to see a deterioration in the amount of contact with other family members, compared with female caregivers, and caregivers who were not a member of an organisation.

Friendships

Cross-sect6ional analysis identified better quality friendships were more likely to be reported by female partner caregivers, while more contact with friends was associated with being female, being younger, having qualifications to at least A level, and being a member of an organisation.

Longitudinal analysis did not identify a significant association between taking on the role of partner caregiver and change in the quality of, or amount of contact with, friends.

Longitudinal analysis found male caregivers were more likely to see a reduction in the quality and amount of contact with friends after taking on the caregiver role, compared with female caregivers. Partner caregivers who were categorised as ‘Not white’ within ELSA experienced a greater increase in contact with friends, compared to ‘White’ partner caregivers.

Clarification

Moving into a partner caregiver role may be detrimental to the quality of the partner relationship however children are likely to contact the caregiver more. The caregiver role seems to have less effect on the overall amount of contact, and the quality of relationships with family and friends.

The quality of relationships, and amount of contact with children, family and friends, appears to be experienced differently for male and female partner caregivers; with males experiencing a comparatively better relationship with their partner but females experiencing a comparatively better relationship with children, family, and friends.

Health and personal relationship connections

Findings

Cross-sectional analysis identified a positive associations between the quality of the partner and children relationships and health outcomes, including quality of life, for partner caregivers. Quality of life was positively associated with the quality and level of contact with other family members and friends. Family quality and having friends was also associated with lower likelihood of experiencing some or significant depressive symptoms. Experiencing fair or better self-rated health was associated with more contact with family.

Longitudinal analysis found partner caregivers who reported better partner relationships before becoming a partner caregiver were less likely to develop some or significant depressive symptoms, and were more likely to experience a relatively better change in the quality of life, compared to partner caregivers who experienced poorer partner relationships before becoming a caregiver. Having friends before becoming a partner caregiver was associated with a lower chance of experiencing a deterioration in self-rated health, and a better chance of experiencing a relatively better change in quality of life, compared to partner caregivers who reported having no friends before becoming a partner caregiver.

Longitudinal analysis also found that reporting some symptoms of depression before becoming a partner caregiver was associated with a subsequent reduction in contact with friends, relative to older adults reporting no symptoms of depression. Quality of life before becoming a caregiver was positively associated with the change in the quality of relationships with partner, children, and friends, taking on the caregiver role.

Evidence from three time points was difficult to interpret due to small numbers.

Clarification: Partner

Partner caregivers who have better partner relationships are more likely to experience better health outcomes, in terms of better overall perceived health and quality of life, and fewer symptoms of depression. The relationship partner caregivers have with their partner before becoming a caregiver seems to influence changes in health and quality of life, with better relationships experiencing comparatively better health changes. Quality of life before becoming a partner caregiver also seems to provide some protection over negative changes in the partner relationship when becoming a caregiver.

Clarification: Children

Partner caregivers who have a better quality of relationship with their children are more likely to experience better health outcomes, in terms of better overall perceived health and quality of life, and fewer symptoms of depression. The quality of life before becoming a partner caregiver may provide some protection over negative changes in the quality of relationship with children after becoming a caregiver. The amount of contact with children does not appear to influence, or be influenced by, health or quality of life.

Clarification: Family

Partner caregivers who have a better quality of relationship with other family members are more likely to experience fewer symptoms of depression and better quality of life; better quality of life was also associated with more contact with family members. The relationship partner caregivers have with other family members, and health and quality of life, before becoming a partner caregiver do not appear to influence later changes in health or relationships with family members, respectively, after becoming a caregiver.

Clarification: Friends

Partner caregivers who have friends, better quality friendships, and more contact with friends are more likely to report better quality of life. Having friends before becoming a partner caregiver seems to be protective of detrimental changes in self-rated health and quality of life after taking on the caregiver role. Quality of life before becoming a partner caregiver seems to positively influence how much the quality of friendships changed after becoming a caregiver, but partner caregivers who experience symptoms of depression before becoming a caregivers may be more likely to experience a negative change in the amount of contact they have with friends after becoming a caregiver.

Connections between different personal relationship types

Cross-sectional analysis found the relationships partner caregivers had with their partner, children, family, and friends were all positively associated.

Longitudinal analysis identified that, in terms of changes over time:

- There was a positive association between the quality of family and friendship relationships before becoming a partner caregiver and change in the quality of relationships with partner and children after taking on the caregiver role.
- The quality of family relationships were positively associated with change in family contact and the quality of friends after becoming a partner caregiver.
- Better quality of partner relationship and more contact with family and friends before becoming a partner caregiver were associated with a positive change in the quality of relationship with children after becoming a caregiver, relative to poorer quality of partner relationship and less contact with family and friends.
- Having a better relationship quality with children before becoming a partner caregiver was also associated with more contact with children after becoming a partner caregiver.

Evidence from three time points was difficult to interpret due to small numbers, however the negative associations identified between changes in relationships when becoming a partner caregiver, and changes in relationships when moving into a longer timer partner caregiver role may suggest that over time partner caregivers adapt their relationships to compensate for negative effects to relationships when first moving into the caregiver role.

Clarification

The positive associations between different personal relationships types suggest that rather than partner caregivers strengthening some relationships to overcome problems in other relationships, partner caregivers with good personal relationships generally experience good relationships across all relationship types. Conversely partner caregivers who experience a poor relationship are more likely to also experience poorer relationship with other relationship types.

The quality of family relationships and friendships before becoming a partner caregiver seem to positively influence changes in personal relationships after becoming a caregiver. The partner relationship before becoming a caregiver seems to positively influence change in the quality of relationship with children after becoming a caregiver. Better relationships with children before becoming a caregiver seem to be more likely to lead to more contact with children after becoming a caregiver.

Demographic factors

Cross-sectional analysis suggest that older adults who are more likely to take on a caregiver role for their partner are older, retired or not working, have fewer qualifications, are less financially well-off, and are already looking after someone else.

Longitudinal analysis found that though there was no difference in the likelihood of being a member of an organisation before starting caring, taking on a partner caregiver role was associated with stopping membership to organisations. This suggests that some older adults who become partner caregivers can no longer participate in the societies, clubs, or other organisations which were part of the usual activities before caregiving.

Interestingly the results from the longitudinal analysis suggest that male caregivers were more likely to become longer term partner caregivers, while females were more likely to transition out of the caregiver role. The reasons for this are unclear and could relate to the health concerns of the partner or possible differences in how males and females define caregiving.

Longitudinal analysis also found that older adults looking after a partner who requires assistance with general activities, such as washing, dressing, bathing, or mobility; and older adults looking after a partner who has had a stroke, has dementia, or has other psychological or emotional problems were more likely to be looking after their partner long term.

8.11.2 Evidence from existing quantitative studies

The findings from this thesis adds to our understanding about the changes in health and personal relationships experienced by older adults who become a partner caregiver, which has previously been heavily reliant of evidence from cross-sectional analyses. This doctoral project appears to be the first study to utilise longitudinal data to explore changes in different personal relationships when becoming a partner caregiver, which provides a unique insight into the connections between different personal relationships and health over time.

This section will present existing evidence from quantitative studies on the connections between health and personal relationship for caregivers

Health

Two longitudinal studies (Beach et al., 2000, Ross et al., 2008) support the results presented in this thesis and suggest that self-rated health is overall fairly stable for older adults moving into the partner caregiver role. The results from one cross-sectional study suggest that older adults who are providing more than 20 hours of care per week may however be more likely to consider their health to be poor.

In support of the findings presented in this thesis on depressive symptoms in partner caregivers, several longitudinal studies have previously found an increased risk of depressive symptoms associated with taking on a caregiver role (Beach et al., 2000, Dunkle et al., 2014, Kramer and Lambert, 1999). A longitudinal study by McGarrigle et al. (2014) also found an increased risk of depression in women moving into a caregiver role, but not men, which again supports the results found in this doctoral study, that women may be at an increased risk of developing more depressive symptoms, compared to males.

Fewer studies have investigated the association between becoming a caregiver and change in quality of life, though several cross-sectional studies have identified poorer quality of life is associated with being a caregiver (McPherson et al., 2011, Roth et al., 2009, Ho et al., 2009). In contrast one cross-sectional study by (Ratcliffe et al., 2013) compared the quality of life; measured using the Index of Capability (ICECAP-O), an instrument intended to measure quality of life in older people (Coast et al., 2008); of 789 caregivers and non-caregivers aged 65 years and over. This study found comparable quality of life between caregivers and non-caregivers, however as this study did not detail who the caregivers were looking after, and the ICECAP-O instrument is, as yet, not a fully validated tool (Makai et al., 2014), it is unclear if these results challenge other findings.

The association between poorer health outcomes for females caregivers and those who are managing less well financially are supported by several, cross-sectional studies (Adelman et al., 2014, Young and Kahana, 1989, Pinquart and Sörensen, 2003, Bakas and Burgener, 2002, Ekwall et al., 2007, Brazil et al., 2009, Guerriere et al., 2015).

Fewer quantitative studies have investigated the effect of being a member of an organisation on health for caregivers, however one meta-analysis of intervention studies

Sörensen et al. (2002) found evidence that support groups can help to reduce caregiver burden. A more recent cross-sectional study by Sun and Hodge (2014) found that church attendance was associated with significantly lower levels of depression in caregivers looking after someone with Alzheimer’s. Both of these studies lend some support to the results presented in this thesis that being a member of an organisation could be beneficial to health for caregivers.

Personal relationships

Studies exploring changes in personal relationship when taking on the partner caregiver role predominantly use qualitative methods; though one longitudinal quantitative study by Kramer and Lambert (1999) focused on male spousal caregivers only and found male spousal caregivers experienced lower marital happiness and were significantly more likely to perceive their marriage to be in trouble at follow-up, compared to males who did not report caring for their spouse. This supports the results presented in this thesis which found the overall quality of the relationship reduced after taking on a partner caregiver role, though the results in this thesis found female partner caregivers experience a greater negative change in their partner relationship after taking on a caregiver role than males.

The suggestion from this thesis that male partner caregivers report a better partner relationship than female caregivers may be partially explained by a cross sectional study by Friedemann and Buckwalter (2014) of 533 caregivers to frail elderly relatives, which found that male spousal caregivers were involved in fewer caregiving tasks and experienced less caregiver burden, compared to female spousal caregivers.

The quantitative results in this thesis suggest that overall the relationships with family and friends are less affected by taking on the caregiver role. Few quantitative studies have explored changes in the relationship with family and friends after becoming a caregiver; however one cross sectional study (Mosher et al., 2013) asked 91 family caregivers of patients with lung cancer, with an average time since diagnosis of one year, to rate different aspects of their relationships in terms of if they were better, worse, or unchanged after becoming a caregiver. They found that only 9 per cent of caregivers thought their relationship with family had got worse, which supports the results in this doctoral study, but 26 per cent though their relationship with friends had got worse, and over half (57 per cent) thought the time they had for social activities with friends had got worse. The results from Mosher et al. (2013) suggest that becoming a caregiver may negatively impact on friendships however as these results were not compared with non-caregivers, to account for the usual changes in friendships over time, it is difficult to access the relevance of these results to the present findings.

Health and personal relationship connections

Quantitative studies provide good evidence of an association between health and personal relationships for caregivers; however again this evidence is predominantly from cross-sectional studies and there is a lack of quantitative studies which have explored changes in personal relationships and health over time for caregivers.

In terms of the evidence available, two meta analyses (Pinquart and Sörensen, 2007, Pinquart and Sörensen, 2011) both found that poorer health, in terms of physical and psychological health, and wellbeing were associated with lower levels of informal support for informal caregivers. Other studies have found that support from family or friends is associated with a reduced risk of caregiver burden (Goldstein et al., 2004, Francis et al., 2010, Burton et al., 2012, Yoon and Kim, 2014). Limited social networks have also been found to be associated with carer burden (Goldstein et al., 2004) and increased levels of depression (Sun and Hodge, 2014) in caregivers. While a cross-sectional study by Rodriguez-Sanchez et al. (2011) found positive associations between family relationships and partner relationships, and quality of life and physical and mental wellbeing. In contrast Burton et al. (2012) found no significant association between number of social networks and impact on health in their cross sectional study of 139 caregivers. The study by Burton et al. (2012) was based on fairly small numbers which resulted in very few significant results and included a wide range of caregivers and care recipient health problems.

Demographic factors

One of the most interesting findings in this quantitative study was that older adults were more likely to stop participating in an organisation outside the home when taking on a partner caregiver role.

This result is partly supported by a study by Choi et al. (2007) which explored the association between volunteering and spousal caregiving, using two waves of the HRS. They found that female caregivers were less likely to be participating in volunteering compared to non-caregivers, but this result was not replicated in males. A study of male partner caregivers (Kramer and Lambert, 1999) however found evidence that males moving into the caregiver role were more likely to experience a reduction in their social activities, but were significantly more likely to experience an increase in their participation at religious social events, perhaps reflecting the support provided by members of a religious organisation. Other cross-sectional studies (Hank and Stuck, 2008, Burr et al., 2005, Farkas and Himes, 1997) found evidence which contradicts the findings in this present quantitative study, suggesting that older caregivers are more likely to be participating in volunteering or other activities outside the home compared to non-caregivers. A possible reason for this difference is that none of these studies focused on spousal caregivers and it may be that older adults who are in a position where they can choose to take on a caregiving role may be also more likely to also participant in other activities. Spousal caregivers are less likely to have a choice in whether they take on the caring responsibility for their partner or not. Farkas and Himes (1997) suggest that caregivers may continue to participant in outside activities to help relieve the stress of caring, which is supported by the results from this doctoral study.

8.11.3 What this study adds

No previous studies have used longitudinal data to explore in such detail the changes in health and personal relationships experienced by older adults when they take on a partner caregiver role. In particular there is little previously published evidence on the changes experienced by different types of personal relationships, and the connections between personal relationships and health outcomes when moving into, and maintaining, a partner caregiver role.

This quantitative study not only supports findings from previous studies, which show a positive association between health and relationships, but also provides evidence that these connections are different for different personal relationship types. While the relationships with partners, children, and family members were positively associated with health and quality of life, quality of life was the only health outcome which was significantly associated with friendships. In terms of change in health outcomes when taking on the partner caregiver role, it was the partner relationship and friendships before taking on the caregiver role which appeared to be most important, with these relationships showing a positive association with change in quality of life and self-rated health after taking on the caregiver role.

The results also shed new light on the connections between different personal relationships and suggest that partner caregivers in better relationships are more likely to report better relationships with other relationship types, and are more likely to experience a comparatively positive change in personal relationships, compared to those who experienced poorer relationships before taking on the caregiver role.

Finally the results from this study also enrich existing knowledge about other factors which significantly influence, or are influenced by taking on the partner caregiver role, especially in terms of the role of participating in organisations outside of the home, and the differences experienced by male and female caregivers.

8.11.4 Limitations

Using secondary data

ELSA is a valuable resource for exploring changes in the lives of older adults in England. Using secondary data has many benefits, some of which were described in section 4.5.1. If research questions can be addressed using existing data it seems sensible to utilise this data now, rather than go through the timely and financial expense of collecting new data. Certainly this thesis could not have been completed if there had not been secondary data already available which detailed older partner caregivers' health and personal relationships over time.

Using secondary data also has its limitations however, which were also briefly described in section 4.5.1.

Time between waves

One potential limitation which was evident before undertaking this study was in the time between waves. Each wave within ELSA was conducted approximately two years apart. For this doctoral project this meant that while some participants may have moved into the partner caregiver role only a short time before they participated in the next ELSA wave, others may have been looking after their partner for upwards of two years. This potential heterogeneity in the duration of caregiving meant that the results for the changes experienced when moving into the partner caregiver role would not only be identifying immediate changes but also, for some, longer term changes. As the results from three time points hinted that some short term changes may be redressed in the long-term, the results for short-term changes may not be a true reflection of the changes experienced in the aftermath of taking on the caregiver role, but also reflect longer-term changes or adaptations.

Two additional limitations which became apparent during the preliminary stages of the study are also worth describing in more detail.

Self-rated health measure

The first, and primary, limitation was that the wording of the self-rated health measure was not the same across the five waves (see section 7.4.3). As the primary health outcome measure for this study was self-rated health, and the objective was to assess changes over time; this was a big problem. To get around this the self-rated health measures across waves were reduced from ordinal, using a five point Likert scale, to binary; separating responses into 'Fair or better' and 'Poor, bad, or very bad'. While using this approach resulted in, what appeared to be, consistency between waves, the ability to detect changes in health perception across waves was severely hampered. The results suggest less movement in self-rated health between waves compared to the measures for depression (CES-D8) and quality of life (CASP19), but the limitations of the transformed self-rated health binary responses make it difficult to determine whether this was because self-rated health changed less than the other health measures, or because changes occurred in the rating of self-rated health, but these changes were largely incorporated within the broad binary categories. Thankfully the decision to include other health outcomes meant that the problem with the self-rated health measure was not so catastrophic, however this problem meant that the interpretation of changes in self-rated health was limited.

Sample size

The second limitation was in the sample size achieved across three waves. This quantitative study wanted to explore the sequence in the changes experienced in health and personal relationships after moving into a caregiver role. While two time points was very informative, in terms of shedding light on the changes experienced in health and personal relationships when taking on a caregiver role, and possible connections between health and personal relationships; using three consecutive time points provides an opportunity to explore the sequence of these changes so that directional associations, and possibly causation, can be inferred. Although three time points were included in the analysis for this study, only 119 ELSA participants provided three consecutive waves of data, moved onto a partner caregiver role in the second wave, and remained a partner caregiver in the third consecutive wave. This small number meant there was much uncertainty within the data and the data was not powered to identify possibly clinically significant differences between groups.

Partner caregivers identified within ELSA

Other possible limitations associated with this study are linked with the problems of identifying partner caregivers, and the problem of including partner caregivers within studies.

Caregiver label

Section 3.2.2 described how caregivers may not accept, or recognise, that they fulfil a caregiver role until such time that they require support from others outside the home (O'Connor, 2007, Corden and Hirst, 2011). Thus a limitation for research into caregivers, if identifying caregivers is based on their own perception of their role, is that some caregivers may not be identified because they do not recognise themselves as fulfilling such a role. As ELSA ask participants if they consider themselves to be caregivers, by asking: “Did you look after anyone in the past week (including your partner or other people in your household)? BY 'LOOK AFTER' WE MEAN THE ACTIVE PROVISION OF CARE” (ELSA, 2002), this limitation affects this study.

Though this issue is common to most studies on caregivers, it has particular relevance to this study as the objective was to explore transitions for older adults moving into a caregiver role. Thus it is likely that some participants were categorised as not caring for a partner, when they may have been providing a caregiver role, and more importantly others may have been categorised as moving into a partner caregiver role when in actuality they were fulfilling a caregiver role in the previous wave. It is difficult to identify a solution to this problem, and certainly this problem could not be overcome within this study, however it is worth acknowledging and bearing in mind when interpreting the results.

Caregivers in ELSA

The results presented in section 8.2.2 report that partner caregivers were less likely to participate in the next ELSA wave. The results presented in section 8.3.1 also suggest that participants were most likely to report being a partner caregiver in wave 1, compared to subsequent waves. These results lead to the deduction what partner caregivers were more likely to drop out of the ELSA study in the next wave, compared to participants who did not report caring for their partner. There may be many possible reasons for this however the outcome of this is that partner caregivers included in this study may not represent all types of partner caregivers. One potential reason for partner caregivers dropping out of the study may be that the burden of caring for their partner meant they no longer had the time to commit to such a large survey. So it is possible that the partner caregivers included in this study are caregivers who are coping better or who are experiencing less caregiver strain.

8.12 Chapter conclusion

Results from this exploration of ELSA data, over one to three time points, provide a wealth of information about the changes older adults experience in their health and personal relationship when taking on a caregiver role.

The main findings coming from the analyses are:

- Taking on a partner caregiving role was associated with a deterioration in psychological health, in terms of symptoms of depression, and quality of life.
- Older adults who started caring for their partner were more likely to experience a deterioration in the quality of the relationship they had with their partner, however contact with children was more likely to increase.

- There were positive associations found between the quality of personal relationships and quality of life for partner caregivers. The longitudinal analyses suggests a bi-directional association between quality of life and personal relationships; with the quality of life experienced by older adults before becoming a partner caregiver positively influencing changes in personal relationships with partners, children, and friends when taking on the caregiver role; and the quality of relationships with partners and having friends, before becoming a partner caregiver positively influencing change in quality of life when becoming a partner caregiver.

- Cross-sectional analyses found better self-rated health was associated with better quality of relationships with partners and children, for partner caregivers. Longitudinal analyses suggests that having friends, may be protective of negative changes in self-rated health when taking on the partner caregiver role.

- Fewer symptoms of depression were associated with better quality of relationship with their partner, children, and family. Longitudinal analyses suggests that caregivers who have better relationships with their partner before becoming a caregiver may be less likely to go on to experience more depressive symptoms when they take on the caregiver role.

- Partner caregivers who experienced negative personal relationships were more likely to also experience negative relationship with other personal relationship types. Good relationships with family and friends before becoming a partner caregiver may protect against negative changes in personal relationships after becoming a partner caregiver.

- Some caregivers, in particular females, older caregivers, and those who were not managing well financially were more likely to experience deteriorations in health, quality of life, and personal relationships when taking on a caregiver role.

- The results also suggest that while participating in an organisation may be beneficial to the health and personal relationship for partner caregivers, partner caregivers were more likely to stop participating in organisations outside the home when they took on the partner caregiver role.

Chapter 9 Synthesis and discussion

9.1 Introduction

This chapter presents the integration of the qualitative and quantitative findings, focusing on synthesising transitions in health and personal relationships when older adults become a caregiver for their partner; and relating these to the theories around health, personal relationships, and lifespan models introduced in Chapter 1. The implications of these results for practice and further research are also described below.

The integration of the studies occurred at multiple points throughout this doctoral thesis. Figure 4-1 (section 4.3.2) provides a summary of the exploratory sequential mixed methods design used in this project. Section 6.6.5 described how the findings of the qualitative study influenced the design of the quantitative study, while section 6.6.4 explained how the findings from the quantitative study were used to reassess the results from the qualitative study. This concluding chapter represents the final integration of the qualitative and quantitative findings. Tables 9-1 to 9-5 below provide a recap of the main findings from the qualitative and quantitative studies by section, consensus and discord between the findings are explored in the narrative which follows these tables.

Though neither the qualitative nor the quantitative studies employed methods which would enable the results to be generalisable, concordance between the qualitative and quantitative results provides further confidence in the reliability of the findings.

9.2 Transitions in health

In terms of transitions in health after taking on the caregiver role, results from the qualitative and quantitative studies are generally complementary (See Table 9-1).

Table 9-1: Recap of the quantitative and qualitative findings for health transitions

Qualitative findings	Quantitative findings
• The extra demands of caring for a partner commonly resulted in increased feelings of stress. • Receiving support from family and friends seemed to help partner caregivers to cope with the increased demands place upon them by the caregiver role.	• Taking on a partner carer role was associated with an increased risk of experiencing more symptoms of depression and a reduction in quality of life. • Poorer partner relationships and having no friends before taking on the partner caregiver role were associated with an increased likelihood of experiencing more depressive symptoms and poorer quality of life when moving into the partner caregiver role. • Change in health outcomes and quality of life after taking on the caregiver role were not significantly associated with the relationships partner caregivers had with their family and children before taking on the caregiver role. • Factors associated with a change in health outcomes when taking on a partner caregiver role were sex, age, economic activity, financial situation, and participating in an organisation.

While the participants in the qualitative study did not explicitly describe themselves as depressed, they commonly spoke about their caregiver role in terms of coping with the situation, and referred to increased feelings of stress due to the demands of the role. These experiences support the increased symptoms of depression and the reduced quality of life found in ELSA participants who moved into the partner caregiver role, in the quantitative study. These complementary results when combined lend further support to the evidence (Pinquart and Sörensen, 2003, McGarrigle et al., 2014) that the demands of taking on a partner caregiver role may lead to increased psychological problems for some older caregivers.

Both the qualitative and quantitative studies found that having friendships seemed to be important to the health of the caregiver. In the qualitative study participants described how the support from friends helped them to cope with the demands of caring for their partner. The quantitative study found that having people in your life who you consider to be friends before moving into the partner caregiver role was associated with a reduced likelihood of reporting poorer self-rated health; and a reduced likelihood of a negative change in quality of life after starting caring for a partner. Previous studies have also suggested that social support may reduce the risk of negative health effects associated with caregiving (Goldstein et al., 2004, Grant et al., 2006, Butterworth et al., 2010, Francis et al., 2010, Burton et al., 2012, Yoon and Kim, 2014), however by exploring separately the quality, level of contact, and having at least one friend, this doctoral project has shed new light onto the means by which social support may benefit caregivers. The results from both studies suggest that it is not the quality of friendships, nor the frequency of contact with friends, but having at least one person in your life who you consider to be a friend, that was associated with a reduced likelihood of negative health affects after taking on the caregiver role.

There is less consensus between the studies in terms of the role of the family and transitions in the health, for the partner caregivers. The qualitative study found that the support from family helped participants to cope with the partner caregiver role. In contrast the results from the quantitative study found no significant associations between the quality of, or level of contact with, family or children, and transitions in health when taking on the caregiver role. This suggests that the relationships with children and other family members were not significantly influencing health changes for partner caregivers. The quantitative analysis which explored associations within one time point did, however, find positive associations between the quality of personal relationships with children and other family members, and better health for partner caregivers; in terms of better self-rated health, fewer symptoms of depression, and better quality of life. Taking on board all of these findings one possible explanation for these results could be that the support from children and other family members was longstanding, provided before taking on the partner caregiver role, and consistent; with the result that while the health of partner caregivers with good support from family was more likely to be better than partner caregivers with poor family support, all were vulnerable to a decrease in health when taking on the partner caregiver role.

The qualitative and quantitative studies suggest that other factors, not just the demands of taking on the partner caregiver role, were associated with health changes for partner caregivers. The qualitative study identified that social support and social engagement in other activities helped participants to cope with the partner caregiver role. The quantitative results also found that partner relationships, friendships, engagement in other activities outside the home and other factors; such as age, sex, financial situation, and engaging in other work; were also linked to the degree to which health changed when taking on the partner caregiver role. These results support the conceptual model of social networks and health, presented by Berkman et al. (2000), which identified upstream and downstream influences on health. While upstream influences in this doctoral project include taking on the partner caregiver role and other factors such as age, sex, economic activity and financial situation; downstream factors include support from others, partner relationships, and engagement in activities outside the home. The model asserts that all of these factors contribute to health through health behaviour and psychological pathways.

9.3 Transitions in partner relationships

Table 9-2 presents the main qualitative and quantitative results for transitions in the partner relationship.

The results from the qualitative study are consistent with the results from other qualitative studies exploring relationships with partners, for partner caregivers (Murray and Livingston, 1998, Coombs, 2007, Ussher et al., 2011, Quinn et al., 2014, Evans and Lee, 2014, Shim et al., 2012), affirming that the relationship partner caregivers have with their partner is likely to change when they take on the partner caregiver role.

Table 9-2: Recap of the qualitative and quantitative findings for partner relationship transitions

Qualitative findings	Quantitative findings
• The roles which had previously been defined within the relationship changed, with the caregiver taking on more responsibility for household tasks as well are caring responsibilities. • Partner caregivers in previously difficult relationships remained difficult, while previously close relationships remained close.	• Taking on a partner caregiver role was associated with a reduction in the quality of the partner relationship. • Partner caregivers who were female, and those with poorer quality of life before taking on the caregiver role, were more likely to experience a reduction in the quality of the partner relationship when taking on the partner caregiver role. • Partner caregivers who reported poorer quality of relationship with friends and family before taking on the partner caregiver role were more likely to experience a deterioration in the partner relationship after moving in to the partner caregiver role. • There was a negative association between change in the quality of friendships when first reporting moving into the caregiver role, and change in partner relationship when continuing to care for a partner in the longer-term.

The qualitative results found that partner caregivers were taking on more of the responsibilities within the relationship, not just in terms of providing care to their partner but also in terms of taking on some of the roles their partners used to provide. The qualitative results also identified that the nature of the relationship before taking on the caregiver role was reflected in the relationship after becoming a partner caregiver; with those in positive relationships before using more positive terms to describe their relationship at the time of the interview, while those in difficult relationships before describing their relationships as problematic after taking on the caregiver role. The quantitative results found that overall older adults taking on a partner caregiver role were more likely to report that the quality of their relationship with their partner had reduced, compared to older adults who did not move in to a partner caregiver role. Together these results suggest that the change in the balance of the relationship experienced by partner caregivers may make them feel that the overall quality of the relationship they have with their partner has reduced, possibly even for those who continue to describe their relationship in positive terms.

This doctoral project offers new insights into the role of family and friends on transitions in partner relationships, when moving into a partner caregiver role. The quantitative study found that poorer quality of relationships with family and friends before becoming a partner caregiver were associated with a relatively worse change in the partner relationship when moving into the caregiver role. This result suggests that those who have less support available to them before becoming a partner caregiver were more likely to experience a reduction in their relationship with their partner. These results gives some cause for concern, suggesting that taking on the caregiver role may be more detrimental to partner relationships when the partner caregiver is isolated, in terms of having few friends or family to turn to. This potentially could lead to some partner caregivers feeling completely isolated while in difficult partner relationships.

The quantitative results also provide new evidence showing that partner caregivers experiencing poor quality of life before becoming a partner caregiver were more likely to experience a reduction in their relationship with their partner. Self-rated health and symptoms of depression before becoming a caregiver were, however, not significantly associated with a change in the partner relationship after taking on the partner caregiver role. While these results cannot be used in isolation to infer directional associations, incorporating these results with the quantitative results presented in section 9.2, suggest a bi-directional association between changes in quality of life and changes in partner relationships. In terms of the association between partner relationships and symptoms of depression, these results combined with those in section 9.2 provide some tentative evidence of a uni-directional relationship, with partner relationships before becoming a partner caregiver influencing change in symptoms of depression, but symptoms of depression before becoming a partner caregiver not significantly influencing change in personal relationships.

Finally for partner relationships, the quantitative study also identified that female partner caregivers were more likely to experience a reduction in the overall quality of the partner relationship when taking on the partner caregiver role, compared to males. The reason for this can only be speculative, as the aim of this project was not to compare male and female caregivers, however it is possible that this is a reflection of the nature of the caring role between males and females. Certainly the study by Friedemann and Buckwalter (2014), which found that female spousal caregivers were involved in more caregiving tasks and experienced more caregiver burden, supports the hypothesis that males and females may be fulfilling different roles. If could also reflect possible differences in when males and females accept the caregiver label.

9.4 Transitions in family relationships

The main findings from the qualitative and quantitative studies are presented in Table 9-3 below.

Table 9-3: Recap of the qualitative and quantitative findings for family relationship transitions

Qualitative findings	Quantitative findings
• Partner caregivers had most contact with, and felt closest to, their children. • Generally the closeness partner caregivers felt towards family members had not changed since taking on the partner caregiver role, suggesting that the nature of these relationship was longstanding. • Support most often came from children and relatives nearby.	• Older adults who started caring for their partner were more likely to experience an increase in the amount of contact they had with their children, but there was no significant change in the overall quality of these relationships or the relationships they had with other family members. • Partner caregivers who had qualifications to at least A level; had poorer quality of life before taking on the caregiver role; had poorer quality of relationships with their partner, other family members, or friends; or less contact with other family members or friends before taking on the caregiver role were more likely to experience a reduction in the quality of relationships with children when taking on the partner caregiver role. • Partner caregivers were more likely to experience a decrease in the amount of contact with other family members if they were male or a member of an organisation before becoming a caregiver. • A reduction in the amount of contact with friends and a reduction in the quality of relationships with other family members when taking on the caregiver role was associated with an improvement in the quality of relationships with children when moving onto a longer-term caring role.

Results from both the qualitative and quantitative studies suggest that the overall strength of the relationship older adults had with their children and other family members did not change when moving into the partner caregiver role, but contact with children increased for some. These results for family relationships support the convoy lifespan model (Kahn and Antonucci, 1980), which suggests that each individual is surrounded throughout life by personal relationships which have been shaped over time and vary in their closeness, quality and function.

The evidence from the quantitative study; that older adults were more likely to experience a negative change in the quality of relationships with their children if they already had poorer relationships with their partner, family, and friends and poorer quality of life before taking on the caregiver role; is concerning as it again highlights that there may be a subset of partner caregivers who are in difficult partner relationships and have little support from family or friends. It is these people who Wenger (1997) identified as having private restrictive support networks and being particularly vulnerable if they became ill.

The quantitative study also highlights again significant differences in the experiences of change in personal relationships between male and female caregivers. In terms of family relationships male caregivers were more likely to experience a reduction in the amount of contact with family members, compared with females. This may reflect a difference in the level of importance placed on family members between the sexes, as the analysis based on associations over one time point showed that female caregivers had significantly better quality and amount of contact with family members, however again this is only speculative.

9.5 Transitions in friendships

Transitions in friendships identified through the quantitative and qualitative studies are summarised in Table 9-4 below.

While the qualitative results suggest that there were more changes within friendships after taking on the partner caregiver role than with other relationships, the results from the quantitative study suggest that there was no significant difference in changes in the overall quality or amount of contact with friends, between older adults to took on a caring role for their partner, and those who did not. At first sight these results seem conflicting, however combined they lend support to the socio-emotional selectivity model (Carstensen, 1991, Carstensen, 1992), which maintains older adults become more selective with their social ties to maximise their social and emotional gains while minimising their social and emotional risks. Thus one explanation for these results is that older adults renegotiated their friendships in order to maintain the level of quality and support. The evidence from the qualitative study that older adults preferred friends who understood their situation also supports the socio-emotional selectivity model, suggesting the partner caregivers were seeking friendships with others who could provide support.

Table 9-4: Recap of the qualitative and quantitative findings for friendship transitions

Qualitative findings	Quantitative findings
• Changes in friendships were common when taking on the partner caregiver role. • Friendships were maintained or blossomed with people who understood what the partner caregivers were going through or who made time for them. • Partner caregivers who had few friends before looking after their partner did not make new friends when they moved into the partner caregiver role. • Partner caregivers with pre-existing health issues had fewer friendships when moving into the partner caregiver role.	• Taking on a partner caregiver role was not significantly associated with a change in the quality or level of contact with friends. • Partner caregivers who were female, those with better quality of life before taking on the caregiver role, and those with better quality of family relationships before taking on the caregiver role were less likely to experience a reduction in the quality of friendships when taking on the partner caregiver role. • Partner caregivers were less likely to experience a reduction on the amount of contact with friends after taking on the caregiver role if they were female, categorised as non-white, had A level or high qualifications, compared with no qualifications or only foreign qualification, and had no depressive symptoms before taking on the caregiver role.

The evidence from the quantitative study; that partner caregivers were more likely to experience a deterioration in their friendships if they had poorer quality of life, more depressive symptoms, or a poorer quality of relationship with family, before taking on the caregiver role; suggests that older adults with less family support or poorer health may be more vulnerable to being even more socially isolated after taking on the caregiver role. Again this is concerning as it suggests that it is those partner caregivers who may have been more vulnerable before taking on the caregiver role who are more likely to experience the most deterioration in other areas.

Summarising the comprehensive analysis of the associations between personal relationships (with partner, family and friends) and demographic and social factors included in this doctoral thesis suggest that the connections between demographic factors and personal relationships, and the connections between different measures of personal relationships, are complex. These results lend some support to the connections between upstream and downstream factors described in Berkman et al. (2000) conceptual model of social integration and health. This model was created by Berkman et al. (2000) to reflect that social networks are influenced by social structural conditions, and do not just influence health through support, but may also influence health, directly or indirectly, through other means, including social influence, social engagement, contact with others, and access to resources.

9.6 Engagement in activities outside the home

In terms of participating in activities outside the home (see Table 9-5) the findings are fairly consistent between the qualitative and quantitative results and suggest that while being a member of a group or organisation may be beneficial to partner caregivers, in terms of their psychological health and quality of life, it is more difficult to maintain these activities due to the demands of the caregiver role.

These results provide some additional support for Berkman et al. (2000) social integration and health model, which suggests that network ties, which may be built up through participating in organisations or groups, provides opportunities for social engagement and social support which can impact on health outcomes through health behaviour, such as exercise, and psychological pathways, such as ability to cope and overall sense of well-being.

Table 9-5: Recap of the quantitative and qualitative findings for activities outside the home

Qualitative findings	Quantitative findings
• Most participants felt that maintaining an activity outside the home was important. • Participating in an activity outside the home seemed to help with partner caregivers overall sense of well-being. • The caregiving role commonly limited the ability to participate in activities outside the home due to the demands of caregiving.	• Being a member of an organisation before becoming a partner caregiver was associated with a reduced likelihood of developing significant depressive symptoms when moving into the partner caregiver role. • Being a member of an organisation was associated with better quality of relationships with partners and more contact with friends, but less contact with children. • Partner caregivers were more likely to stop being a member of an organisation when taking on the partner caregiver role.

9.7 Evaluation of the use of a mixed methods approach

The mixed methods approach adopted in this exploratory doctoral project not only resulted in a richer understanding of the ways in which health and personal relationships may change when older adults take on a partner caregiver role, through the synthesis of the quantitative and qualitative studies; but also enhanced both the qualitative and quantitative studies, when each is viewed as stand-alone pieces of research.

To recap (see sections 6.6.5 and 6.6.6), the themes which emerged from the qualitative study were revisited in light of the findings from the quantitative study. This resulted in a realisation that the changes in the roles and responsibilities within couples, which had previously been assessed only in terms of defining the caregiver role, were also reflecting a change in the overall quality of the partner relationships. The qualitative study also greatly enhanced the quantitative study. Originally only one health measure and only one variable, for each personal relationship type, were to be included in the analyses. The qualitative study, however, highlighted that participants more commonly spoke about the psychological issues affecting them, and their feelings of coping or well-being. The qualitative study also showed that the quality of relationships and the amount of contact with individuals were not necessarily directly related. This resulted in two additional health outcomes being included in the quantitative study, and the quality and amount of contact being assessed separately within personal relationship types. These changes greatly enhanced the quantitative results in terms of understanding the connections between health, personal relationships, and caregiving,

The synthesis of the qualitative and quantitative findings identified much consensus in the results between the studies, which provided reassurance of the reliability of the findings from each study. Although there were occasions when the results, on first inspection, suggested contrasting results, it was these occasions which proved to be most insightful, such as the interpretation of changes in friendships when taking on the partner caregiver role.

Thus the integrations of the qualitative and quantitative studies, through using a mixed methods approach, enhanced not only the individual studies but also enabled a more comprehensive picture to emerge from the results.

9.8 Implications for further research

The outcomes from this project increase our understanding of the connections between health and personal relationship transitions when taking on a partner caregiver role. As this doctoral project was exploratory, however, it is likely that the greatest impact will be on informing future research.

This section will focus on exploring how the findings from this project can be carried forward into future research.

9.8.1 Further utilisation of existing longitudinal datasets

As a first step the main findings from the quantitative analyses should be confirmed using other appropriate longitudinal datasets, such as SHARE or HRS; where a-priori hypotheses and analyses methodologies would be informed by the outcomes from this doctoral project. The expectation would be that the results from these confirmatory analyses would substantiate the findings presented here.

It was unfortunate that the quantitative analysis over three time points was greatly underpowered due to small numbers, which limited the potential to infer causal relationships between transitions in health and personal relationships for older partner caregivers. Though ELSA wave 7 was due for release in January 2016 it is likely that, even when combining all seven waves, the analyses will remain underpowered. Potentially, however, complementary longitudinal datasets of older adults could be combined to provide enough power to enable the identification of significant directional relationships.

The results from this doctoral project shed light on potential causal relationships between health and personal relationships. These results should help to inform future research into causal relationships between health and personal relationship in older adults, especially where directional relationship assumptions are required to populate directed acyclic graphs (DAG).

9.8.2 Undertaking a prospective longitudinal mixed methods study

The following section provides a justification, a brief outline, and the anticipated benefits of expanding this doctoral project by conducting a three year longitudinal mixed methods study to investigate changes in health and personal relationships for older partner caregivers.

Justification

This doctoral project appears to be the first study to explore changes in different aspects of health and different personal relationships for older adults taking on a partner caregiver role; however measuring these changes over time was limited by several factors. Firstly the two year gap between ELSA waves meant that while some partner caregivers may have only recently moved into the partner caregiver role, others may have fulfilled the role for upwards of two years. Thus partner caregivers who were all identified as moving into a partner caregiver role between ELSA waves may actually have been in very different transitioning periods.

Secondly the qualitative interviews required participants to recall changes in their health and personal relationships. Though participants were asked to complete a relationship diagram, as an aid to recall personal relationships, the problem of inaccurate recall is well established in the literature and it is likely that the participant’s recall of their past health and personal relationship experiences may have included omissions or inaccuracies (Bernard et al., 1984), particularly when recalling less important personal relationships (Brewer, 2000). Finally the qualitative interviews were limited by the small number of participants who were recruited to the study. This meant that the experiences of different groups, such as men and women, participants from different cultures, or participants with different family or friendship compositions, could not be compared.

A prospective longitudinal mixed methods study could overcome the problems described above and build on the findings from this doctoral project. Participants could be recruited from first entering into the partner caregiver role and followed up at regular intervals over several years. This would ensure that the study would not be relying on participant recall, but instead the experiences of partner caregivers could be collected as participants’ transition into, and adapt to, the partner caregiver role.

Outline of proposed study

Participants recruited into this longitudinal study would, most likely, be identified via the NHS; based on the NHS services provided to their partners. It would be sensible to limit recruitment to those participants whose partners had experienced an acute health event, such as stroke. This would help reduce the problem of a time lag between participants taking on a partner caregiver role and caregivers actually defining themselves by such a term (Harding and Higginson, 2001, O'Connor, 2007, Corden and Hirst, 2011). Eligibility would need to include requirements around the health of the partner and the expectation that partners would, at some point, be returning home; and would be supported, at least in part, by their partner.

Assessments of the health and personal relationships surrounding the partner caregivers’ could be first collected while their partners remain in hospital, providing baseline information before participants move into the partner caregiver role. Follow-up would need to be regular, perhaps at one month, six months, and one year to capture changes experienced by caregivers.

It is anticipated that the methods used to elicit information would include questionnaires and interviews, informed by the outcomes of this doctoral project, and existing validated measures, such as the CES-D (Radloff, 1977), CASP-19

(Hyde et al., 2003), the Caregiver Burden Scale (Elmståhl et al., 1996), and the Caregiver Strain Index (Robinson, 1983). Assessments of their partners health needs may also need to be assessed, using, for example the ADL (Katz et al., 1970) or the Stroke Impact Scale (Duncan et al., 2003).

This study would require careful consideration of the potential ethical implications of conduction such a study, including receiving notification of all partner deaths to avoid contacting partner caregivers who have recently lost their partner.

Benefits

Including larger participant numbers within this longitudinal qualitative study would mean that the experiences of different partner caregiver groups could be compared. This doctoral project highlighted several areas where further investigation is particularly warranted. Comparing the experiences of male and female partner caregivers was unfortunately not possible within the qualitative study, as only one male was included, however the quantitative results suggest that the experiences of male and female caregivers may differ, in terms of both health and personal relationship transitions. A larger longitudinal qualitative study would provide the means to explore if and how these differences manifest for males and females and help identify potential reasons why this may be the case. These results could then help to highlight if different approaches are required when providing professional support services to male and female partner caregivers. The results from this doctoral project also provide some evidence that older partner caregivers without family and friends may be particularly vulnerable, in terms of experiencing deteriorations in their health and having little support available. A larger qualitative study would be justified to help understand the experiences of isolated older partner caregivers; the transitions they go through when taking on the partner caregiver role; and the resources, such as health care professionals, which help them cope with their caring role. This knowledge could help identify mechanisms and resources to support vulnerable older adults caring for their partners in the community.

9.8.3 The friendship role fulfilled by paid carers

One of the interesting, and potentially important, outcomes from the qualitative interviews was the suggestion that new friendships may evolve between partner caregivers and paid social or health care support workers who are also looking after their partner. Results from the qualitative interviews found that the paid support workers who were considered friends were those who had supported the couple over a period of time, sometimes from when help from outside the home was first sought. These friendships had developed not only because the proximity and frequency of contact between the partner caregiver and the paid support workers provided a situation where friendships could develop naturally; but also because a trust and supportive relationship had developed through a mutual understanding of the needs of the partner and the situation of the couple.

Though there was a suggestion from the qualitative interviews that partner caregivers who particularly benefitted from friendships with paid support workers where those who required a lot of support to care for their partner, were confined to the home for much of the time, and who had little support from family and friends locally; this was based on only one participant and there remains many unanswered questions. It remains unclear for example under what circumstances these friendships develop, whether the perceptions of the friendship are consistent between the partner caregiver and the paid support worker, if a friendship role to the family is an anticipated holistic part of the paid support worker role, and what the benefits of these friendships are to both the partner caregiver and the paid support worker.

On the face of it, however, there seems great potential for these friendships to provide support to the most vulnerable and isolated partner caregivers, and further exploration in this area appears merited. A systematic review of the friendship role of paid support workers to informal caregivers would provide a firm basis from which to decide if further exploration is required in this area. If further exploration is needed this could be included in a longitudinal study, such as the one described in section 9.8.2. Ultimately the outcomes from the systematic review and, if required, longitudinal study could be used to inform an intervention study which would assess the benefit of including an explicit friendship support to partner caregiver role within the usually paid support worker role. The outcomes from this intervention study could have great potential to redefine the role of health or social care support workers, both nationally and internationally.

9.8.4 The importance of activities outside the home.

Finally both the qualitative and quantitative studies found that participating in activities outside the home was beneficial to health for partner caregivers, but partner caregivers found it more difficult to maintain activities outside the home once they had taken on the caregiver role. These findings intimate that providing a means to enable partner caregivers to pursue activities outside the home may be beneficial to their health.

An intervention study to assess the effectiveness of enablers to pursue activities outside the home for partner caregivers would be beneficial, however before undertaking an intervention study further research in this area is required. Further work should include assessing the health benefits of undertaking different types of activities outside the home for partner caregivers, identifying other benefits and costs in continuing or starting activities outside the home for partner caregiver, and classifying enablers and impeders to participating in activities outside the home. This research is likely to be broad and could include a review of the current evidence base in this area, qualitative interviews with partner caregivers, and further secondary analyses of existing longitudinal cohort data.

9.9 Implications for practice

The implications for practice from this doctoral thesis can be only speculative as this was an exploratory project and further research is necessary before evidence based recommendations can be proposed. This section covers areas identified within this doctoral thesis which may, following further research, lead to future practice implications.

Preliminary findings suggest that there is a subset of partner caregivers who are at a greater risk of experiencing adverse health effects through taking on the partner caregiver role. Partner caregivers who may be particularly vulnerable are those who experienced the following before taking on the partner caregiver role: difficult partner relationship, little or no support from family or friends, and existing health problems. This doctoral thesis also found that the quality and level of contact across all personal relationship types was connected, suggesting partner caregivers who, for example, reported poor relationships with their partner were also more likely to report poor relationships with all other personal relationship types. Identifying and supporting particularly vulnerable older partner caregivers at the earliest opportunity is important. The Care Act (2014) includes an assessment of the support needs of the carer and cared for, which hopefully will provide a holistic approach to the management of the health and care needs of the caregiver. Further research leading from this doctoral thesis may ultimately provide an aid to assist health and social care professionals to identify those partner caregivers who are at particular risk.

Evidence from the quantitative results within this doctoral thesis suggest that male and female partner caregivers have different experiences in the personal relationships which surround them, with male caregivers being more likely to report better partner relationships, and female caregivers being more likely to report better relationships with family and friends. These results suggest that the informal support available to male and female caregivers, and thus their corresponding unmet support needs, may be different. Further research in this area will help to highlight if health and social care support professionals need to be aware of these apparent differences when assessing the support needs of partner caregivers.

As discussed in section 9.8.3, the results from this exploratory project suggest that paid social and health care workers may be providing a friendship role to vulnerable partner caregivers. Following further research in this area these results have potential to lead to a change in the approach adopted by paid support care workers.

Finally, the importance of initiating or continuing with activities outside the home for partner caregivers may ultimately, following further research described in section 9.8.4, lead to an increased understanding and support for partner caregivers to engage in regular activities outside the home.

9.10 Conclusion

Overall this project suggests that the connections between transitions in health and personal relationships, for older adults who have taken on a caring role for their partners, differ for different relationships. It is the relationships with partners and friends which are most associated with changes in health and quality of life when moving into this role. While relationships with children and family appear more stable during the transitioning into the partner caregiver role, partner relationships are more likely to suffer, and friendships may experience more change, as partner caregivers possibly source those friendships which provide the most support.

The positive associations found between different personal relationship types, for partner caregivers, and between personal relationships before becoming a partner caregiver and changes in other personal relationships when moving into the partner caregiver role, suggest that partner caregivers who experience difficulties in one relationship are more likely to also experience difficulties in their other relationships. This highlights that there is likely to be a subset of older partner caregivers who may be in problematic partner relationships and have little or no contact with other family or friends.

Chapter 10 References

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Appendix A. Literature review

A.1. Literature review search terms

Number	Search term
1	(social adj1 engagement*).mp.
2	(social adj1 tie*).mp.
3	(social adj1 participat*).mp.
4	(social adj1 interact*).mp.
5	(social adj1 network*).mp.
6	(social adj1 support*).mp.
7	(social adj1 integrat*).mp.
8	(social adj1 relation*).mp.
9	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8
10	relative*.mp.
11	relation.mp.
12	marital.mp.
13	married.mp.
14	partner.mp.
15	husband.mp.
16	wife.mp.
17	spouse.mp.
18	companion.mp.
19	couple.mp.
20	friend*.mp.
21	(family or families).mp.
22	mother.mp.
23	father.mp.
24	sister.mp.
25	brother.mp.
26	sibling.mp.
27	cousin.mp.
28	aunt*.mp.
29	uncle.mp.
30	children.mp.
31	son.mp.
32	daughter.mp.
33	10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32
34	older.m_titl.
35	oldest.m_titl.

Number	Search term
36	mature.m_titl.
37	elderly.m_titl.
38	ageing.m_titl.
39	aging.m_titl.
40	aged.m_titl.
41	"middle age*".m_titl.
42	"old age*".m_titl.
43	(later adj1 life).m_titl.
44	life course.m_titl.
45	life management.m_titl.
46	"gerontolog*".m_titl.
47	34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46
48	adapt*.mp.
49	adjust*.mp.
50	transform*.mp.
51	chang*.mp.
52	trajector*.mp.
53	evolution*.mp.
54	longitudinal.mp.
55	48 or 49 or 50 or 51 or 52 or 53 or 54
56	9 and 33 and 47 and 55

A.2. Excluded studies

Not a primary study (n = 14)

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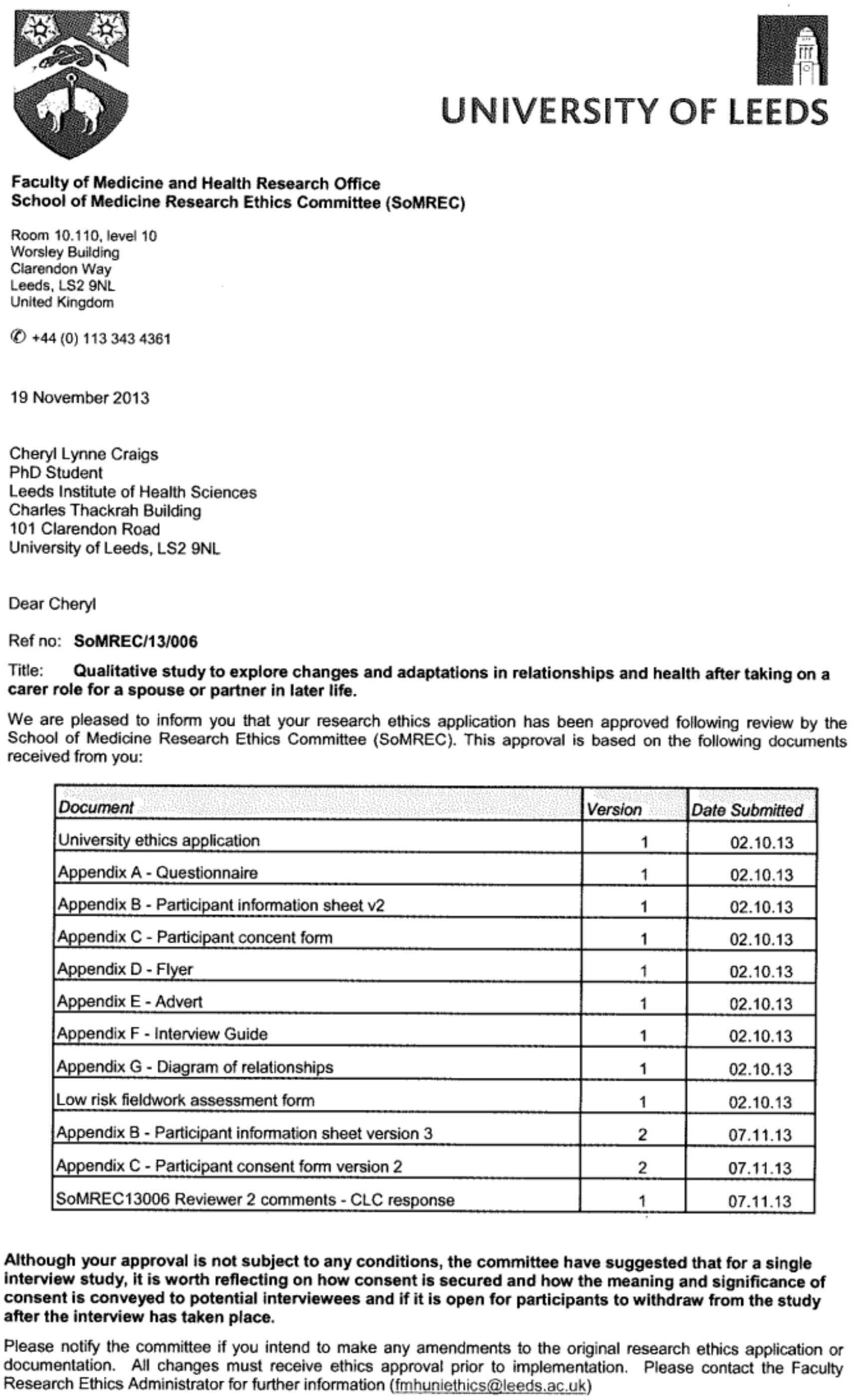
Appendix B. Qualitative study

B.1. Ethical approval letter



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Faculty of Medicine and Health Research Office
School of Medicine Research Ethics Committee (SoMREC)

Room 10.110, level 10
Worsley Building
Clarendon Way
Leeds, LS2 9NL
United Kingdom

✆ +44 (0) 113 343 4361

19 November 2013

Cheryl Lynne Craigs
PhD Student
Leeds Institute of Health Sciences
Charles Thackrah Building
101 Clarendon Road
University of Leeds, LS2 9NL

Dear Cheryl

Ref no: **SoMREC/13/006**

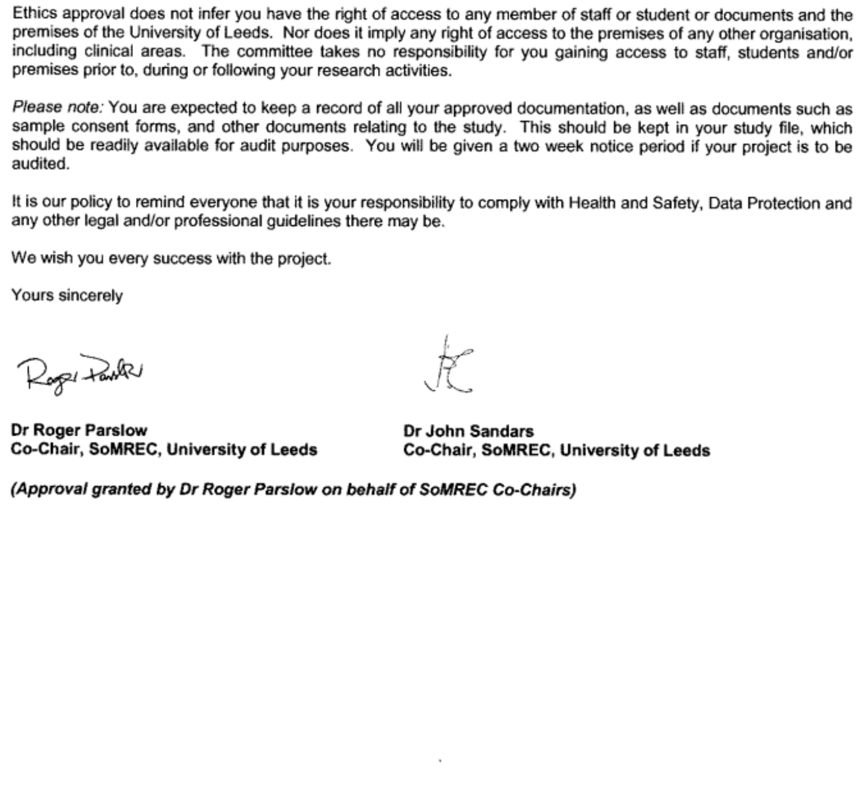
Title: **Qualitative study to explore changes and adaptations in relationships and health after taking on a carer role for a spouse or partner in later life.**

We are pleased to inform you that your research ethics application has been approved following review by the School of Medicine Research Ethics Committee (SoMREC). This approval is based on the following documents received from you:

Document	*Version*	*Date Submitted*
University ethics application	1	02.10.13
Appendix A - Questionnaire	1	02.10.13
Appendix B - Participant information sheet v2	1	02.10.13
Appendix C - Participant concent form	1	02.10.13
Appendix D - Flyer	1	02.10.13
Appendix E - Advert	1	02.10.13
Appendix F - Interview Guide	1	02.10.13
Appendix G - Diagram of relationships	1	02.10.13
Low risk fieldwork assessment form	1	02.10.13
Appendix B - Participant information sheet version 3	2	07.11.13
Appendix C - Participant consent form version 2	2	07.11.13
SoMREC13006 Reviewer 2 comments - CLC response	1	07.11.13

Although your approval is not subject to any conditions, the committee have suggested that for a single interview study, it is worth reflecting on how consent is secured and how the meaning and significance of consent is conveyed to potential interviewees and if it is open for participants to withdraw from the study after the interview has taken place.

Please notify the committee if you intend to make any amendments to the original research ethics application or documentation. All changes must receive ethics approval prior to implementation. Please contact the Faculty Research Ethics Administrator for further information (fmhuniethics@leeds.ac.uk)



Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

We wish you every success with the project.

Yours sincerely

Dr Roger Parslow
Co-Chair, SoMREC, University of Leeds

Dr John Sandars
Co-Chair, SoMREC, University of Leeds

(Approval granted by Dr Roger Parslow on behalf of SoMREC Co-Chairs)

B.2. Carers Leeds advert

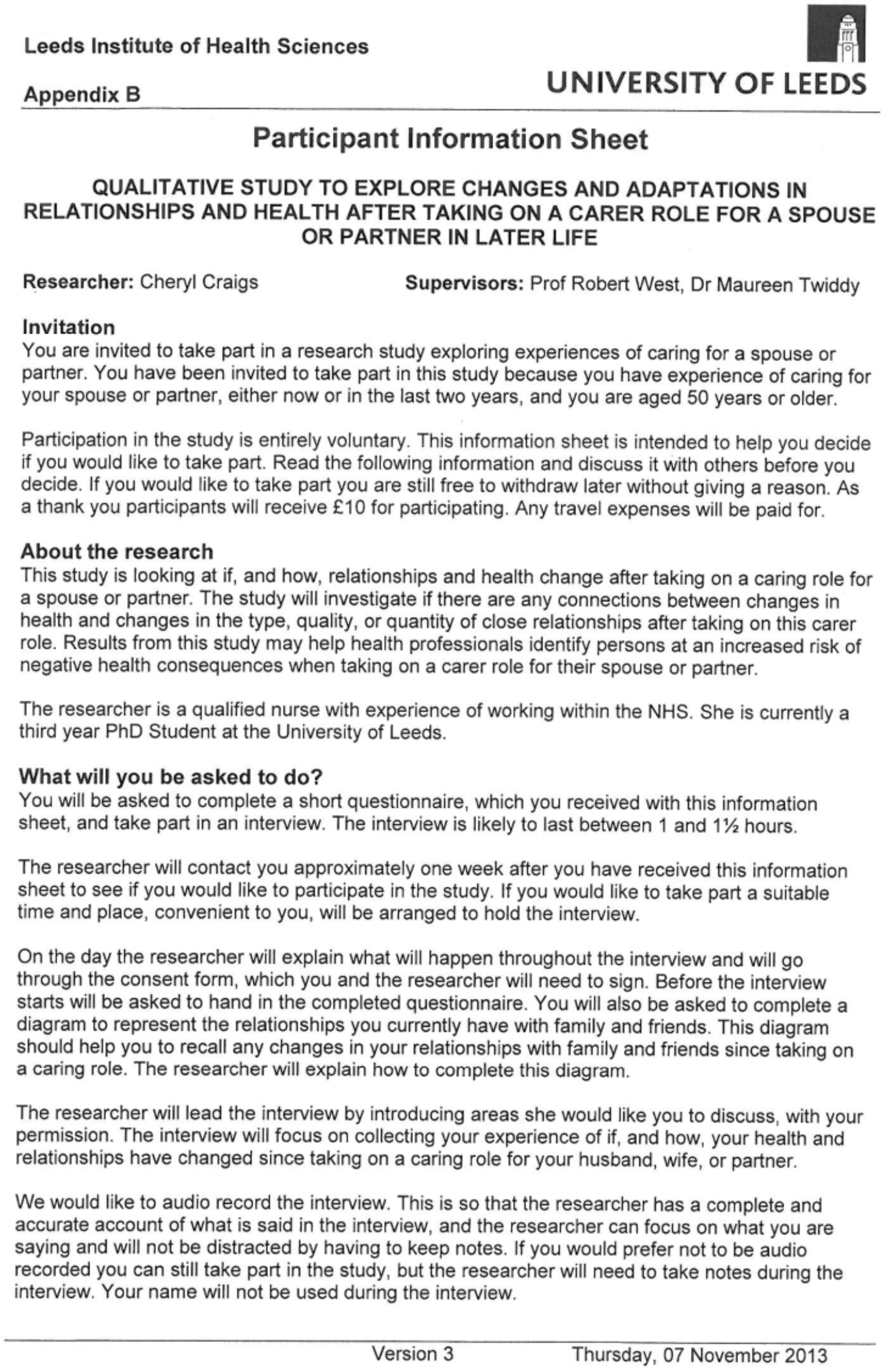
Your chance to participate in a study exploring how relationships and health change when you take on a caring role for a spouse or partner

Researchers at the University of Leeds are interested in hearing about peoples' experiences of caring for a spouse or partner. In particular they are interested in hearing if, how, and in what way this role can impact on a carers' health and relationships. This may include their relationships with their spouse or partner, other family members, or friends.

The study involves completing a one page questionnaire and undertaking an interview, which will be conducted at a time and place convenient for participants. Travel expenses will be paid for and, as a thank you for taking part in the study, participants will receive **£10**.

If you are aged at least 50 years, have experience of providing care for your spouse or partner (now or in the past), and are interested in participating please contact Cheryl Craigs, either by email (c.l.craigs@leeds.ac.uk) or by phone (0113 3431688 or 07534355731).

B.3. Information sheet



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Appendix B

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Participant Information Sheet

QUALITATIVE STUDY TO EXPLORE CHANGES AND ADAPTATIONS IN RELATIONSHIPS AND HEALTH AFTER TAKING ON A CARER ROLE FOR A SPOUSE OR PARTNER IN LATER LIFE

Researcher: Cheryl Craigs **Supervisors:** Prof Robert West, Dr Maureen Twiddy

Invitation

You are invited to take part in a research study exploring experiences of caring for a spouse or partner. You have been invited to take part in this study because you have experience of caring for your spouse or partner, either now or in the last two years, and you are aged 50 years or older.

Participation in the study is entirely voluntary. This information sheet is intended to help you decide if you would like to take part. Read the following information and discuss it with others before you decide. If you would like to take part you are still free to withdraw later without giving a reason. As a thank you participants will receive £10 for participating. Any travel expenses will be paid for.

About the research

This study is looking at if, and how, relationships and health change after taking on a caring role for a spouse or partner. The study will investigate if there are any connections between changes in health and changes in the type, quality, or quantity of close relationships after taking on this carer role. Results from this study may help health professionals identify persons at an increased risk of negative health consequences when taking on a carer role for their spouse or partner.

The researcher is a qualified nurse with experience of working within the NHS. She is currently a third year PhD Student at the University of Leeds.

What will you be asked to do?

You will be asked to complete a short questionnaire, which you received with this information sheet, and take part in an interview. The interview is likely to last between 1 and 1½ hours.

The researcher will contact you approximately one week after you have received this information sheet to see if you would like to participate in the study. If you would like to take part a suitable time and place, convenient to you, will be arranged to hold the interview.

On the day the researcher will explain what will happen throughout the interview and will go through the consent form, which you and the researcher will need to sign. Before the interview starts will be asked to hand in the completed questionnaire. You will also be asked to complete a diagram to represent the relationships you currently have with family and friends. This diagram should help you to recall any changes in your relationships with family and friends since taking on a caring role. The researcher will explain how to complete this diagram.

The researcher will lead the interview by introducing areas she would like you to discuss, with your permission. The interview will focus on collecting your experience of if, and how, your health and relationships have changed since taking on a caring role for your husband, wife, or partner.

We would like to audio record the interview. This is so that the researcher has a complete and accurate account of what is said in the interview, and the researcher can focus on what you are saying and will not be distracted by having to keep notes. If you would prefer not to be audio recorded you can still take part in the study, but the researcher will need to take notes during the interview. Your name will not be used during the interview.

Version 3 Thursday, 07 November 2013

Confidentiality

Discussions within the interview will remain confidential however there are exceptional instances where confidentiality cannot be guaranteed. Such instances include if it is felt that you, or your partner, are at risk of harm. In the extremely unlikely event that such an issue should occur, the researcher will stop the interview and talk to you about this. All efforts will be made to retain your anonymity, but the researcher would have to discuss this issue with her supervisors and others with expertise in this area, and they would collaboratively determine the appropriate course of action. Please speak to the researcher if you have any queries or concerns around confidentiality.

What will happen to this information?

You will receive a copy of the signed consent form to take home with you. A copy of the consent form and the questionnaire will be kept by the researcher and stored in a locked filing cabinet within a secure university building.

The interview will be transcribed and stored in a password protected computer file. Participants will be identifiable only by a code on all electronic documents. To ensure anonymity and confidentiality all electronic documents will be stored on a secure server within the University.

You can receive a copy of your interview transcript, by letting the researcher know on the day of the interview, or by contacting the researcher using the details below. If, after reading your transcript, you identify sections which you do not want included in the analysis, these sections can be removed, if your request is received within a specified date. You will be told beforehand of this date. It is likely to be three weeks from the date your interview transcript was sent, however this can be negotiable. Your transcript will not be included in the analyses until after this date and you can also still choose to withdraw completely from the study if you prefer, up to this time point. After this date, unless you have requested otherwise, your transcript will be included in the analyses.

Your transcript will be analysed alongside transcripts from interviews with other participants. Differences and similarities between the experiences described in the transcripts will be analysed to provide a better understanding of how relationships and health can change after taking on a caring role for a spouse or partner.

What will happen to the results of the study?

Results from this study will form part of the researcher's PhD thesis. The researcher will provide feedback on the results in the form of a summary report which will be made available to Carer Leeds. The researcher and her supervisors are also keen to have these results published in a professional journal.

What are the benefits and risks to taking part in the study?

Benefits: You may find it useful to discuss your experiences with the researcher
Risks: You may be asked to discuss experiences which cause you to feel emotional. You will be free to decline to respond to any topics you are not comfortable discussing, without question. You are also free to stop the interview at any time, should you wish to.

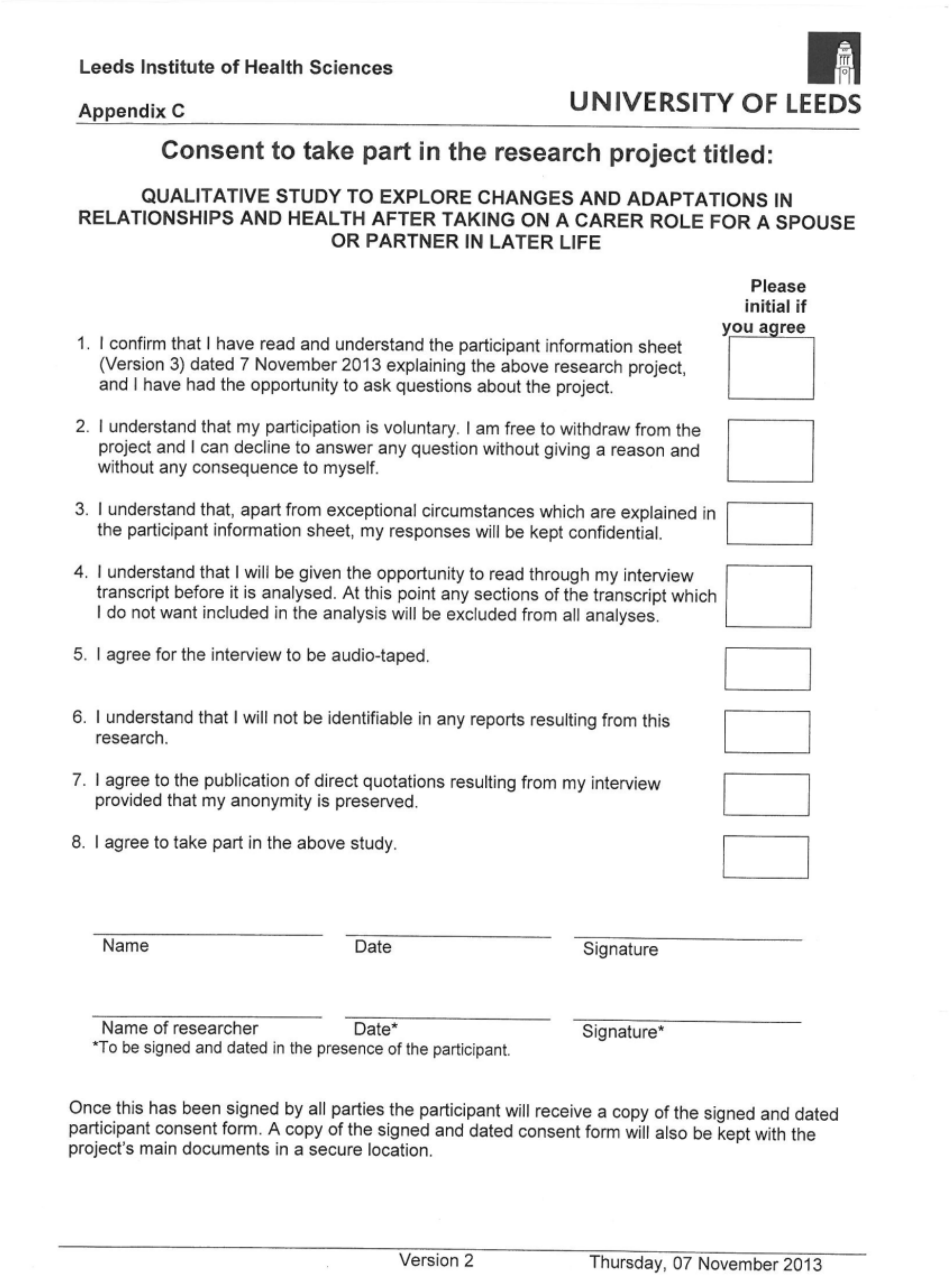
Contact details for further information

If there is anything you are unsure of, or if you would like to speak to the researcher about any issues please contact the researcher using the details below.

Researcher: Cheryl Craigs
Email: c.l.craigs@leeds.ac.uk
Address: Leeds Institute of Health Sciences, The University of Leeds, LS2 9LJ.
Telephone: 0113 3431688 or 07534355731

THANK YOU

B.4. Consent form



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Appendix C

Consent to take part in the research project titled:

QUALITATIVE STUDY TO EXPLORE CHANGES AND ADAPTATIONS IN RELATIONSHIPS AND HEALTH AFTER TAKING ON A CARER ROLE FOR A SPOUSE OR PARTNER IN LATER LIFE

Please initial if you agree

1. I confirm that I have read and understand the participant information sheet (Version 3) dated 7 November 2013 explaining the above research project, and I have had the opportunity to ask questions about the project. ☐
2. I understand that my participation is voluntary. I am free to withdraw from the project and I can decline to answer any question without giving a reason and without any consequence to myself. ☐
3. I understand that, apart from exceptional circumstances which are explained in the participant information sheet, my responses will be kept confidential. ☐
4. I understand that I will be given the opportunity to read through my interview transcript before it is analysed. At this point any sections of the transcript which I do not want included in the analysis will be excluded from all analyses. ☐
5. I agree for the interview to be audio-taped. ☐
6. I understand that I will not be identifiable in any reports resulting from this research. ☐
7. I agree to the publication of direct quotations resulting from my interview provided that my anonymity is preserved. ☐
8. I agree to take part in the above study. ☐

Name ____________ Date ____________ Signature ____________

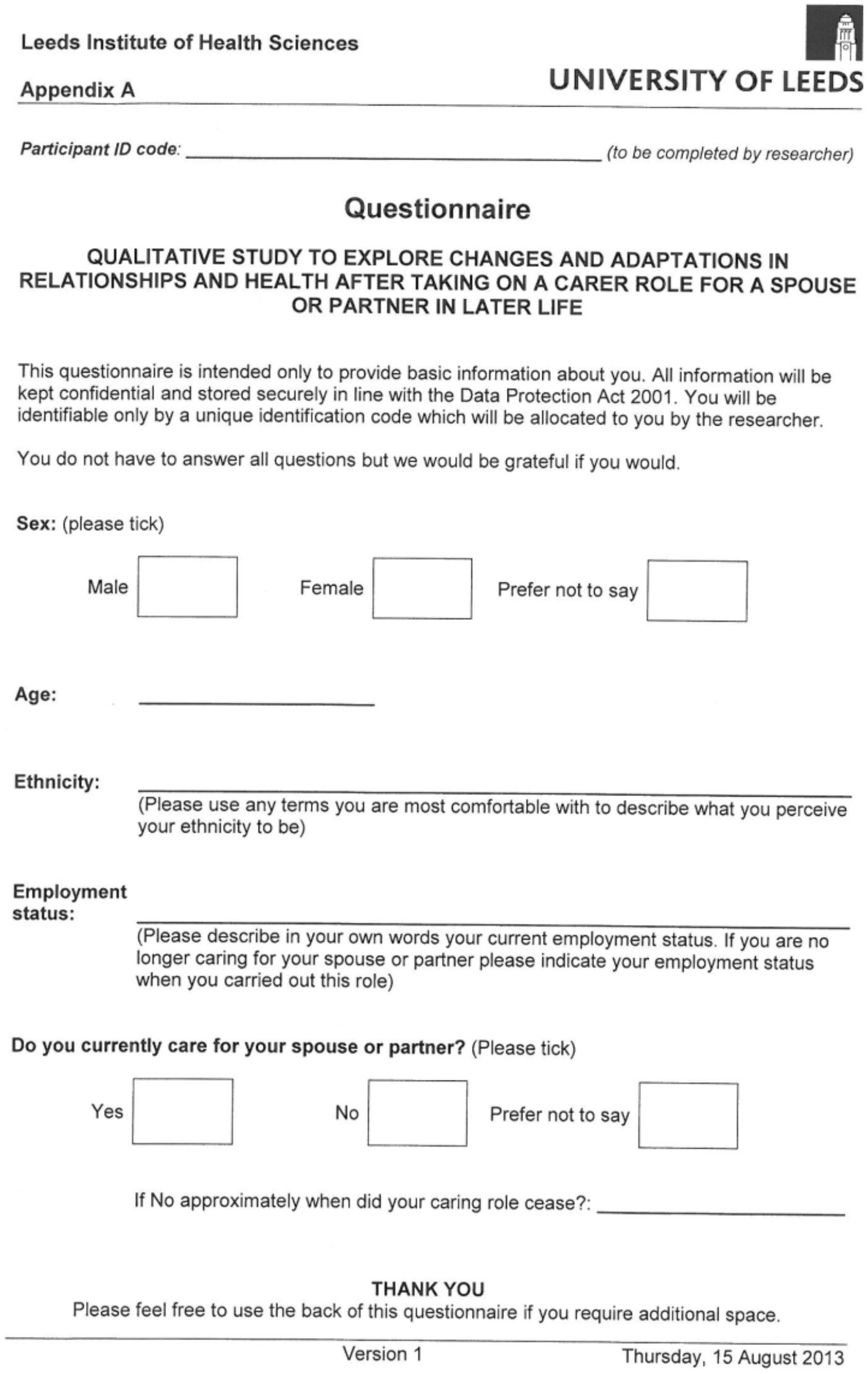
Name of researcher ____________ Date* ____________ Signature* ____________

*To be signed and dated in the presence of the participant.

Once this has been signed by all parties the participant will receive a copy of the signed and dated participant consent form. A copy of the signed and dated consent form will also be kept with the project's main documents in a secure location.

Version 2 Thursday, 07 November 2013

B.5. Questionnaire



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Appendix A

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Participant ID code: ________________________ *(to be completed by researcher)*

Questionnaire

QUALITATIVE STUDY TO EXPLORE CHANGES AND ADAPTATIONS IN RELATIONSHIPS AND HEALTH AFTER TAKING ON A CARER ROLE FOR A SPOUSE OR PARTNER IN LATER LIFE

This questionnaire is intended only to provide basic information about you. All information will be kept confidential and stored securely in line with the Data Protection Act 2001. You will be identifiable only by a unique identification code which will be allocated to you by the researcher.

You do not have to answer all questions but we would be grateful if you would.

Sex: (please tick)

Male ☐ Female ☐ Prefer not to say ☐

Age: ________________

Ethnicity: ________________________

(Please use any terms you are most comfortable with to describe what you perceive your ethnicity to be)

Employment status: ________________________

(Please describe in your own words your current employment status. If you are no longer caring for your spouse or partner please indicate your employment status when you carried out this role)

Do you currently care for your spouse or partner? (Please tick)

Yes ☐ No ☐ Prefer not to say ☐

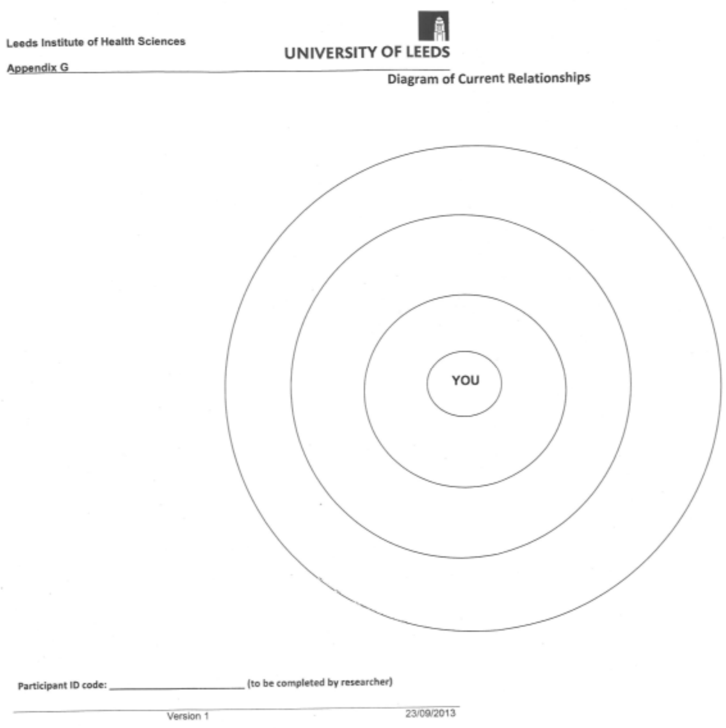
If No approximately when did your caring role cease?: ________________

THANK YOU

Please feel free to use the back of this questionnaire if you require additional space.

Version 1 Thursday, 15 August 2013

B.6. Relationship diagram



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Appendix G

Diagram of Current Relationships

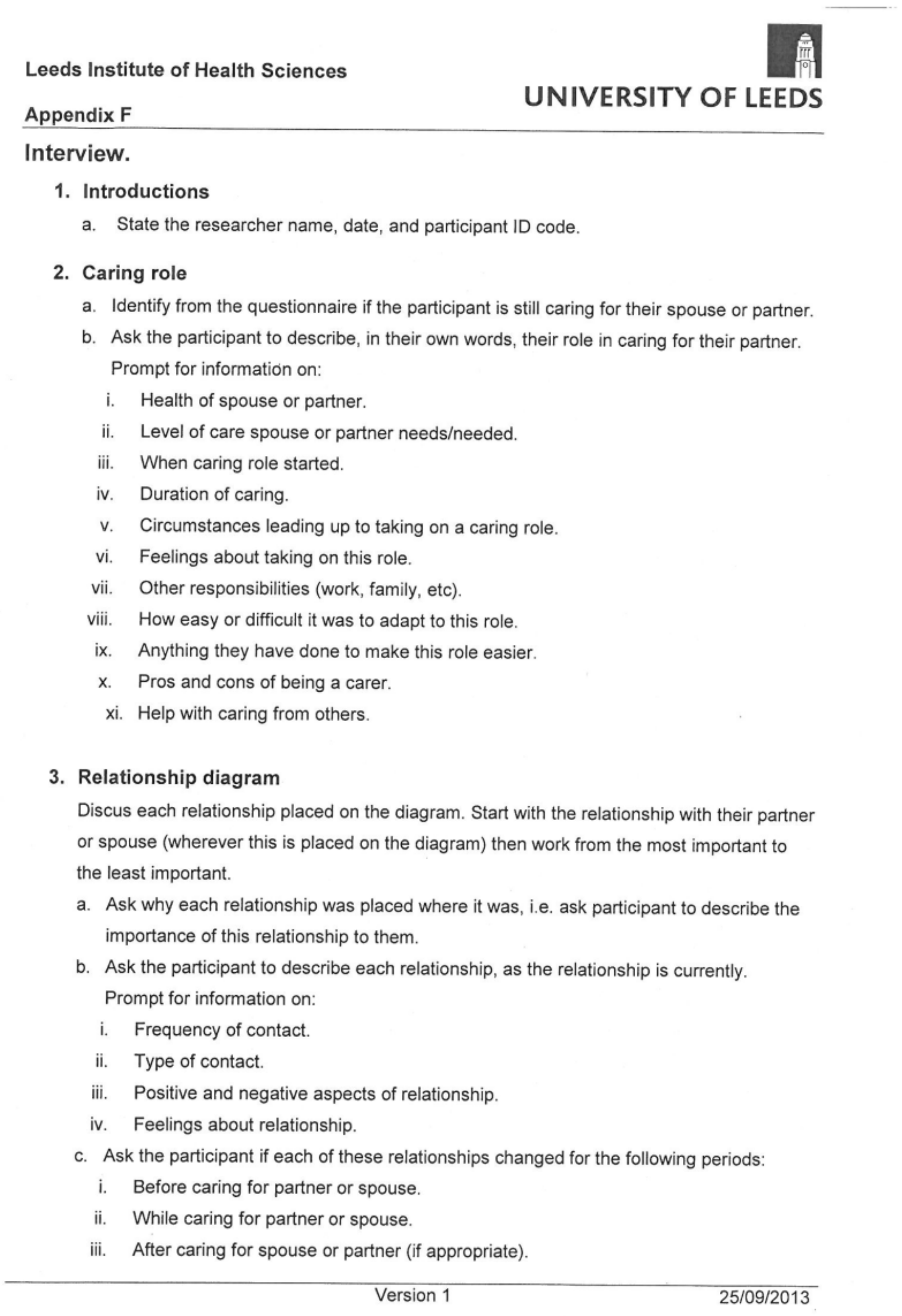
YOU

Participant ID code: ____________________ **(to be completed by researcher)**

Version 1 23/09/2013

(provided on A3 landscape)

B.7. Topic guide



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Appendix F

Interview.

1. **Introductions**
   a. State the researcher name, date, and participant ID code.

2. **Caring role**
   a. Identify from the questionnaire if the participant is still caring for their spouse or partner.
   b. Ask the participant to describe, in their own words, their role in caring for their partner. Prompt for information on:
      i. Health of spouse or partner.
      ii. Level of care spouse or partner needs/needed.
      iii. When caring role started.
      iv. Duration of caring.
      v. Circumstances leading up to taking on a caring role.
      vi. Feelings about taking on this role.
      vii. Other responsibilities (work, family, etc).
      viii. How easy or difficult it was to adapt to this role.
      ix. Anything they have done to make this role easier.
      x. Pros and cons of being a carer.
      xi. Help with caring from others.

3. **Relationship diagram**

   Discus each relationship placed on the diagram. Start with the relationship with their partner or spouse (wherever this is placed on the diagram) then work from the most important to the least important.

   a. Ask why each relationship was placed where it was, i.e. ask participant to describe the importance of this relationship to them.
   b. Ask the participant to describe each relationship, as the relationship is currently. Prompt for information on:
      i. Frequency of contact.
      ii. Type of contact.
      iii. Positive and negative aspects of relationship.
      iv. Feelings about relationship.
   c. Ask the participant if each of these relationships changed for the following periods:
      i. Before caring for partner or spouse.
      ii. While caring for partner or spouse.
      iii. After caring for spouse or partner (if appropriate).

d. Where changes have occurred ask participant to describe these changes.
Prompt for information on:
   i. What these changes were (change in importance, frequency of contact, type of contact, quality of relationship).
   ii. Where participant would place this relationship previously.
   iii. Positive and negative aspects of relationship before.
   iv. Feelings about this change.
   v. Why they thought this change has happened.
   vi. Anything they could have done or did to improve current relationship.

e. Ask if there are any additional relationships which do not appear on the map but which were important before taking on a carer role for spouse or partner. Repeat a-d for each of these relationships.

4. Health

a. Inform the participant that you would like them to think about their health, from before they started caring for their spouse or partner, to the present day.

b. Ask them how their health is currently
Prompt for information on:
   i. Any diagnosed health conditions.
   ii. How they feel generally.
   iii. Any difficulty getting around.

c. Ask how their health was before taking on a carer role for their spouse or partner (see prompts above).

d. If their health has changed ask them to describe the circumstances around this change (better or worse).
Prompt for information on:
   i. When this happened (at the start of caring, during caring, after caring).
   ii. Events marking this change in health.
   iii. The extent of change.
   iv. How this change in health makes them feel.
   v. What do they attribute this change in health to.
   vi. Any support from family and/or friends. If yes who?
   vii. Any hindrance from family and/or friends. If yes who?

e. If their health has remained the same ask them if their health has remained consistent throughout, from before taking on a carer role to now.

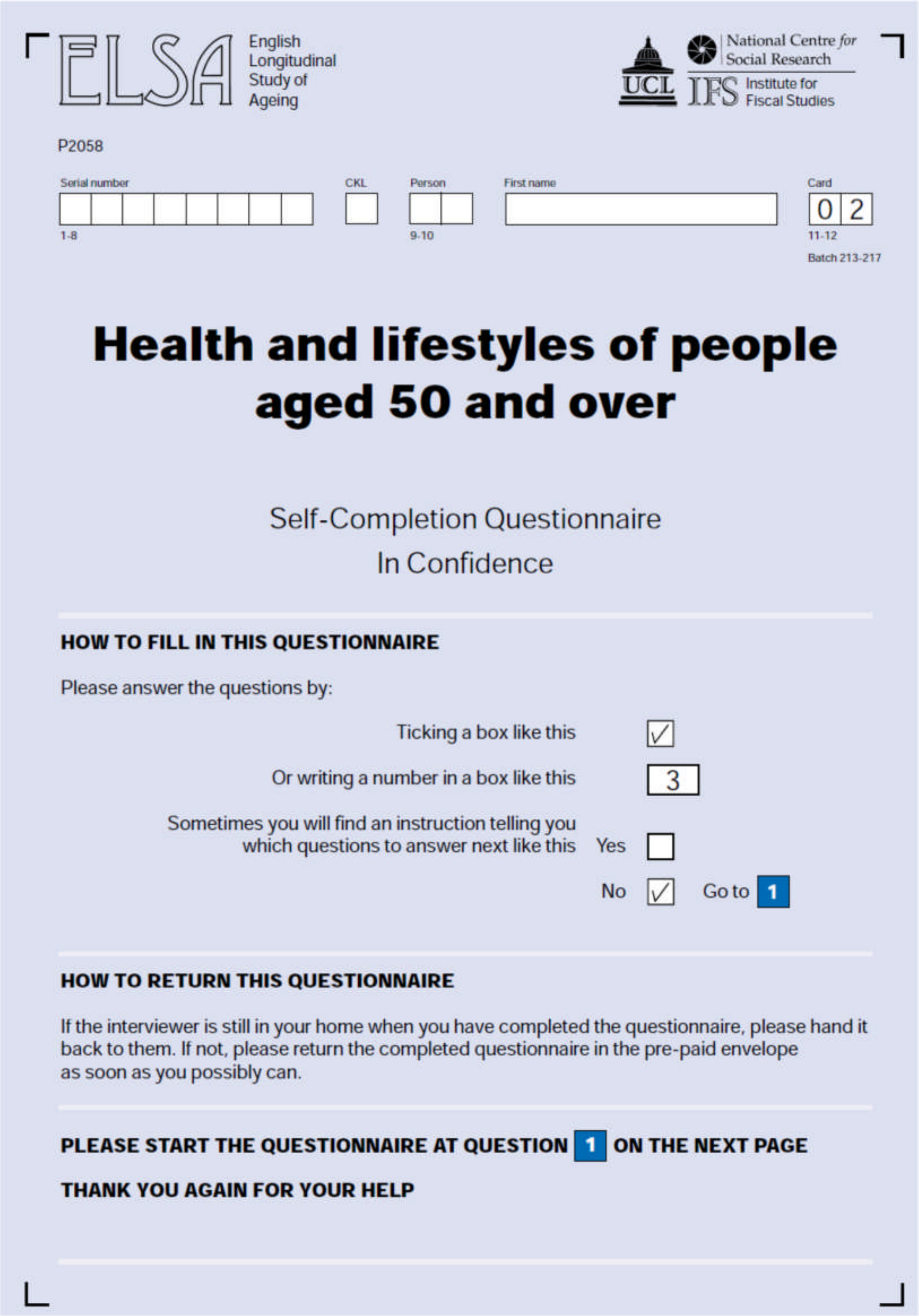
f. If yes (to previous question) ask them to think about and discuss why they thought they had maintained their health over this period.
   Prompt for information on:
   i. Why they think their health has been maintained.
   ii. Any support from family and/or friends. If yes who?
   iii. Any hindrance from family and/or friends. If yes who?

g. If no please refer to d. above.

5. Any other information
   a. Ask the participant if there is anything else they would like to report about their experience of caring for their spouse or partner which they think would be useful for the study and which hasn't been mentioned.

Appendix C. Quantitative study

C.1. ELSA Self-Completion questionnaire



ELSA English Longitudinal Study of Ageing

UCL National Centre *for* Social Research

IFS Institute for Fiscal Studies

P2058

Serial number	CKL	Person	First name	Card
☐☐☐☐☐☐☐☐	☐	☐☐	☐	0 2
1-8		9-10		11-12

Batch 213-217

Health and lifestyles of people aged 50 and over

Self-Completion Questionnaire
In Confidence

HOW TO FILL IN THIS QUESTIONNAIRE

Please answer the questions by:

Ticking a box like this ☑

Or writing a number in a box like this 3

Sometimes you will find an instruction telling you which questions to answer next like this
Yes ☐
No ☑ Go to **1**

HOW TO RETURN THIS QUESTIONNAIRE

If the interviewer is still in your home when you have completed the questionnaire, please hand it back to them. If not, please return the completed questionnaire in the pre-paid envelope as soon as you possibly can.

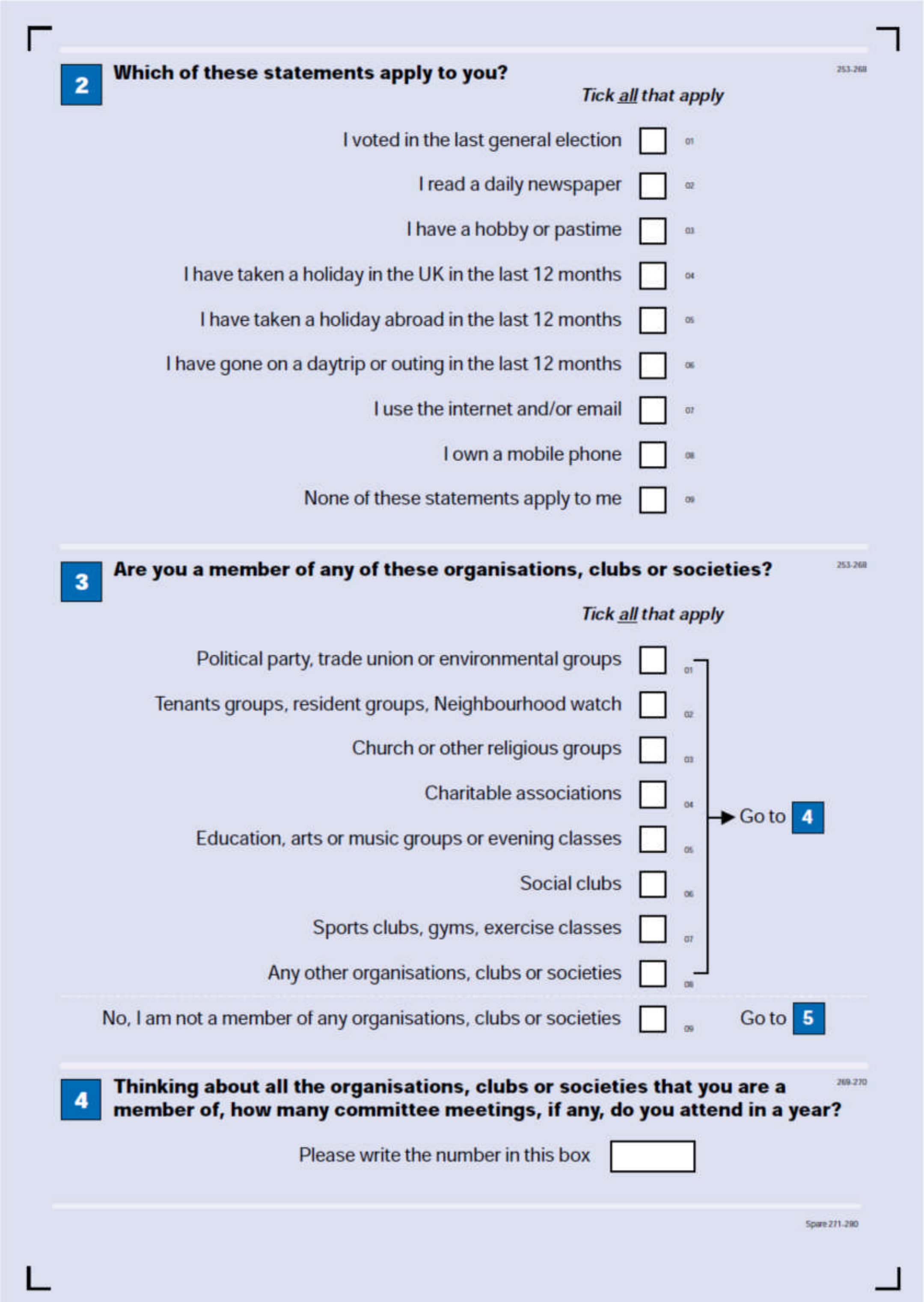
PLEASE START THE QUESTIONNAIRE AT QUESTION 1 ON THE NEXT PAGE

THANK YOU AGAIN FOR YOUR HELP

1 **Here is a list of statements that people have used to describe their lives or how they feel. We would like to know how often, if at all, you think they apply to you.**

Tick one box on each line

	Often	Some-times	Not Often	Never	
My age prevents me from doing the things I would like to	☐ 1	☐ 2	☐ 3	☐ 4	218
I feel that what happens to me is out of my control	☐ 1	☐ 2	☐ 3	☐ 4	219
I feel free to plan for the future	☐ 1	☐ 2	☐ 3	☐ 4	220
I feel left out of things	☐ 1	☐ 2	☐ 3	☐ 4	221
I can do the things that I want to do	☐ 1	☐ 2	☐ 3	☐ 4	222
Family responsibilities prevent me from doing what I want to do	☐ 1	☐ 2	☐ 3	☐ 4	223
I feel that I can please myself what I do	☐ 1	☐ 2	☐ 3	☐ 4	224
My health stops me from doing things I want to do	☐ 1	☐ 2	☐ 3	☐ 4	225
Shortage of money stops me from doing the things I want to do	☐ 1	☐ 2	☐ 3	☐ 4	226
I look forward to each day	☐ 1	☐ 2	☐ 3	☐ 4	227
I feel that my life has meaning	☐ 1	☐ 2	☐ 3	☐ 4	228
I enjoy the things that I do	☐ 1	☐ 2	☐ 3	☐ 4	229
I enjoy being in the company of others	☐ 1	☐ 2	☐ 3	☐ 4	230
On balance, I look back on my life with a sense of happiness	☐ 1	☐ 2	☐ 3	☐ 4	231
I feel full of energy these days	☐ 1	☐ 2	☐ 3	☐ 4	232
I choose to do things that I have never done before	☐ 1	☐ 2	☐ 3	☐ 4	233
I feel satisfied with the way my life has turned out	☐ 1	☐ 2	☐ 3	☐ 4	234
I feel that life is full of opportunities	☐ 1	☐ 2	☐ 3	☐ 4	235
I feel that the future looks good for me	☐ 1	☐ 2	☐ 3	☐ 4	236



2 **Which of these statements apply to you?** 253-268

Tick all that apply

I voted in the last general election ☐ 01
I read a daily newspaper ☐ 02
I have a hobby or pastime ☐ 03
I have taken a holiday in the UK in the last 12 months ☐ 04
I have taken a holiday abroad in the last 12 months ☐ 05
I have gone on a daytrip or outing in the last 12 months ☐ 06
I use the internet and/or email ☐ 07
I own a mobile phone ☐ 08
None of these statements apply to me ☐ 09

3 **Are you a member of any of these organisations, clubs or societies?** 253-268

Tick all that apply

Political party, trade union or environmental groups ☐ 01
Tenants groups, resident groups, Neighbourhood watch ☐ 02
Church or other religious groups ☐ 03
Charitable associations ☐ 04
Education, arts or music groups or evening classes ☐ 05
Social clubs ☐ 06
Sports clubs, gyms, exercise classes ☐ 07
Any other organisations, clubs or societies ☐ 08
→ Go to **4**

No, I am not a member of any organisations, clubs or societies ☐ 09 Go to **5**

4 **Thinking about all the organisations, clubs or societies that you are a member of, how many committee meetings, if any, do you attend in a year?** 269-270

Please write the number in this box ☐

Spare 271-290

5 **How easy or difficult would it be for you to get to each of the following places, using your usual form of transport?**

SN 1-8
PN 9-10
Card 11-12

Tick one box on each line

	Very easy	Quite easy	Quite difficult	Very difficult	
Bank or cash point	☐ 1	☐ 2	☐ 3	☐ 4	313
Chiropodist	☐ 1	☐ 2	☐ 3	☐ 4	314
Dentist	☐ 1	☐ 2	☐ 3	☐ 4	315
General Practitioner	☐ 1	☐ 2	☐ 3	☐ 4	316
Hospital	☐ 1	☐ 2	☐ 3	☐ 4	317
Local Shops	☐ 1	☐ 2	☐ 3	☐ 4	318
Optician	☐ 1	☐ 2	☐ 3	☐ 4	319
Post Office	☐ 1	☐ 2	☐ 3	☐ 4	320
Shopping Centre	☐ 1	☐ 2	☐ 3	☐ 4	321
Supermarket	☐ 1	☐ 2	☐ 3	☐ 4	322

6 **We should like to know how your health has been in general over the past few weeks.**

Have you recently...

Tick one box on each line

	Better than usual	Same as usual	Less than usual	Much less than usual	
...been able to concentrate on whatever you're doing?	☐ 1	☐ 2	☐ 3	☐ 4	323

	Not at all	No more than usual	Rather more than usual	Much more than usual	
...lost much sleep over worry?	☐ 1	☐ 2	☐ 3	☐ 4	324

	More so than usual	Same as usual	Less useful than usual	Much less useful	
...felt you were playing a useful part in things?	☐ 1	☐ 2	☐ 3	☐ 4	325

Have you recently...

Tick <u>one</u> box on each line

	More so than usual	Same as usual	Less so than usual	Much less capable
...felt capable of making decisions?	☐ 1	☐ 2	☐ 3	☐ 4 326
	Not at all	No more than usual	Rather more than usual	Much more than usual
...felt constantly under strain?	☐ 1	☐ 2	☐ 3	☐ 4 327
	Not at all	No more than usual	Rather more than usual	Much more than usual
...felt you couldn't overcome your difficulties?	☐ 1	☐ 2	☐ 3	☐ 4 328
	More so than usual	Same as usual	Less so than usual	Much less than usual
...been able to enjoy your normal day-to-day activities?	☐ 1	☐ 2	☐ 3	☐ 4 329
	More so than usual	Same as usual	Less able than usual	Much less able
...been able to face up to your problems?	☐ 1	☐ 2	☐ 3	☐ 4 330
	Not at all	No more than usual	Rather more than usual	Much more than usual
...been feeling unhappy and depressed?	☐ 1	☐ 2	☐ 3	☐ 4 331
	Not at all	No more than usual	Rather more than usual	Much more than usual
...been losing confidence in yourself?	☐ 1	☐ 2	☐ 3	☐ 4 332
	Not at all	No more than usual	Rather more than usual	Much more than usual
...been thinking of yourself as a worthless person?	☐ 1	☐ 2	☐ 3	☐ 4 333
	More so than usual	About same as usual	Less so than usual	Much less than usual
...been feeling reasonably happy, all things considered?	☐ 1	☐ 2	☐ 3	☐ 4 334

7 **Here are some questions about how you feel about your life in general. Please say how much you agree or disagree with the following statements.**

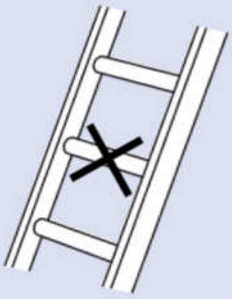
Tick <u>one</u> box on each line

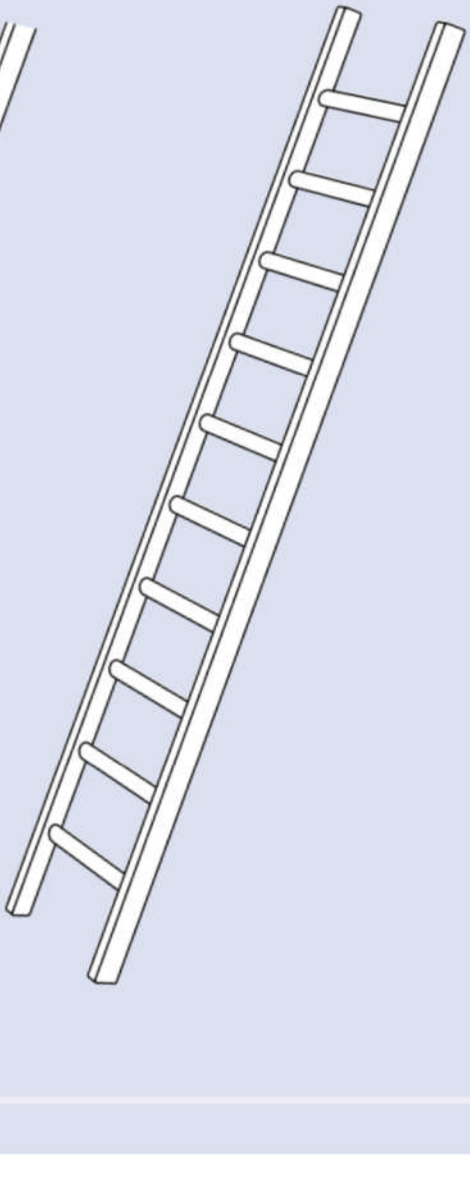
	Strongly agree	Moder-ately agree	Slightly agree	Slightly disagree	Moder-ately disagree	Strongly disagree	I do not work	
At home, I feel I have control over what happens in most situations	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6		335
At work, I feel I have control over what happens in most situations	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	336
I feel that what happens in my life is often determined by factors beyond my control	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6		337
In general, I have different demands that I think are hard to combine	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6		338
In general, I have enough time to do everything	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6		339
Considering the things I have to do at work, I have to work very fast	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	340
Considering the things I have to do at home, I have to work very fast	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6		341

8 **Think of this ladder as representing where people stand in our society. At the top of the ladder are the people who are the best off – those who have the most money, most education and best jobs. At the bottom are the people who are the worst off – who have the least money, least education, and the worst jobs or no jobs. The higher up you are on this ladder, the closer you are to the people at the very top and the lower you are, the closer you are to the people at the very bottom.**

Please mark a cross on the __rung__ on the ladder where you would you place yourself.

Example:





342-343

☐☐

9 **Do you have a husband, wife or partner with whom you live?** 344

Tick one box

Yes ☐ 1 **Go to 10**

No ☐ 2 **Go to 12**

10 **We would now like to ask you some questions about your spouse or partner. Please tick the box which best shows how you feel about each statement.**

Tick one box on each line

	A lot	Some	A little	Not at all	
How much do they really understand the way you feel about things?	☐ 1	☐ 2	☐ 3	☐ 4	345
How much can you rely on them if you have a serious problem?	☐ 1	☐ 2	☐ 3	☐ 4	346
How much can you open up to them if you need to talk about your worries?	☐ 1	☐ 2	☐ 3	☐ 4	347
How much do they criticise you?	☐ 1	☐ 2	☐ 3	☐ 4	348
How much do they let you down when you are counting on them?	☐ 1	☐ 2	☐ 3	☐ 4	349
How much do they get on your nerves?	☐ 1	☐ 2	☐ 3	☐ 4	350

11 **How close is your relationship with your spouse or partner?** 351

Tick one box

Very close ☐ 1

Quite close ☐ 2

Not very close ☐ 3

Not at all close ☐ 4

12 **Do you have any children?**

352

Tick one box

Yes ☐ 1 **Go to 13**

No ☐ 2 **Go to 16**

13 **We would now like to ask you some questions about your children.**
Please tick the box which best shows how you feel about each statement.

Tick one box on each line

	A lot	Some	A little	Not at all	
How much do they really understand the way you feel about things?	☐ 1	☐ 2	☐ 3	☐ 4	353
How much can you rely on them if you have a serious problem?	☐ 1	☐ 2	☐ 3	☐ 4	354
How much can you open up to them if you need to talk about your worries?	☐ 1	☐ 2	☐ 3	☐ 4	355
How much do they criticise you?	☐ 1	☐ 2	☐ 3	☐ 4	356
How much do they let you down when you are counting on them?	☐ 1	☐ 2	☐ 3	☐ 4	357
How much do they get on your nerves?	☐ 1	☐ 2	☐ 3	☐ 4	358

14 **On average, how often do you do each of the following with any of your children, not counting any who live with you?**

Tick one box on each line

	Three or more times a week	Once or twice a week	Once or twice a month	Every few months	Once or twice a year	Less than once a year or never	
Meet up (include both arranged and chance meetings)	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	359
Speak on the phone	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	360
Write or email	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	361

15 **How many of your children would you say you have a close relationship with?**

362-363

Please write the number in this box ☐

16 **Do you have any other immediate family, for example, any brothers or sisters, parents, cousins or grandchildren?** 364

Tick one box

Yes ☐ 1 **Go to 17**

No ☐ 2 **Go to 20**

17 **We would now like to ask you some questions about these family members. Please tick the box which best shows how you feel about each statement.**

Tick one box on each line

	A lot	Some	A little	Not at all	
How much do they really understand the way you feel about things?	☐ 1	☐ 2	☐ 3	☐ 4	365
How much can you rely on them if you have a serious problem?	☐ 1	☐ 2	☐ 3	☐ 4	366
How much can you open up to them if you need to talk about your worries?	☐ 1	☐ 2	☐ 3	☐ 4	367
How much do they criticise you?	☐ 1	☐ 2	☐ 3	☐ 4	368
How much do they let you down when you are counting on them?	☐ 1	☐ 2	☐ 3	☐ 4	369
How much do they get on your nerves?	☐ 1	☐ 2	☐ 3	☐ 4	370

18 **On average, how often do you do each of the following with any of these family members, not counting any who live with you?**

Tick one box on each line

	Three or more times a week	Once or twice a week	Once or twice a month	Every few months	Once or twice a year	Less than once a year or never	
Meet up (include both arranged and chance meetings)	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	371
Speak on the phone	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	372
Write or email	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	373

19 **How many of these family members would you say you have a close relationship with?** 374-375

Please write the number in this box ☐

376

20 **Do you have any friends?**

Tick one box

Yes ☐ 1 **Go to 21**

No ☐ 2 **Go to 24**

Spare 377-380

SN 1-8
PN 9-10
Card 11-12

21 **We would now like to ask you some questions about your friends.**
Please tick the box which best shows how you feel about each statement.

Tick one box on each line

	A lot	Some	A little	Not at all	
How much do they really understand the way you feel about things?	☐ 1	☐ 2	☐ 3	☐ 4	413
How much can you rely on them if you have a serious problem?	☐ 1	☐ 2	☐ 3	☐ 4	414
How much can you open up to them if you need to talk about your worries?	☐ 1	☐ 2	☐ 3	☐ 4	415
How much do they criticise you?	☐ 1	☐ 2	☐ 3	☐ 4	416
How much do they let you down when you are counting on them?	☐ 1	☐ 2	☐ 3	☐ 4	417
How much do they get on your nerves?	☐ 1	☐ 2	☐ 3	☐ 4	418

22 **On average, how often do you do each of the following with any of your friends, not counting any who live with you?**

Tick one box on each line

	Three or more times a week	Once or twice a week	Once or twice a month	Every few months	Once or twice a year	Less than once a year or never	
Meet up (include both arranged and chance meetings)	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	419
Speak on the phone	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	420
Write or email	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	421

23 **How many of your friends would you say you have a close relationship with?**

422-423

Please write the number in this box ☐

24 **How do you feel about your local area, that is everywhere within a 20 minute walk or about a mile of your home? Please tick one box on each line. The closer your tick is to a statement the more strongly you agree with it.**

Tick one box on each line

I really feel part of this area	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	I feel that I don't belong in this area	424
Vandalism and graffiti are a big problem in this area	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	There is no problem with vandalism and graffiti in this area	425
I often feel lonely living in this area	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	I have never felt lonely living in this area	426
Most people in this area can be trusted	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	Most people in this area can't be trusted	427
People would be afraid to walk alone in this area after dark	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	People feel safe walking alone in this area after dark	428
Most people in this area are friendly	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	Most people in this area are unfriendly	429
People in this area will take advantage of you	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	People in this area will always treat you fairly	430
This area is kept very clean	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	This area is always full of litter and rubbish	431
If you were in trouble, there are lots of people in this area who would help you	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	If you were in trouble, there is nobody in this area who would help you	432

25 **If there is anything else you would like to tell us please write in the space below. We shall be very interested to read what you have to say.** 433

Thank you very much for taking the time to answer our questions. Please give the questionnaire to the interviewer or post it back in the envelope provided. All your answers will remain confidential.

C.2. Study data dictionary

Variable	Description	Code	Label	Source	Wave
Identifier variables					
wave	Wave in which data was collected	1	Wave 1	Created based on data file wave	All
		2	Wave 2		
		3	Wave 3		
		4	Wave 4		
		5	Wave 5		
idauniq	Unique participant number			All	All
couple_id	Identifier to link couples together, within and across waves, irrespective if one is living in an institution.			IFS	All
idauniq_p	Unique participant number for spouse/partner			IFS	All
elsa	Whether participant is an ELSA sample member	-1	Inapplicable	IFS	All
		0	No		
		1	Yes		
Demographic variables					
couple	Part of a couple	0	No	IFS	All
		1	Yes		
	Note: If one member of a couple is in an institution, this variable still defines them as a couple				
sex	Sex of participant	0	male	IFS	All
		1	female		
	Note: RECODED from original values where 1=Male, 2=Female				
ageg10	Age of participant - 10 year bands	-1	under 50	IFS	All
		1	50-59		
		2	60-69		
		3	70-79		
		4	80+		
nonwhite	Ethic origin (white/non-white)	0	White	IFS	All
		1	Not White		
		99	Information not available		
work	Economic activity	1	Working	Created from IFS data item	All
		2	Not working		
		3	Retired		
		99	Information not available		

	Generation of work variable:
	If (ecpos = 2 OR 3) work = 1; IF (ecpos = 4 OR 5 OR 6 OR 8) work = 2;
	IF(ecpos = 7) work = 3
	Ecpos: 1=Position not recorded, 2=Employee, 3=Self-employed, 4=Seeking work, 5=Sick but seeking, 6=Sick and not seeking, 7=Retired, 8=Unoccupied				

edqual	Educational qualification	1	A level/higher	IFS	All
		4	NVQ 1-2/O level equiv		
		6	Foreign/other		
		7	no qualification		
		99	Information not available (previously -1,-2, -8, or -9)		
findiff	How is respondent (and partner) getting along financially these days?	1	manage very well	IFS	All
		2	manage quite well		
		3	get by alright		
		4	don't manage very well		
		5	have some financial difficulties		
		6	have severe financial difficulties		
		99	Information not available (previously -1, -8, or -9)		
Member-org	Member of an organisation	0	No	Altered CORE data item	All
		1	Yes		
		99	Information not available		
	Alteration: OrgMem=0 IF (scorg9=1); OrgMem=1 IF(scorg9=0); OrgMem=99 IF(scorg9=-1 OR scorg9=-9) scorg9: 0=No (I am a member), 1=Yes (Not a member)				

Variable	Description	Code	Label	Source	Wave
Attrition variables					
Died	Died before next wave	0	No	Index file	All
		1	Yes		
InterNW	Interviewed next wave	0	No	Index file	All
		1	Yes		
Carer status variables					
Carer_partner	Reported caring for spouse or partner in the last week (active provision of care)	0	Did not report caring for spouse or partner	Created from CORE data items	All
		1	Reported caring for spouse or partner		
	Generation of Carer_partner variable: Wave 1: IF (spcaa = 1 & (spcab1=1 OR spcab2 = 1 OR spcab3 = 1 OR spcab4 = 1) Carer_partner = 1. Wave 2: IF (ErCAA = 1 & (ercanu1 >= 1)) Carer_partner=1. Wave 3, wave 4, wave 5: IF (ercaa = 1 & (ercansp >= 1) Carer_partner=1. spcaa = ErCAA = ercaa = Whether respondent looked after anyone in the past week. 1=Yes. spcab1=spcab2=spcab3=spcab4=What relation is this person or people to you?. 1=spouse/partner. ercanu1 = ercansp = Number of spouses/partners respondent looked after in past week.				
Carer_other	Reported caring for someone who was not their spouse or partner in the last week or not defined	0	Did not report caring for others	Created from CORE data items	All
		1	Report caring for others		
	Generation of Carer_other variable: Wave 1: IF (spcaa = 1 & (any spcab1 to spcab4 ≠ 1) Carer_other=1. Wave 2: IF (ErCAA = 1 & (any ercanu2 to ercanu8 >= 1)) Carer_other=1. Wave 3: IF (ercaa = 1 & (ercanch >= 1 OR ercangc >= 1 OR ercanpa >= 1 OR ercanpl >= 1 OR ercanor >= 1 OR ercanfr >= 1 OR ercanot >= 1)) Carer_other=1. spcaa = ErCAA = ercaa = Whether respondent looked after anyone in the past week. 1=Yes. spcab1=spcab2=spcab3=spcab4=What relation is this person or people to you?. 1=spouse/partner. ercanu2 = ercanch = Number of children respondent looked after in past week. ercanu3 = ercangc = Number of grandchildren respondent looked after in past week. ercanu4 = ercanpa = Number of parents respondent looked after in past week, ercanu5 = ercanpl = Number of parents-in-law respondent looked after in past week. ercanu6 = ercanor = Number of other relatives respondent looked after in past week. ercanu7 = ercanfr = Number of friends/neighbours respondent looked after in past week. ercanu8 = ercanot = Number of other people respondent looked after in past week				
Health variables					
SRH_bin	SRH at start of health questions converted to binary	-1	No valid response	Created from CORE data items	All
		0	Fair or better		
		1	Poor/bad/very bad		
	See Chapter six for description of the creation of SRH_bin generation				
SRH_bin_flag	SRH binary based on Excellent to poor?	-1	No valid response	Created from CORE data items	All
		0	No		
		1	Yes		
	Notes: Variable created to identify if the SRH responses the participant made were based on a likert range from very good to very poor presented at the start of the health questions section.				
CESD_TOTAL	CESD total score 0-8	0-8	Valid CESD score	Created from CORE	ALL
		Sys_mis	Missing values - Information not available		
	Generation of CESD_TOTAL variable: CESD_TOTAL = 0; CESD_TOTAL=sysmis IF (psceda to pscedh LESS THAN 0) (i.e. any missing values); Negatively worded questions (1=Yes, 2=No) RECODE (2=0) for psceda, pscedb, pscedc, pscede , pscedg , pscedh Postively worded questions (1=Yes, 2=No) RECODE (2=1) (1=0) for pscedd, pscedf IF CESD_TOTAL=0 (i.e. no missing values) CESD_TOTAL = psceda + pscedb + pscedc + pscede + pscedg + pscedh + pscedd_neg + pscedf_neg.				
CESD-DCat	CESD categories?	0	Not depressive symptoms	Created from CORE data items	All
		1	One to three depressive symptoms		
		2	Four or more depressive symptoms		
		99	Information not available		
	Notes: Variable created to identify if the SRH responses the participant made were based on a likert range from very good to very poor presented at the start of the health questions section.				

<table>
<tr><th>Variable</th><th>Description</th><th>Code</th><th>Label</th><th>Source</th><th>Wave</th></tr>
<tr><td rowspan="3">CASP19_TOTAL</td><td rowspan="2">CASP-19 total score</td><td>0-57</td><td>Valid CASP-19 score</td><td rowspan="2">Created from CORE</td><td rowspan="2">All</td></tr>
<tr><td>Sys-mis</td><td>Missing values - Information not available</td></tr>
<tr><td colspan="5">Generation of CASP19_TOTAL variable:
CASP19_TOTAL = 0
CASP19_TOTAL = sysmis IF (scqola to scqols LESS THAN 0) (i.e. any missing values)
Negatively worded questions RECODE (-9=SYSMIS) (-1=SYSMIS) (1=0) (2=1) (3=2) (4=3) for scqola, scqolb, scqold, scqolf, scqolh.
Positively worded questions RECODE (-9=SYSMIS) (-1=SYSMIS) (1=3) (2=2) (3=1) (4=0) for scqolc, scqole, scqolg, scqolj, scqolk, scqoll, scqolm, scqoln, scqolo, scqolp, scqolq, scqolr, scqols.
IF CASP19 = 0 CASP19_TOTAL= scqola scqolb scqold scqolf scqolh scqolc scqole scqolg scqolj scqolk scqoll scqolm scqoln scqolo scqolp scqolq scqolr scqols</td></tr>
<tr><td rowspan="6">Partner_ ADL</td><td rowspan="5">Partner ADL</td><td>0</td><td>No difficulty with any ADL</td><td rowspan="5">Created from CORE dataset</td><td rowspan="5">All</td></tr>
<tr><td>1</td><td>Difficulty with one ADL</td></tr>
<tr><td>2</td><td>Difficulty with 2 to 4 ADL</td></tr>
<tr><td>3</td><td>Difficulty with 5 or 6 ADL</td></tr>
<tr><td>99</td><td>Information not available</td></tr>
<tr><td colspan="5">Generation of ADL_TOTAL variable
ADL_TOTAL=0.
ADL_TOTAL = 99 IF (headldr to headlwc < 0) (i.e. any missing values)
IF (ADL_TOTAL=0) ADL_TOTAL= 1 IF (headldr + headlwa + headlba + headlea + headlbe + headlwc)>0.</td></tr>
<tr><td rowspan="4">Partner_ Stroke</td><td rowspan="3">Spouse/partner reported doctor ever told them that they have had a stroke?</td><td>0</td><td>No</td><td rowspan="3">Created from CORE dataset</td><td rowspan="3">All</td></tr>
<tr><td>1</td><td>Yes</td></tr>
<tr><td>99</td><td>Information not available</td></tr>
<tr><td colspan="5">Wave 1: IF (hedia01 = 8 OR hedia02 = 8 OR hedia03 = 8 OR hedia04 = 8 OR hedia05 = 8 OR hedia06 = 8 OR hedia07 = 8 OR hedia08 = 8 OR hedia09 = 8 OR hedia10 = 8) Partner_Stroke =1.
Wave 2: IF (HeDiaW8 = 8 OR hedim01 = 8 OR hedim02 = 8 OR hedim03 = 8 OR hedim04 = 8 OR hedim05 = 8 OR hedim06 = 8 OR hedim07 = 8 OR hedim08 = 8) STROKE=1.
Waves 3, 4, 5: IF (hedawst = 8 OR dhedimst = 1) Partner_Stroke =1.
OTHERWISE Partner_Stroke = 0</td></tr>
<tr><td rowspan="4">Partner_ Heart</td><td rowspan="3">Spouse/partner reported doctor ever told them that they have a heart condition?</td><td>0</td><td>No</td><td rowspan="3">Created from CORE dataset</td><td rowspan="3">All</td></tr>
<tr><td>1</td><td>Yes</td></tr>
<tr><td>99</td><td>Information not available</td></tr>
<tr><td colspan="5">Wave 1: IF ((hedia01 >= 1 AND hedia01 <= 6) OR (hedia02 >= 1 AND hedia02 <= 6) OR (hedia03 >= 1 AND hedia03 <= 6) OR (hedia04 >= 1 AND hedia04 <= 6) OR (hedia05 >= 1 AND hedia05 <= 6) OR (hedia06 >= 1 AND hedia06 <= 6) OR (hedia07 >= 1 AND hedia07 <= 6) OR (hedia08 >= 1 AND hedia08 <= 6) OR (hedia09 >= 1 AND hedia09 <= 6) OR (hedia10 >= 1 AND hedia10 <= 6) OR hedia01 = 95 OR hedia02 = 95 OR hedia03 = 95 OR hedia04 = 95 OR hedia05 = 95 OR hedia06 = 95 OR hedia07 = 95 OR hedia08 = 95 OR hedia09 = 95 OR hedia10 = 95) Partner_HeartCond =1.
Wave 2: IF (hediaw1 = 1 OR HeDiaW2 = 2 OR HeDiaW3 = 3 OR HeDiaW4 = 4 OR HeDiaW5 = 5 OR HeDiaW6 = 6 OR HeDiaW9 = 9 OR (hedim01 >= 1 AND hedim01 <= 6) OR (hedim02 >= 1 AND hedim02 <= 6) OR (hedim03 >= 1 AND hedim03 <= 6) OR (hedim04 >= 1 AND hedim04 <= 6) OR (hedim05 >= 1 AND hedim05 <= 6) OR (hedim06 >= 1 AND hedim06 <= 6) OR (hedim07 >= 1 AND hedim07 <= 6) OR (hedim08 >= 1 AND hedim08 <= 6) OR hedim01 = 95| hedim02 = 95| hedim03 = 95| hedim04 = 95| hedim05 = 95| hedim06 = 95 OR hedim07 = 95| hedim08 = 95) Partner_HeartCond =1.
Wave 3, 4, 5: IF (hedawbp = 1 OR hedawan = 2 OR hedawmi = 3 OR hedawhf = 4 OR hedawhm = 5 OR hedawar = 6 OR hedawot = 95 OR hedimbp = 1 OR hediman = 1 OR hedimmi = 1 OR hedimhf = 1 OR hedimhm = 1 OR hedimar = 1) Partner_HeartCond =1. OTHERWISE Partner_HeartCond = 0</td></tr>
<tr><td rowspan="4">Partner_ Cancer</td><td rowspan="3">Spouse/partner has been diagnosed with cancer in the last two years</td><td>0</td><td>No</td><td rowspan="3">Created from CORE dataset</td><td rowspan="3">All</td></tr>
<tr><td>1</td><td>Yes</td></tr>
<tr><td>99</td><td>Information not available</td></tr>
<tr><td colspan="5">Wave 1, 3, 4, 5: IF (hecanb = 1) Partner_Cancer =1.
Wave 2: IF (HeCanb = 1) Partner_Cancer =1.
OTHERWISE Partner_Cancer = 0</td></tr>
</table>

Variable	Description	Code	Label	Source	Wave
Partner_ Emot	Spouse/partner reported doctor ever told them that they have any emotional,	0	No	Created from CORE dataset	All
		1	Yes		
		99	Information not available		
	Wave 1: IF (hedib01 = 7 OR hedib02 = 7 OR hedib03 = 7 OR hedib04 = 7 OR hedib05 = 7 OR hedib06 = 7 OR hedib07 = 7 OR hedib08 = 7 OR hedib09 = 7 OR hedib10 = 7) Partner_Emot =1. Wave2: IF (HeDibW7 = 7 OR hedib01 = 7 OR hedib02 = 7 OR hedib03 = 7 OR hedib04 = 7) Partner_Emot =1. Wave 3, 4, 5: IF (hedbwps = 7 OR dhedibps = 1) Partner_Emot =1. OHERWISE Partner_Emot = 0.				
Partner_Alz	Spouse/partner reported doctor ever told them that they have Alzheimer or	0	No	Created from CORE dataset	All
		1	Yes		
		99	Information not available		
	Wave 1: IF (hedib01 = 8 OR hedib02 = 8 OR hedib03 = 8 OR hedib04 = 8 OR hedib05 = 8 OR hedib06 = 8 OR hedib07 = 8 OR hedib08 = 8 OR hedib09 = 8 OR hedib10 = 8 OR hedib01 = 9 OR hedib02 = 9 OR hedib03 = 9 OR hedib04 = 9 OR hedib05 = 9 OR hedib06 = 9 OR hedib07 = 9 OR hedib08 = 9 OR hedib09 = 9 OR hedib10 = 9) Partner_Alz = 1. Wave 2: IF (HeDibW8 = 8 OR HeDibW9 = 9 OR hedib01 = 8 OR hedib02 = 8 OR hedib03 = 8 OR hedib04 = 8 OR hedib01 = 9 OR hedib02 = 9 OR hedib03 = 9 OR hedib04 = 9) Partner_Alz = 1. Wave 3, 4, 5: IF (hedbwad = 8 |OR hedbwde = 9 OR hedibad = 1 OR hedibde = 1) Partner_Alz = 1. OTHERWISE Partner_Alz = 0.				
Personal relationship variables (See Appendix C.3. for details)					
ParValid	Do you have a spouse or partner	0	No	Created from CORE dataset	All
		1	Yes		
		99	Information not available		
ParQual	Spouse/partner relationship quality latent variable			Created from CORE dataset	All
ParQualInd	Number of valid responses	0	Complete responses	Created from CORE data items	ALL
		1	Incomplete responses		
ChdValid	Do you have any children?	0	No	Created from CORE dataset	All
		1	Yes		
		99	Information not available		
ChildQual	Children relationship quality latent variable			Created from CORE dataset	All
ChdQualInd	Number of valid responses to children quality questions	0	Complete responses	Created from CORE data items	ALL
		1	Incomplete responses		
ChildCont	Children level of contact latent variable			Created from CORE dataset	All
ChdContInd	Number of valid responses to children contact questions	0	Complete responses	Created from CORE data items	ALL
		1	Incomplete responses		
FamValid	Do you have any other family?	0	No	Created from CORE dataset	All
		1	Yes		
		99	Information not available		
FamQual	Family relationship quality latent variable			Created from CORE dataset	All
FamQualInd	Number of valid responses to family quality questions	0	Complete responses	Created from CORE data items	ALL
		1	Incomplete responses		
FamCont	Family level of contact latent variable			Created from CORE dataset	All
FamContInd	Number of valid responses to family contact questions	0	Complete responses	Created from CORE data items	ALL
		1	Incomplete responses		

Variable	Description	Code	Label	Source	Wave
FrdValid	Do you have any friends?	0	No	Created from CORE dataset	All
		1	Yes		
		99	Information not available		
FrdQual	Friends relationship quality latent variable			Created from CORE dataset	All
FrdQualInd	Number of valid responses to friends quality questions	0	Complete responses	Created from CORE	ALL
		1	Incomplete responses		
FrdCont	Friends level of contact latent variable			Created from CORE dataset	All
FrdContInd	Number of valid responses to friends contact questions	0	Complete responses	Created from CORE data items	ALL
		1	Incomplete responses		

C.3. Latent trait modelling of personal relationships

Introduction

This section describes the methods used to transform the personal relationship questions included in the ELSA self-completion questionnaire (Appendix C.1., questions 9 to 23) into a smaller number of latent trait variables.

One latent trait variable was generated to represent the quality of the partner relationship.

Two latent trait variables, representing the quality of the personal relationships and the amount of contact, were generated for each personal relationship type; that is with children, other family, and friends.

Personal relationship questions used to generate latent trait variables

Responses collected from questions asked within ELSA's self-completion questionnaire were mainly used to generate the latent trait factor scores for the latent trait variables. ELSA's self-completion questionnaire is presented in Appendix C.1. Within this questionnaire responders were initially asked to if they had a spouse or partner (Question 9), if they had any children (Question 12), if they had any other family members (Question 16), and if they had any friends (Question 20).

For these questions they were required to respond either 'Yes' or 'No'. Only responders who responded 'Yes' were asked additional questions about that particular personal relationship type; all additional question responses were set to 'Item not applicable' for participants who responded 'No'.

Positive and negative aspects of personal relationships

Responders were asked six questions (labelled A to F in Table C3-i) relating to their feelings about different positive and negative aspects of their personal relationships. These questions were posed separately for their relationships with their partner, children, family, and friends. Responders were required to select one response from four possible responses. The questions, possible responses, and the coding value ELSA used for each questions are detailed in Table C3-i.

Table C3-i: ELSA coding values used for the self-completion questions about positive and negative aspects of personal relationships

Question	A lot	Some	A little	Not at all
A: How much do they really understand the way you feel about things?	1	2	3	4
B: How much can you rely on them if you have a serious problem?	1	2	3	4
C: How much can you open up to them if you need to talk about your worries?	1	2	3	4
D: How much do they criticise you?	1	2	3	4
E: How much do they let you down when you are counting on them?	1	2	3	4
F: How much do they get on your nerves?	1	2	3	4

Closeness of personal relationships

Participants who reported that they had a spouse or partner were asked to rate the closeness they felt by ticking one of four possible responses. The question, response categories and coding values are detailed in Table C3-ii.

Table C3-ii: ELSA coding values used for the self-completion question on closeness with spouse or partner

Question	Very close	Quite close	Not very close	Not at all close
How close is your relationship with your spouse or partner?	1	2	3	4

Closeness with children, family, and friends were captured by asking participants to write the number of children, family members, and friends who they would say they had a close relationship with, providing separate numbers for children, family, and friends. For this study these values were transformed into the following six categories: 0, 1, 2, 3, 4-5, and 6 or more.

Contact with personal relationships

Participants were asked to describe the amount of contact they have with children, family, and friends on average using the questions in Table C3-iii. These questions (labelled G to I) were provided separately for children, family, and friends.

One limitation with the questions reported in Table C3-iii is that they explicitly state to exclude children, family, or friends who responders live with, whereas in contrast family or friends living with the responders were not excluded from questions A to G or the question about closeness For this study it was important to identify family or friends who responders lived with as it is likely that the respondent will see these people regularly and they could potentially be providing a great deal of support.

Table C3-iii: ELSA coding values for the self-completion questions on contact with children, family and friends

Question	Three or more times a week	Once or twice a week	Once or twice a month	Every few weeks	Once or twice a year	Less than once a year or never
On average, how often do you do each of the following with any of your children/family members/ friends, not counting any who live with you?						
G: Meet up *	1	2	3	4	5	6
H: Speak on the phone	1	2	3	4	5	6
I: Write or email	1	2	3	4	5	6

** Including both arranged and chance meetings*

When generating the latent trait variables for amount of contact an additional question was included alongside the questions from the self-completion questionnaire to account for any family or friends with whom the responders lived with. This question is included within the main ELSA interview and asked responders to describe their relationship with all other members of the household. Up to 16 household members could be included and was asked consistently across all waves. The details about the possible responses and associated values are reported in Table C3-iv. From this question three new manifest variables were created to identify participants who were living with children, other relatives, and friends, respectively, at the time of the interview. These new variables are described in Table C3-v. In order to create these variables some assumptions were made. Firstly children were identified as either natural or adopted; foster children were identified as another type of relative. There was no code to identify participants living with friends but there was an option of ‘Other non relative’ which was used as a proxy for living with friends.

Table C3-iv: Relationship of respondent to other members of the household

Value	Label
-9	Refusal
-8	Don't Know
-1	Not applicable
1	Husband/Wife
2	Partner/cohabitee
3	Natural son/daughter
4	Adopted son/daughter
5	Foster son/daughter
6	Step son/daughter/child of partner
7	Son/daughter-in-law
8	Natural parent
9	Adoptive parent
10	Foster parent
11	Stepparent/parent s partner
12	Parent-in-law
13	Natural brother/sister
14	Half-brother/sister
15	Step-brother/sister
16	Adopted brother/sister
17	Foster brother/sister
18	Brother/sister-in-law
19	Grandchild
20	Grandparent
21	Other relative
22	Other non-relative

ELSA item name = dhr

Table C3-v: Additional variables to identify children, family and friend household members

Variable	Criteria	Values
Living with at least one child	Participants reported that they were a natural or adoptive parent (values 8 and 9)	1=No (did not report) 2=Yes (did report)
Living with at least one relative	Participants reported they were living with a relative other than their spouse or partner or children (values 3-7, 10-21)	1=No (did not report) 2=Yes (did report)
Living with at least one friend	Participants who reported they were living with a non-relative (value 22)	1=No (did not report) 2=Yes (did report)

Data transformations

Before undertaking the generation of the latent trait variables all the personal relationship variables listed above were recoded so that higher scores reflected more positive values.

Latent trait variables generated

The latent trait variables which were generated reflected two aspects of personal relationships, the quality of the personal relationships and the level of contact.

Quality of relationships

Four latent trait variables reflecting the quality of relationships responders experienced with their partner, children, family, and friends, respectively, were created.

The personal relationship questions included in the making of these latent trait factor scores were questions A to F, listed in Table C-i which relate to positive and negative aspects of their personal relationships, and the additional question about the closeness responders feel to their partner, children, family, and friends.

Level of contact

Three latent variables reflecting the level of contact responders had with their children, family, and friends, respectively, were generated.

The questions included in the latent trait modelling to generate these latent trait factor scores were questions G, H, and I and the additional manifest variables reflecting others living within the same household as responders.

Latent Trait Analysis

Latent trait analysis was undertaken within R version 3.0.1, via R Studio, using the ltm package.

Graded Response Model

The Graded Response Model (GRM) was used (Samejima, 1969) as the personal relationship variables were all dichotomous or ordinal. Before latent trait modelling was undertaken two key assumptions about the data, which need to be met, were made. The first assumption was that all the manifest variables included in the latent trait analysis were measuring the same underlying latent trait, that is, there was uni-dimensionality between the personal relationship variables. The second assumption was that after controlling for the latent variable all these variables were locally independent.

This model takes the form:

$$P(x_{im} = k|z_m) = g(\eta_{ik}) - g\left(\eta_{i,k+1}\right), \eta_{ik} = \alpha_i(z_m - \beta_{ik}),$$

$where\ x_{im} is\ the\ ordinal\ manifest\ variable\ i\ for\ participant\ m,$

$z_m\ is\ the\ position\ of\ participant\ m\ on\ the\ latent\ trait\ contiuum,$

$k\ represents\ possible\ responses\ for\ variable\ i,$

$g(.) represents\ the\ link\ function,$

$\alpha_i\ denotes\ the\ discrimination\ parameter\ for\ variable\ i,$

$and\ \beta_{ik}\ are\ the\ extremity\ parameters\ such\ that\ \beta_{i,1} <..< \beta_{i,k} <..< \beta_{i,K_{i-1},}$

$where\ \beta_{i,K_i} = \infty$

Generating latent trait factor scores

The latent trait factor scores represent the modal posterior distribution for each possible observed permutation of manifest personal relationship variable responses and were created using the formula:

$$\hat{z}_m = arg\,max\{p\left(x_m\middle|z_m;\hat{\theta}\right)p(z_{m)}\}$$

R commands

The command *grm* was used to fit GRM regression models using the personal relationship manifest variables, while the *factor.scores* command was used to generate latent trait factors scores for every observed permutation of manifest responses.

Fitting the Graded Response Model

Deciding if any personal relationship manifest variables should be removed from the generation of each of the latent trait variables was based on the following:

- The degree of association between the manifest variables, using the R command *rcor.test (<latent trait model>, method = "kendall")*

- Cronbach's alpha to compare internal consistency between manifest variables after excluding each manifest variable in turn, to help identify the degree to which a set of variables measure the same latent construct, using the R command *descript*

- Producing plots representing item response category characteristic curves, using the *plot* command within R

- The percentage of the total information each included manifest variable provided, using the R command *information*

- Subjective decisions on which manifest variables to include, based on what the data represents and the importance the researcher places on retaining manifest variables within the modeling.

- In addition the analysis included a comparison of the constrained and equivalent unconstrained models. While the constrained model assumes equal discrimination parameters across variables, the unconstrained model does not make this assumption.

Using longitudinal data

The motivation for generating latent trait factor scores for different aspects of personal relationships within this study was so that changes over time in these scores could be explored. To be able to assess any change in latent trait scores between waves consistent latent trait scores, attributed to each possible range of manifest outcomes, needed to be applied for each wave of the ELSA data.

The problem with using longitudinal data to generate these latent trait factor scores was that the responses within participants across waves are not independent. Different methods were investigated which avoided using longitudinal data in the generation of latent trait factor scores, including creating scores separately for each year, and creating latent trait factor scores for one year and applying the same score values, corresponding to the same manifest outcome values, across all waves.

Both of these methods resulted in critical problems. Calculating latent trait factor scores for each wave resulted in different latent trait factor score values attributed to the same manifest outcome values; meaning that differences in scores between waves would not necessarily reflect a true difference but may only reflect a different distribution of manifest outcomes between waves. Attributing the same latent trait scores generated for one wave across all waves was not possible because not all possible permutations of manifest outcome values were presented at each wave. Thus there were missing latent trait factor score values for some possible manifest outcomes.

After some consideration it was decided to generate the latent scores using the longitudinal data, that is using all five ELSA waves. Though responses were not independent, adopting this method meant that consistent latent trait scores between waves could be generated. Although non independence between responses was not accounted for in the generation of the latent trait scores, this part of the project was not assessing differences but only creating scores. Crucially non independence was taken into account during the analysis stage of this study.

Raw data from self-completion questionnaire

Tables C3-vi to C3-viii provide a summary of the number and percentage of responses for each of the manifest variables included within the latent trait modelling, for ELSA waves 1 to 5 combined.

Table C3-vi: Personal relationship identifiers. Waves 1 to 5 combined

Response	Do you have a husband, wife or partner with whom you live?		Do you have any children?		Do you have any other immediate family?		Do you have any friends?	
	Count	%	Count	%	Count	%	Count	%
No	29	0.1%	2,777	7.8%	2,090	5.9%	1,538	4.3%
Yes	31,472	88.9%	28,668	80.9%	29,258	82.6%	29,758	84.0%
Missing response	386	1.1%	442	1.2%	539	1.5%	591	1.7%
No self-completion questionnaire	3,529	10.0%	3,529	10.0%	3,529	10.0%	3,529	10.0%
Grand Total	35,416		35,416		35,416		35,416	

Table C3-vii: Frequency of responses to questions reflecting the quality of personal relationships. Waves 1 to 5 combined

Response	Spouse/partner		Children		Family		Friends	
	Count	%	Count	%	Count	%	Count	%
a) How much do they really understand the way you feel about things?								
1 - Not at all	487	1.4%	734	2.1%	3,406	9.6%	622	1.8%
2 - A little	2,258	6.4%	3,587	10.1%	7,941	22.4%	5,818	16.4%
3 - Some	10,273	29.0%	13,061	36.9%	11,715	33.1%	13,804	39.0%
4 - A Lot	18,132	51.2%	11,053	31.2%	5,620	15.9%	9,254	26.1%
Not reported	4,266	12.0%	6,981	19.7%	6,734	19.0%	5,918	16.7%
b) How much can you rely on them if you have a serious problem?								
1 - Not at all	317	0.9%	679	1.9%	3,414	9.6%	888	2.5%
2 - A little	858	2.4%	1,764	5.0%	5,038	14.2%	4,495	12.7%
3 - Some	2,266	6.4%	4,741	13.4%	7,336	20.7%	9,717	27.4%
4 - A Lot	27,798	78.5%	21,308	60.2%	12,977	36.6%	14,418	40.7%
Not reported	4,177	11.8%	6,924	19.6%	6,651	18.8%	5,898	16.7%
c) How much can you open up to them if you need to talk about your worries?								
1 - Not at all	653	1.8%	1,240	3.5%	4,678	13.2%	1,676	4.7%
2 - A little	2,060	5.8%	4,131	11.7%	7,127	20.1%	6,540	18.5%
3 - Some	7,160	20.2%	9,880	27.9%	8,911	25.2%	10,813	30.5%
4 - A Lot	21,338	60.2%	13,201	37.3%	7,985	22.5%	10,468	29.6%
Not reported	4,205	11.9%	6,964	19.7%	6,715	19.0%	5,919	16.7%
d) How much do they criticise you?								
1 - A Lot	1,806	5.1%	717	2.0%	702	2.0%	168	0.5%
2 - Some	10,706	30.2%	5,736	16.2%	3,852	10.9%	2,835	8.0%
3 - A little	13,095	37.0%	12,007	33.9%	9,859	27.8%	11,286	31.9%
4 - Not at all	5,575	15.7%	9,859	27.8%	13,811	39.0%	14,629	41.3%
Not reported	4,234	12.0%	7,097	20.0%	7,192	20.3%	6,498	18.3%
e) How much do they let you down when you are counting on them?								
1 - A Lot	914	2.6%	741	2.1%	1,240	3.5%	585	1.7%
2 - Some	2,888	8.2%	3,003	8.5%	3,060	8.6%	2,809	7.9%
3 - A little	5,166	14.6%	6,752	19.1%	6,331	17.9%	7,303	20.6%
4 - Not at all	22,172	62.6%	17,886	50.5%	17,687	49.9%	18,520	52.3%
Not reported	4,276	12.1%	7,034	19.9%	7,098	20.0%	6,199	17.5%
f) How much do they get on your nerves?								
1 - A Lot	839	2.4%	349	1.0%	992	2.8%	138	0.4%
2 - Some	4,424	12.5%	2,711	7.7%	3,049	8.6%	1,946	5.5%
3 - A little	14,588	41.2%	10,583	29.9%	10,813	30.5%	11,537	32.6%
4 - Not at all	11,319	32.0%	14,792	41.8%	13,688	38.6%	15,734	44.4%
Not reported	4,246	12.0%	6,981	19.7%	6,874	19.4%	6,061	17.1%
How close is your relationship? (with spouse/partner)								
1 - Not at all	139	0.4%						
2 - Not very	974	2.8%						
3 - Quite close	6,351	17.9%						
4 - Very close	23,736	67.0%						
Not reported	4,216	11.9%						
Number of close relationships with children/family/friends								
None			636	1.8%	3,449	9.7%	2,701	7.6%
One			5,969	16.9%	6,987	19.7%	3,102	8.8%
Two			13,185	37.2%	6,420	18.1%	6,834	19.3%
Three			5,314	15.0%	3,649	10.3%	4,350	12.3%
Four-five			2,065	5.8%	3,695	10.4%	5,887	16.6%
Six plus			252	0.7%	2,686	7.6%	5,220	14.7%
Not reported			7,995	22.6%	8,530	24.1%	7,322	20.7%

Table C3-viii: Frequency of responses to questions reflecting amount of contact with children, family, and friends. Waves 1 to 5 combined

	Children		Family		Friends	
Response	**Count**	**%**	**Count**	**%**	**Count**	**%**
g) Meet up (including both arranged and chance meetings)						
1 - Less than once per year	614	1.7%	2,948	8.3%	510	1.4%
2 - Once or twice per year	966	2.7%	4,234	12.0%	1,194	3.4%
3 - Every few months	4,032	11.4%	6,435	18.2%	3,809	10.8%
4 - Once or twice per month	5,972	16.9%	5,757	16.3%	8,587	24.2%
5 - Once or twice per week	9,293	26.2%	6,429	18.2%	11,779	33.3%
6 - Three or more times per week	6,014	17.0%	2,784	7.9%	3,454	9.8%
NA	8,525	24.1%	6,829	19.3%	6,083	17.2%
h) Speak on the phone						
1 - Less than once per year	408	1.2%	1,608	4.5%	834	2.4%
2 - Once or twice per year	180	0.5%	1,592	4.5%	919	2.6%
3 - Every few months	491	1.4%	3,780	10.7%	3,136	8.9%
4 - Once or twice per month	2,634	7.4%	7,328	20.7%	8,857	25.0%
5 - Once or twice per week	11,963	33.8%	9,646	27.2%	11,984	33.8%
6 - Three or more times per week	11,376	32.1%	4,779	13.5%	3,507	9.9%
NA	8,364	23.6%	6,683	18.9%	6,179	17.4%
i) Write or email						
1 - Less than once per year	10,549	29.8%	13,261	37.4%	11,579	32.7%
2 - Once or twice per year	2,972	8.4%	4,007	11.3%	2,974	8.4%
3 - Every few months	2,504	7.1%	3,124	8.8%	3,020	8.5%
4 - Once or twice per month	3,622	10.2%	2,954	8.3%	3,976	11.2%
5 - Once or twice per week	3,097	8.7%	1,423	4.0%	2,789	7.9%
6 - Three or more times per week	1,341	3.8%	470	1.3%	978	2.8%
NA	11,331	32.0%	10,177	28.7%	10,100	28.5%
Living with Children/family/friends						
No	26854	75.80%	33767	95.30%	35076	99.00%
Yes	8562	24.20%	1649	4.70%	340	1.00%

Latent traits - Quality of relationships

The associations between all paired manifest variables related to the quality of personal relationships were statistically significant ($p<0.05$) for all four latent trait models relating to the quality of relationships.

Table C3-ix shows that the overall level of internal consistency was reasonably high (between 0.62 and 0.81) for all four latent trait variables, representing the quality of relationships responders have with their partner, children, family and friends. The overall fit, or level of internal consistency, was slightly better when question D (‘How much do they criticise you?’) was removed from the latent trait modelling for the quality of relationships with partners, family or friends. The change in Cronbach’s alpha after removing question D was small however so, as the researcher felt that this question was important to understand the quality of relationships, this question was retained for all four latent trait models.

Comparing constrained and unconstrained models (see Table C3-x) shows that for all four quality latent traits the unconstrained models were significantly better fit than the constrained models. The unconstrained model was chosen to generate the latent trait factor scores.

Table C3-ix: Cronbach's alpha values for quality of relationship model fitting

Variables excluded	Spouse/partner		Children		Family		Friends	
	Value	Fit	Value	Fit	Value	Fit	Value	Fit
All 7 variables	0.81		0.71		0.74		0.62	
Exclude A)	0.76	Worse	0.64	Worse	0.68	Worse	0.53	Worse
Exclude B)	0.79	Worse	0.65	Worse	0.67	Worse	0.52	Worse
Exclude C)	0.76	Worse	0.65	Worse	0.67	Worse	0.52	Worse
Exclude D)	0.83	Better	0.71	Same	0.75	Better	0.64	Better
Exclude E)	0.79	Worse	0.66	Worse	0.72	Worse	0.6	Worse
Exclude F)	0.77	Worse	0.67	Worse	0.72	Worse	0.59	Worse
Exclude Closeness	0.77	Worse	0.73	Worse	0.76	Worse	0.66	Worse
Decision	Keep all variables		Keep all variables		Keep all variables		Keep all variables	

Fit here related to internal consistency between variables

Table C3-x: Latent trait model fitting to compare constrained versus unconstrained models

	Spouse/partner		Children		Family		Friends	
	Con	Uncon	Con	Uncon	Con	Uncon	Con	Uncon
BIC	330729	323763	394219	385733	462513	444142	445392	427880
Likelihood ratio	-165249	-161734	-196983	-192709	-231130	-221913	-222570	-213782
d.f.	6		6		6		6	
p value	<0.001		<0.001		<0.001		<0.001	
Decision	Unconstrained		Unconstrained		Unconstrained		Unconstrained	

Con: Constrained, Uncon: Unconstrained

In terms of the percentage of information each manifest personal relationship variable contributed to the total information (see Table C3-xi), Closeness and Question A contributed the most to the Partner quality latent trait variable, while Questions A, B, and C all contributed the most to the latent trait variables for children, family and friends. Question D provided no information for the friendship quality latent trait. The contribution of each manifest variable to the latent trait variables are presented as item response category characteristic curves in Figures C3-i to C3-iv.

Table C3-xi: Total information provided by each variable included in the latent trait models

	Spouse/partner		Children		Family		Friends	
	Uncon	Percent	Uncon	Percent	Uncon	Percent	Uncon	Percent
All variables	38.72		27.1		34.02		27.52	
Question A	7.78	20.10%	6.22	23.00%	7.52	22.10%	6.99	25.40%
Question B	6.37	16.50%	7.23	26.70%	9.29	27.30%	7.76	28.20%
Question C	7.09	18.30%	6.35	23.40%	11.67	34.30%	9.68	35.20%
Question D	1.83	4.70%	0.88	3.20%	0.13	0.40%	0	0.00%
Question E	3.15	8.10%	2.59	9.60%	1.66	4.90%	0.98	3.60%
Question F	4.19	10.80%	2.12	7.80%	1.28	3.80%	0.57	2.10%
Closeness	8.3	21.40%	1.72	6.30%	2.47	7.30%	1.55	5.60%

Uncon = α unconstrained for all variables

Figure C3-i: Partner quality item response curves

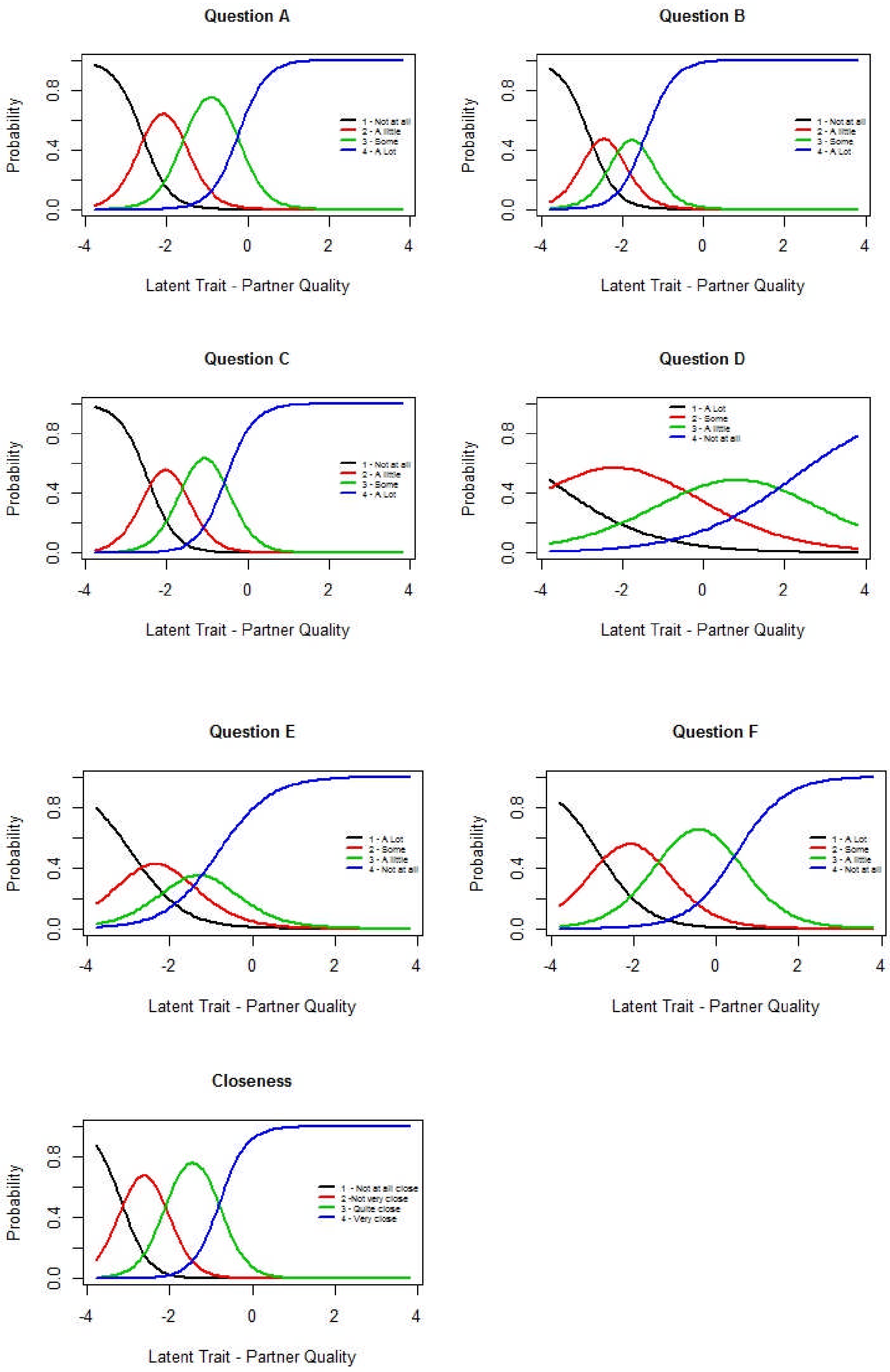


Figure C3-ii: Children quality item response curves

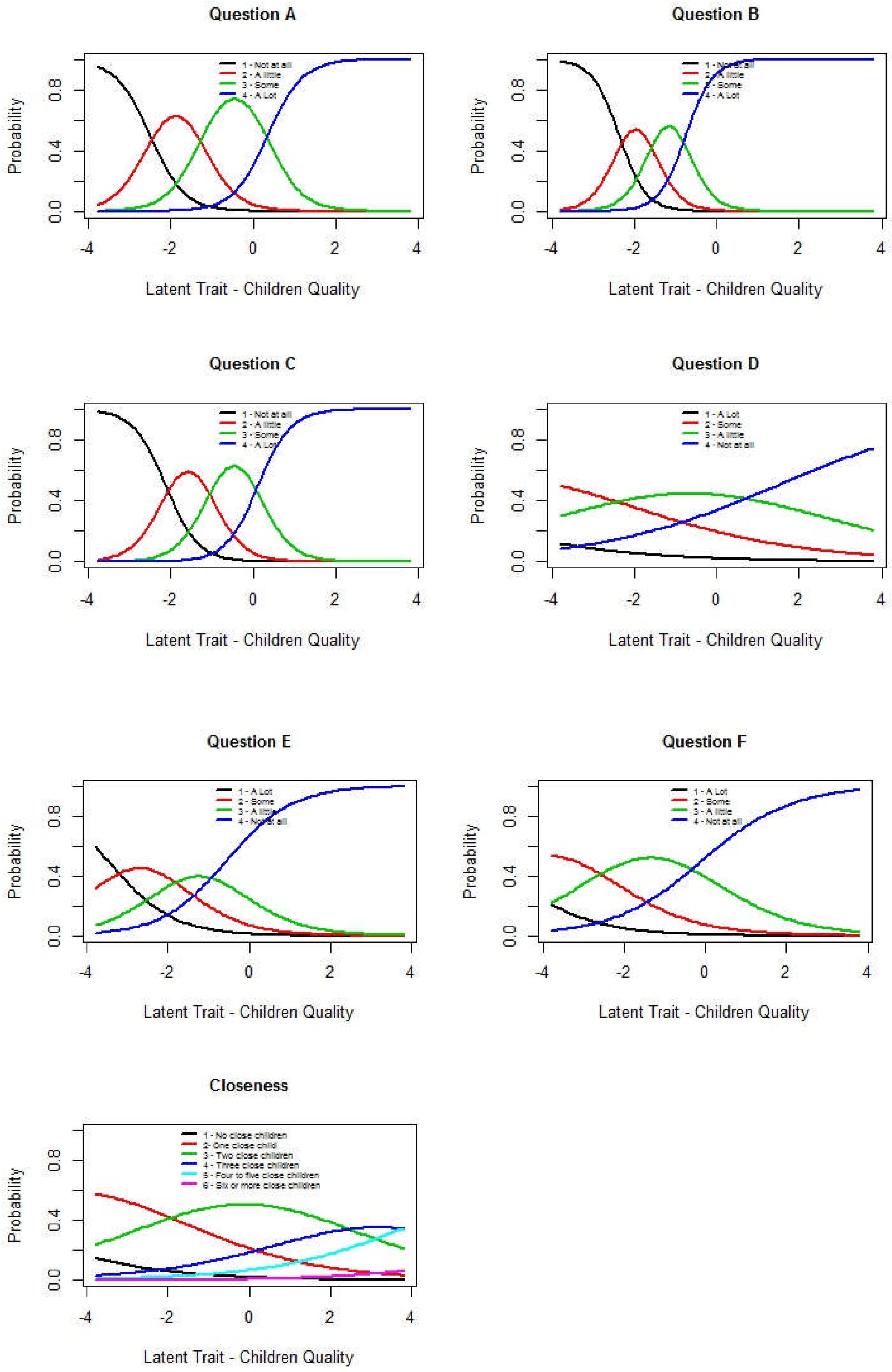


Figure C3-iii: Family quality item response curves

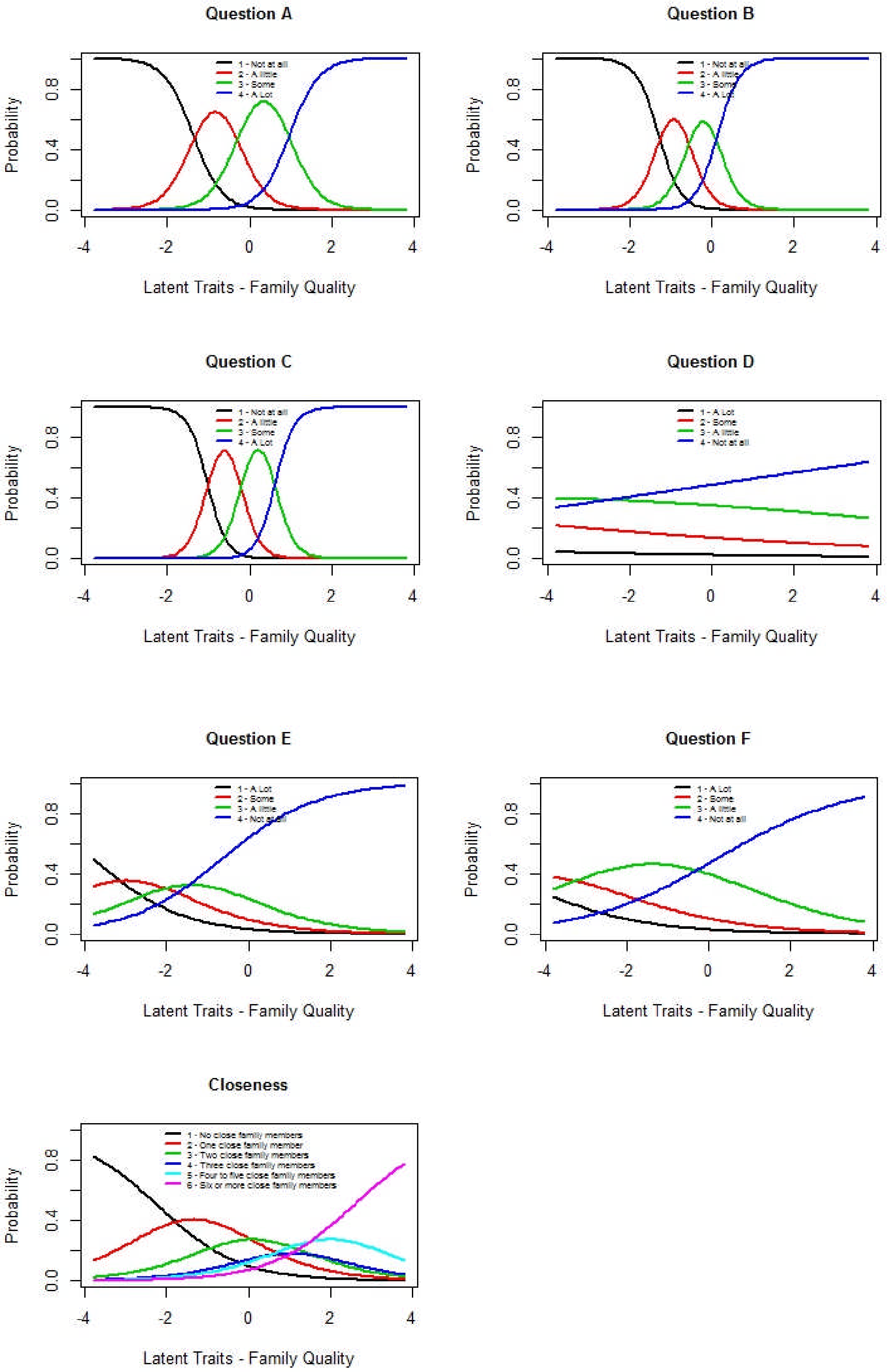
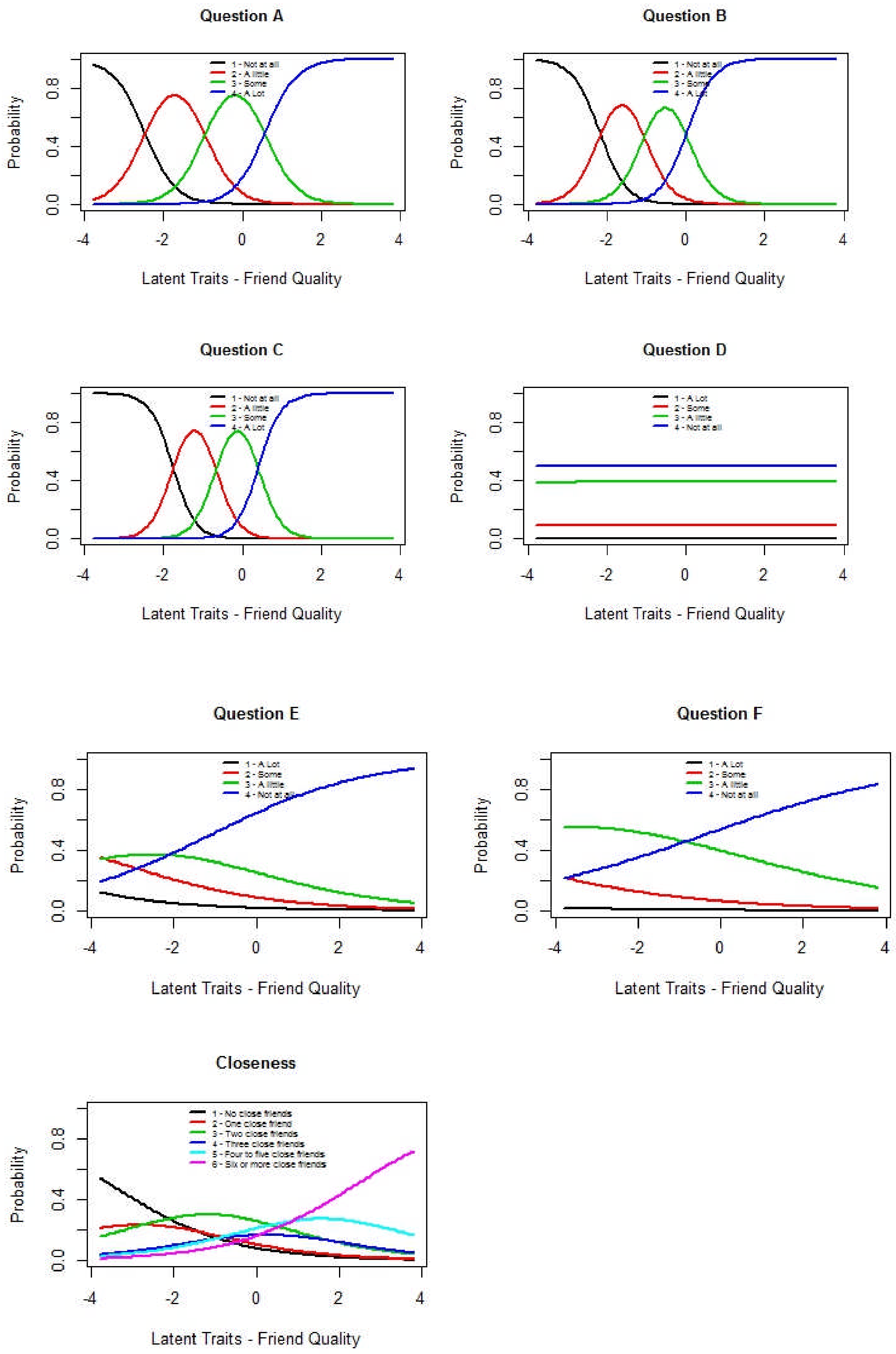


Figure C 3-iv: Friends quality item response curves



Level of contact

The responses to question G, H and I were all significantly associated with each other, however the additional manifest variable representing living with children was only significantly associated with question G. Living with family and friends were not significantly associated with any of the other personal relationship questions relating to level of contact (G, H, and I).

Table C3-xii shows that the overall level of internal consistency after removing each of the manifest variables in turn for the three latent trait variables, representing the level of contact responders have with their children, family and friends. Including the variables relating to living with children, family, and friends reduced the fit for all three latent trait models but the researcher decided to include this variable within the model as it was felt removing this value would remove important information about the amount of contact responders had with their children, family and friends.

The three latent trait models for level of contact were a better fit when Question I was removed (How often they write or email?). This variable was excluded from the latent trait modelling for level of contact with children as excluding this variable resulted in a much better fit. There were smaller improvements when this variable was removed from the family and friends latent trait modelling but the researcher decided to leave these variables in as writing or emailing may be important source of contact for family and friends.

Table C3-xii: Cronbach's alpha values for level of contact model fitting

	Children		Family		Friends	
	Value	Fit	Value	Fit	Value	Fit
All 4 variables	0.27		0.52		0.46	
excluding G	0.14	Worse	0.28	Worse	0.3	Worse
excluding H	-0.09	Worse	0.1	Worse	0.16	Worse
excluding I	0.49	Better	0.59	Better	0.51	Better
excluding living with …	0.3	Better	0.59	Better	0.52	Better
Decision	Exclude I		Keep all variables		Keep all variables	

Table C3-xiii shows that for all three latent trait variables the unconstrained models were significantly better fit than the constrained models and the unconstrained models were used to generate the latent trait factor scores.

Table C3-xiii: Latent trait model fitting to compare constrained versus unconstrained models

	Children		Family		Friends	
	Con	Uncon	Con	Uncon	Con	Uncon
BIC	177934	177293	266843	256041	242330	237955
Likelihood ratio	-88904	-86392	-133333	-127915	-121076	-118872
d.f.		2		2		2
p value		<0.001		<0.001		<0.001
Decision	Use unconstrained		Use unconstrained		Use unconstrained	

Question G and H, reflecting the amount of time responders meet or talk on the phone respectively, contributed most to all three level of contact latent trait variables (see Table C-xiv). Item response category characteristic curves for the personal relationship manifest variables included in the level of contact latent trait modelling, for children, family, and friends, are represented in Figures C3-v, C3-vi, and C3-vii below.

Table C3-xiv: Total information provided by each variable included in the latent trait models

	Children		Family		Friends	
	Ucon	Percent	Uncon	Percent	Uncon	Percent
All variables	8.33		12.5		13.07	
Question G	3.72	44.7%	3.86	30.9%	4.39	33.6%
Question H	3.32	39.9%	3.88	31.0%	4.16	31.8%
Question I	Not included		3.37	27.0%	3.15	24.1%
Living with …	1.29	15.5%	1.39	11.1%	1.36	10.4%

Note:- Con = α constrained model for all variables, Uncon = α unconstrained for all variables

Figure C3-v: Children level of contact item response curves

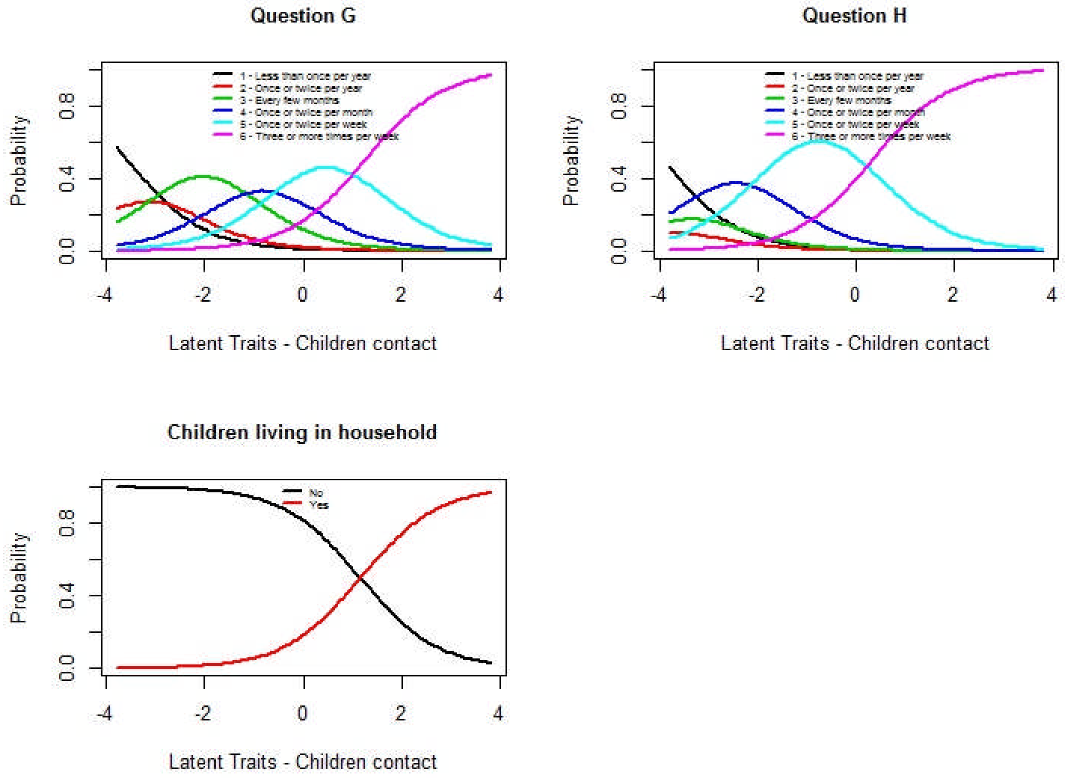


Figure C3-vi: Family level of contact item response curves

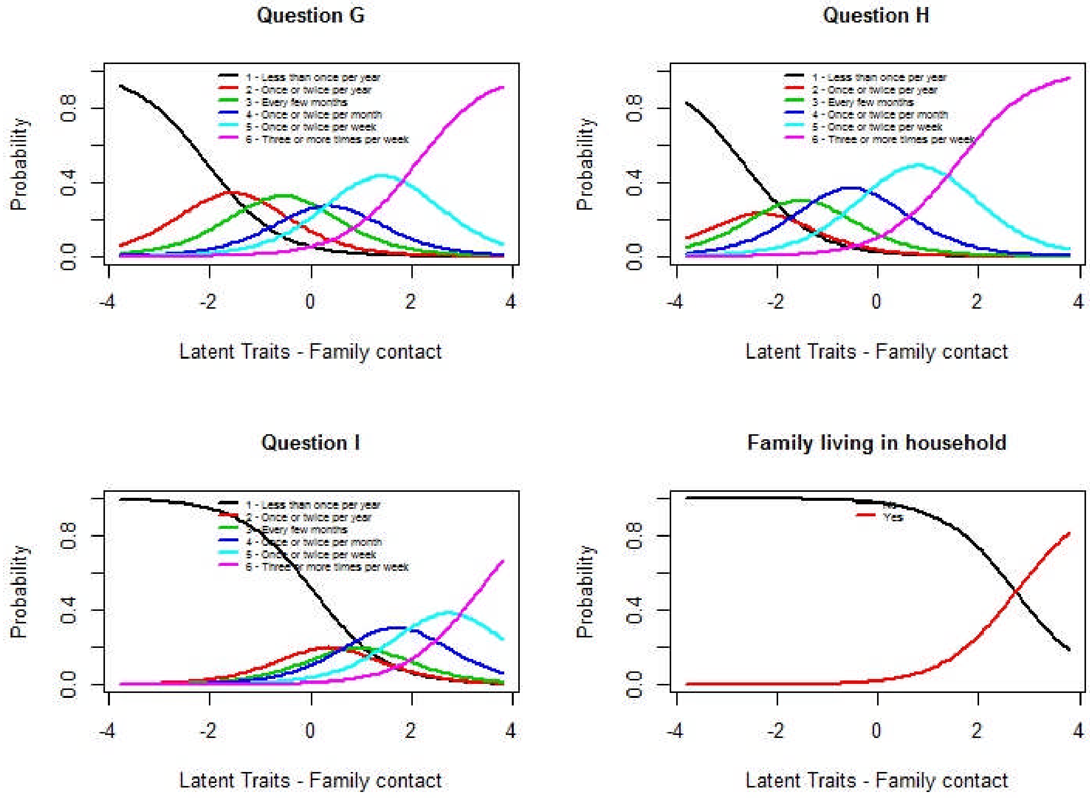


Figure C3-vii: Friends level of contact item response curves