



Living and Caring? An Investigation of the Experiences of Older Carers

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Hayley Cheshire

**A report of research carried out by the National Centre for
Social Research on behalf of the ILC-UK**

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About this Report

This document contains a report of research carried out by the National Centre for Social Research (NatCen) on behalf of the ILC-UK.

The original research design was developed by James Lloyd of the ILC-UK. The initial stages of the study were carried out by Hayley Cheshire with the support of Andreas Cebulla. The analysis was then continued and completed by Andy Ross and Michael Weinhardt of NatCen.

A policy report, entitled *Living and Caring for All*, was published simultaneously by the ILC-UK to provide accompanying policy analysis and discussion.

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¹ <http://www.nuffieldfoundation.org>

² <http://www.data-archive.ac.uk>

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Executive summary

Comparatively little quantitative research comparing the lives of carers and non-carers in the UK has been undertaken due, in particular, to the dearth of suitable data sources. This report uses data from Wave 2 (2004) and Wave 3 (2006) of the English Longitudinal Study of Ageing (ELSA) to compare the lives of carers and non-carers across five key policy domains: income and work; mobility and access to services; participation in leisure and community activities; health; and housing. For the most part, carers are divided into three main groups; those caring for a spouse or partner³, a child, and a parent or parent in-law. Within each of these carer groups we look at whether the level of care provided is associated with poorer outcomes in each policy domain. Level of care is defined in terms of light care (0-19 hours per week) and moderate to heavy care (20+ hours per week). Quality of life is treated as an outcome measure and is covered in the last two chapters where we identify how the lives of carers could be improved relative to non-carers.

When comparing carers and non-carers, we use ELSA data from 2004. The longitudinal analysis explores the changes associated with moving into, or out of, a caring role and incorporates ELSA data from 2006.

Demographics and Characteristics of Caring

In 2004, 10 per cent of individuals aged 52 and over had provided active provision of care to someone in the last week and so, for the purpose of this study, were defined as carers. Of these, 39 per cent were caring for a spouse, 11 per cent for a child, 34 per cent for a parent or parent in-law and 24 per cent for a relative, friend or other person. Those caring for a spouse had an average age of 68.4 (men) and 67.2 (women), and the majority were found to care only for that person (86.5 per cent). In comparison, carers from the other groups (looking after a child or a parent or parent in-law) had a younger age profile and were more likely to be caring for several people (not necessarily related to them in the same way). Despite this, those caring for a spouse had the greatest care burden in terms of mean number of hours per week (spouse - 105 hours; child(ren) - 92 hours; parent or parent in-law - 32 hours). Unsurprisingly, they were also more likely to live with a person they cared for in comparison to those providing care for the other care groups. The most popular reason given for caring by all care groups was 'they felt needed' (81.1 per cent of those caring for a spouse, 80.5 per cent of those caring for a child or children, 84.7 per cent of those caring for a parent or parent in-law. A feeling of obligation was felt most heavily amongst those caring for a parent or parent in-law (40.6 per cent).

Income and Work

Engagement in paid work by carers was affected by the level of care provided. Carers providing a moderate to heavy amount were significantly less likely to have carried out paid work in the last month than non-carers. Small base sizes make it difficult to assess the impact that caring has on those that are employed, however the number of hours worked per week by those providing moderate to heavy care for a parent or parent in-law compared was significantly less than non-carers (25.7 and 33.4 hours per week respectively).

³ Just 4 per cent were providing care to a partner, so for reasons of brevity both will be referred to as caring for a spouse

There were clear differences between carers and non-carers in levels of personal income and of family wealth. Carers providing care to a child or a spouse with moderate to heavy levels of care, had lower average levels of personal income when compared with non-carers. For example those caring for a child had an average income of £180 per week while carers for a spouse received £208 per week. This compares with £266 a week for non-carers. The same pattern was found for family wealth, with these same carer groups, providing moderate to heavy levels of care, having significantly lower levels of family wealth on average compared with non-carers (£121,591 for carers of dependent child and £120,039 for carers of a spouse, compared with £172,156 for non-carers). In contrast, those caring for a parent or parent-in-law tended to have much higher levels of wealth compared with non-carers; £205,475 for those providing light care to a parent or parent-in-law.

The longitudinal analysis found that a move into a caring role was associated with a significant reduction in family earnings, personal earnings and total family income relative to those who remained non-carers. Interestingly, those who moved out of a care role also experienced a decline in family earnings and total family income, relative to those who remained non-carers.

Mobility and Access to Services

There were seemingly few differences between carers and non-carers in the ability to access a car or in the use of public transport.

There were some services that carers had more difficulty accessing using their usual form of transportation compared with non-carers. However significant results were only found for those carers providing moderate to heavy levels of care. Indeed, these carers had greatest difficulty accessing key health services. A quarter of those caring for a spouse, or a parent or parent-in-law had difficulty accessing a hospital (24.8 per cent and 24.9 per cent respectively) compared with 9.9 per cent of non-carers. Difficulty accessing a GP was greatest for those caring for a parent or parent-in-law (21.3 per cent versus 2.1 per cent for non-carers).

The relationship between the number of hours spent caring and difficulty accessing some services indicates that those carers with high levels of care responsibility might be restricted by time rather than specific transport issues.

Leisure and Community Activities

The longitudinal analysis identified how a move into caring is clearly associated with reduced opportunities for taking foreign holidays. However, the comparative analysis found only those providing care to a spouse were less likely to have taken a holiday in the UK in the last 12 months compared to non-carers, 40 per cent of those who provided light care to a spouse, and 34 per cent of those who provided moderate to heavy care took a holiday abroad compared to 58 per cent of non-carers. Those providing moderate to heavy levels of care to a spouse were also less likely to have taken a holiday abroad or a day trip over the same time period, and belonged to fewer organisations on average than non-carers.

Apart from those providing light care to a spouse, carers were more likely to want to go to the cinema more often than they currently do, in comparison with non-carers. Of all the carer groups, only those providing moderate or heavy care to a spouse were more likely to say they wanted to eat out more often than they currently were able to, compared with non-carers (60 per cent

compared to 42 percent of non-carers). Those caring for a child or providing moderate to heavy care for a parent or parent in-law were significantly more likely to want to go art galleries or museums more often, compared with non-carers. This suggests that different carer groups may prefer to undertake, or feel they are missing out on, different types of leisure activities.

Health

The health of carers and non-carers was explored using a range of subjective and objective measures. These included physical health and cognitive ability measures. Overall few differences were found between the health of carers and non-carers, and where differences were found, it was the carers who seemed to fair better than the non-carers. The main deviation from this was for carers providing moderate to heavy levels of care to a spouse who reported significantly more difficulties with performing physical activities on average than non-carers.

Importantly, carers reported a higher capability for tasks associated with everyday living (e.g. preparing a hot meal, managing money) than non-carers. There were no differences in overall cognitive ability between carers and non-carers.

Overall, it appears that good general health may be a prerequisite for caring for others (or that carers do not report their own health issues). The longitudinal analysis provided some support for this theory, as self-reported health remained consistent between 2004 and 2006 for all except those who move out of caring (i.e. carers in 2004 but no longer caring in 2006). Indeed this group saw a rise in the proportion reporting 'poor' health from 3.9 per cent in 2004 to 7 per cent in 2006. In addition, those who moved out of caring in 2006 also reported an increase in the difficulties they experience for both self-care and tasks associated with independent living. In part, this may reflect individuals withdrawing from care that they provided in the past because they no longer feel physically able to do so.

Housing

Unsurprisingly, those providing care to a spouse were found to have more housing adaptations in their home than non-carers. Those caring for a spouse that required a moderate to heavy level of care were more likely to have adaptations suited to a disability than non-carers. Home adaptations associated with frailty were also more common, on average, in the homes of those caring for a spouse, or those providing moderate to heavy care to a parent or parent in-law, when compared with non-carers. Longitudinal analysis showed there was a significant increase in the number of housing adaptations over time for those caring in 2004 and 2006 (both time points) compared to non-carers – as we would hope. Those who had moved into caring were found to have significantly more adaptations associated with frailty than non-carers.

While the findings on home adaptations are much as we would expect, those providing care to a spouse were significantly less likely to own their own home than non-carers. Furthermore, all carers reported slightly more housing problems relating to lack of space, darkness and infestations, on average, than non-carers. However, the difference was only statistically significant for those providing moderate to heavy care to a spouse, or a child. Over time the experience of these housing problems were found to increase for those who had moved into caring, relative to non-carers, and to decrease for those moving out of caring.

Quality of Life and the Policy Domains

Quality of life was measured using CASP19 in a separate self-completion document given to ELSA respondents. The CASP19 scale has been constructed for use with the elderly population and is conceptually based on four dimensions 'Control, Autonomy, Self-realisation and Pleasure'.

Those who provided moderate to heavy levels of care showed significantly lower levels of quality of life than non-carers.

Key factors measured within each policy domain were also analysed to identify those areas most important to the quality of life of carers, although one must remain cautious in assuming any causal link.

The strongest relationship was found between carers' health and their quality of life. An increase in the number of activities representing impairment in physical mobility was associated with a significant decrease in quality of life. Other factors associated which showed a strong link with quality of life included the experience of financial hardship, family income, and difficulties with getting to a number of community services (doctor, hospital, local shops, and supermarket).

Having a hobby or past-time, taking a holiday abroad and going on a day trip or outing were also all important for the quality of life of carers.

Quality of Life and the Cared for

Interview data collected from both the carer and the spouse being cared for was used to explore the relationship between carers' quality of life and the characteristics of their spouse.

The cognitive capacity of the spouse being cared for appeared to have the greatest impact on the quality of life of the carer. Specifically the memory function of the person cared for was found to play a major role over and above the actual physical demands of the caring role.

1 Introduction

1.1 Background

Why Research Older Carers?

The UK population is ageing. It is projected that by 2031, the UK population will include 3 million people aged over-85 increasing from 1.2 million in 2006 and around 0.6 million in 1981. The ratio of the number of people of working age for every person above the state pension age will reduce from 3.32 in 2006 to 2.91 by 2031.⁴

Commensurate with population ageing, the demand for long-term care is forecast to increase. It has been projected that the number of disabled people aged 65 and over will grow from 2.3 million in 2002 to 4 million in 2031. Similarly, the number of disabled people aged 85 and over is expected to increase from 0.6 million in 2002 to 1.3 million in 2031.⁵

It is widely anticipated that the majority of long-term care will continue to be provided as unpaid, informal care offered by a family member or friend. Almost one third of unpaid carers in England are aged 60 or over and the growing demand for long-term care is expected to be met increasingly by older cohorts of carers.⁶ Most unpaid care for older people is provided by a spouse or adult child. However, it is expected that care by spouses will be increasingly important in the future given various long-term trends, which include the declining elderly support ratio, improvements in male (healthy) life expectancy, the decline of parent-child co-residence, and increasing participation by women in the labour force. It is projected that by 2031, 1.2 million people over 65 will receive care from a spouse, up from 0.6 million in 2002 and the number of people receiving care from an adult child is expected to increase from 0.7 million in 2002 to 1.1 million in 2031.⁷

Given the growing importance and role of older carers in meeting the demand for long-term care, there is an important need to understand the effects of unpaid care provision on the lives of older people.

Previous Research on Carers

Comparatively little quantitative research comparing the lives of carers and non-carers in the UK has been undertaken due, in particular, to the dearth of suitable data sources. Research has tended to focus on the physical and mental health effects of caring on carers of all ages. Hirst used the *British Household Panel Survey* to explore the incidence of 'carer distress', i.e. symptoms

⁴ ONS (2008) *Population Trends*, No. 131, London: HMSO,

www.statistics.gov.uk/downloads/theme_population/Population_Trends_131_web.pdf

⁵ Pickard L et al. (2007) "Care by Spouses, Care by Children: Projections of Informal care for Older People in England to 2031" in *Social Policy & Society*, Vol. 6, No. 3, p353-366

⁶ Pickard L et al. (2000). "Relying on care in the new century? Informal care for elderly people in England to 2031" in *Ageing & Society*, Vol. 20, p745-772

⁷ Pickard L et al. (2007) "Care by Spouses, Care by Children: Projections of Informal care for Older People in England to 2031" in *Social Policy & Society*, Vol. 6, No. 3, p353-366

indicative of anxiety and depression, social dysfunction, loss of confidence and self-esteem.⁸ His analysis found that increased distress was associated with the provision of intense care over long-periods, although more so for women than men. The study also found that several groups of carers experienced psychological health inequalities when compared to non-carers. Particular disadvantage was experienced by those looking after a spouse or partner and mothers caring for a sick or disabled child.

An earlier study by Singleton et al. looked at the incidence of neurotic symptoms among carers.⁹ The research found that female carers (21 per cent) were more likely than males (12 per cent) to be assessed as having high levels of neurotic symptoms. When compared to the general population using age-standardised ratios, female carers were found to be 23 per cent more likely to have neurotic symptoms than women in general. The same comparison for men found no significant difference between carers and men in general.

1.2 The English Longitudinal Study of Aging (ELSA)

The English Longitudinal Study of Ageing (ELSA) offers a new opportunity for analysis of this important policy area and in this report, data from Wave 2 (2004) and Wave 3 (2006) of ELSA has been used to explore informal care. ELSA is a comprehensive study of people aged 50 and over and their partners in England. It explores the dynamic relationships between health and functioning, social networks and participation, and economic position as people plan for, move into and progress beyond retirement. ELSA has been developed through a collaboration between University College London, the Institute of Fiscal Studies, and the National Centre for Social Research (NatCen), with specialist advice provided by academics at the Universities of Cambridge, Manchester, East Anglia and elsewhere. Funding for the first four waves of the study was provided by the US National Institute on Aging and a consortium of UK Government Departments. Every two years, the same participants are approached to measure changes in their health, economic, and social circumstances.

The original ELSA sample was drawn from households that had previously responded to the Health Survey for England in 1998, 1999, or 2001. The first wave of ELSA fieldwork was in 2002 when a total of 12,100 interviews were achieved. For the second wave of ELSA in 2004 the same participants were approached, and any new partners invited to join the study, resulting in a total of 9433 interviews. In the third wave, the original cohort was supplemented with people aged between 50 and 53 in order to maintain coverage of the younger age group¹⁰. The additional sample members were recruited from the 2001-2004 HSE years. Wave 3 interviews took place in 2006 with a total of 9771 interviews conducted. This wave was followed by a retrospective interview recording key events before the sample members joined the study, but this does not form part of the research presented here. Wave 4 is currently in field.

The survey design for ELSA provides a wealth of information about the lives of those aged 50 and over. At each wave there is a face-to-face computer-aided personal interview (CAPI) and a self-completion questionnaire. Broad topics included at each wave include household composition, work and pensions, income and assets, housing circumstances, cognitive function, health behaviours and social participation. At Wave 2 (and previously at the HSE visit) respondents were

⁸ Hirst M (2005) "Carer distress: A prospective, population-based study" in *Social Science & Medicine*, Vol. 61, Issue 3, p697-708

⁹ Singleton N et al. (2002) *Mental health of carers*, Office of National Statistics

¹⁰ Respondents aged 53 to under 54 were accidentally excluded and will be visited during Wave 4.

approached by a qualified nurse who capture a wide variety of health measures, including biometric measures such as lung function, blood samples and blood pressure, as well as physical performance tests (these were not included in the HSE) to assess the respondents' strength and balance. The intention is to conduct interviews every two years, and to have a nurse visit every four years.

ELSA provides the ideal data source to investigate the impact that caring has on the lives of older people. ELSA has a wide variety of measures which cover key social policy domains that could be tackled by public policy intervention. It also provides a representative sample of carers and non-carers amongst those aged 50 and over so that findings can be generalised to the population level. The use of ELSA data also minimises the risk of bias compared with other studies, which have recruited carers through support groups or chosen to focus on carers of people with specific conditions (though like all surveys of its kind it suffers from non-response and attrition).

Data from the first three waves of ELSA is available through the Data Archive which is part of the UK's Economic and Social Data Service. The data has been weighted to take account of non-response and attrition: the tendency for survey participants to drop out of the study over time. (<http://www.esds.ac.uk/aandp/access/introduction.asp>).

Defining Carers in ELSA

Within the ELSA sample, carers are self-defined, i.e., respondents have described themselves as 'looking after' someone else in the last week. To be routed to this survey question they need to have answered previously that they had 'cared for someone' in the last month (see Appendix A for full question wording). Our non-carers sample comprise of those who have not cared for someone in the last month.

A positive response to 'looking after' someone in the last week was necessary to prompt follow-up questions which related to the caring role. Unfortunately, no further information was collected from those who were caring in the last month but not looking after someone in the last week, so they have been excluded from the analyses.

The criteria adopted by ELSA means that individuals do not necessarily need to associate themselves with being a "carer" to have been asked the follow up questions about the care provided. This is important, as the problem of carers who do not self-identify is a significant challenge, which has received attention from both academics and policymakers. For example, the Government's 'Supporting Carers' programme specifically sought to devise best-practice among local authorities for the identification of carers who do not 'self-identify'. The sample of carers identified by ELSA is likely to contain a greater proportion of people caring for a spouse who would not, under a stricter definition, have defined themselves as being a "carer". This is a consideration if choosing to compare our prevalence rates with other carer surveys.

The experience of carers has been found to differ depending on the locus of care, the characteristics of the carer and the person cared-for, and the burden associated with caring. Follow-up questions in ELSA identify the number of people being cared for, their relationship to the carer (including whether they live together) and the number of hours of care provided. The analysis presented in this report includes three main carer groups; those caring for a spouse, those caring for a parent or parent-in-law, and those caring for a child. The decision was taken to exclude those who only cared for grandchildren from the analysis. Information about the characteristics of a parent or child being cared for is not collected during the ELSA interview, for example we do not know their age, sex, or type of care required. However, some spouses being

cared-for are eligible to complete an ELSA interview in their own right so the data collected from them has been used to investigate different aspects of the caring relationship (see Chapter 8: Quality of life and the cared for).

1.3 The analysis strategy

Chapter two: Demographic analysis

In chapter two we explore the demographic background of older carers to identify who the individuals are that are providing unpaid, informal care in England. We then look at characteristics of the care role, including who is being cared for, the intensity of the care provided, why individuals care, and the personal rewards and acknowledgement they receive.

In chapters three to seven we compare the lives of carers and non-carers across five key policy domains: income and work; mobility and access to services; participation in leisure and community activities; health; and housing. Utilising the longitudinal design of ELSA, we then explore the propensity of individuals' experiences to change over time, including change associated with moving into, or out of, a caring role. In chapter eight we examine the importance of factors measured in each of the five policy domains to the quality of life of the carer. Finally, in chapter nine, we explore how characteristics of the person being cared for impacts upon the quality of life of the carer.

Chapters three to seven: Comparative analysis

Our first aim was to explore whether providing unpaid care was associated with poorer outcomes in a number of key policy areas including income and work, mobility and access to services, participation in leisure and community activities, health and housing.

In an early exploration of the data, we identified very few differences between carers and non-carers when treating carers as a single homogenous group. However, by looking at care groups separately, depending on the person they cared for and the level of care that was provided, we were able to identify many more differences. In this study we focus on those who provide care to a spouse or partner, a dependent child, or a parent or parent in-law, and distinguish between those who provide 'light care' (up to 19 hours of care a week), and those who provide 'moderate to heavy care' (20 hours and above).

Of course, by examining subgroups in the caring population we reduce the size of the samples we analyse, and in doing so also reduce the power for identifying statistically significant differences. We discuss the implications of sample size further below.

In order to compare differences between carers and non-carers we used regression analysis. The method allows you to examine the association of one or more measures on a specific outcome. For this study we explored the association between being a carer (differentiating between care type and level of care) and outcomes relating to the five key policy domains identified above. A benefit of the approach is that it allows you to adjust for other factors that might account for the associations of interest. In this analysis we adjust for gender, age, marital status and education, as well as characteristics of care, including the number of people cared for, and whether the individual lives with the person they care for (i.e. their spouse or partner).

For convenience we have converted the regression coefficients into 'adjusted means' or 'adjusted proportions' (adjusted because we have controlled for effects associated with the other factors outlined above). As we estimate the effects associated with each care group simultaneously, we

also deal with any overlap between care groups (carers who care for more than one kind of care recipient). Statistically significant differences between carers and non-carers are indicated by a ‘*’ and denote that a difference is significant at 5 per cent¹¹. For the sake of brevity, throughout the report we have only produced graphs and tables for statistically significant findings. Non-significant findings have been summarised in the text.

Chapters 3 to 7: Longitudinal analysis

Following analysis that compares carers and non-carers in 2004, we conduct a longitudinal analysis exploring the propensity of the experiences of carers to change over time, as well as change associated with a move into, or out of, caring. We achieve this by comparing the experiences of three groups, individuals who are non-carers in 2004 but carers in 2006 (into caring), individuals who are carers in 2004 but non-carers in 2006 (out of caring), and individuals who are carers at both time points, with a fourth group, individuals who remain non-carers in ELSA waves 2004 and 2006.

Again we used regression analysis to estimate the differences, however this time carrying out three regressions for each outcome. First we estimated the differences between those who remain non-carers and the three other care groups in 2004. We then estimated the differences between those who remain non-carers and the three other care groups in 2006. In both instances we adjusted gender, age, marital status and education. Similar to the comparative analysis outlined above we converted the regression coefficients into adjusted means or proportions and plotted these onto graphs indicating change overtime for each care group (see for example graphs Figure 3-9 to Figure 3-14). In a final step, we re-estimate the differences between those who remain non-carers and the three other care groups in 2006, this time adjusting for the outcome in 2006. By doing this we are able to ascertain whether differences that may exist in 2006 between a care group and those who remain non-carers is associated with their carer status (for example a move into care) as opposed to differences that already existed in 2004.

As a hypothetical example, we may find that the proportion of those who engaged in paid work is the same in 2006 as it was in 2004 among those who remain non-carers. At the same time we might also see a drop in the proportions who engaged in paid work among those who move into caring. By also adjusting for the outcome in 2004, we take account of any differences that may have existed prior to the change in care status. This way we get closer to unravelling causal relationships between caring and various outcomes in social policy domains. However, we must always remain cautious and avoid making strong causal links as there may be other plausible explanations. For example, causality may occur in the other direction; it may be that because someone has been made redundant, they have more time to provide informal care. Or there may be an external factor that affects both change in care status and employment status which we have not included in the analysis. Nevertheless, this approach is far superior to a cross-sectional approach for identifying causal processes.

Statistically significant differences between a care group (into caring, out of caring, those that remain carers at both time points) and those who remain non-carers is indicated by ‘*’ and denotes a statistically significant difference at 5 per cent. A ‘†’ signifies that a difference between a care group and those who remain non-carers is statistically significant after adjusting for the outcome in 2004.

Unlike the comparative analysis we are unable here to distinguish between different care types and different burdens of care. The numerous associated pathways would make the sample sizes

¹¹ Meaning there is only 5 per cent chance (or less) that a difference does not exist in the wider population

untenable for analysis. We must accept this as a limitation. Nevertheless, as the report will demonstrate, we are still able to illuminate some very interesting differences to do with changes in care role status.

Chapter 8: Quality of Life analysis – policy domains

To conclude this first stage of analysis we examine the importance of the factors measured in each of the five policy domains to the quality of life of the carer. Throughout the report we identify many instances where the lives of carers could be improved relative to non-carers. In chapter eight we try to illustrate which of these factors would be the most important for improving carers' quality of life.

Quality of life is notoriously difficult to measure. You cannot simply ask someone to rate their quality of life on a scale of 1 – 10 and expect to receive a meaningful measure which is comparable across individuals. The question will mean different things to different people, and will also be susceptible to someone's mood on the day. Researchers have sought to overcome this difficulty by constructing sets of thoroughly tried and tested questions, each designed to focus on an aspect of the person's life, which together can be taken to measure quality of life.

For this study we use CASP19, a measure of quality of life which has been designed for and developed using the elderly population. It is a continuous measure constructed from the responses to nineteen questions, which cover the domains of 'Control', 'Autonomy', 'Self-realisation', and 'Pleasure' (for the full list of questions see Appendix A). Individual scores across all nineteen questions are summed, giving a well-being scale from 0 to 57, with a high score reflecting positive well-being. For a thorough introduction to CASP19, as well as a demonstration of the validity and reliability of the measure see Wiggin's et. al. (2007)¹².

Regression analysis was used to explore the influence of the factors measured in each of the five policy domains on the quality of life of the carer. As with the longitudinal analysis, we were unable to distinguish between care type or care burden because of issues relating to sample size. The sample used is all those who were providing care in 2004. We adjusted the analysis for gender, age, marital status, level of education, care type, number of care hours, number of people cared for, and whether the person lives with a person they care for. Where appropriate we also adjusted for additional measures, which we have indicated in the chapter. Further details of the analysis are given in chapter eight.

Chapter 9: Quality of Life analysis – co respondent analysis

In a separate, although complementary analysis, we explore how the characteristics of the person being cared for impacts upon the quality of life of the carer. In ELSA 2004, there were about 300 individuals who cared for a partner or spouse, for whom we have interview data for both the person providing the care and the care receiver. This presents a unique opportunity to explore the relationship between the carers' well-being and the characteristics of their partner or spouse, including their health status, cognitive function and the level of care required. Details of the analysis approach is outlined within the chapter.

¹² Wiggins, R. D., Netuveli, G., Hyde, M., Higgs, P., Blane, D. (2007) The evaluation of a self-enumerated scale of quality of life (CASP-19) in the context of research on ageing: A combination of exploratory and confirmatory approaches *Social Indicators Research* Vol. 89, No. 1, pp 61-77

1.4 Sample sizes

The weighted base sample used in the first stage of the analysis, the comparative analysis, was 8388. This comprised of 829 carers, and 7579 non-carers. 265 individuals were excluded from the study because although they had reported that they had cared for someone in the last month, they had not reported looking after someone in the last week. They were not asked the necessary follow up questions relating to their care activities that were required for further analysis (see definition of carers in ELSA above for further details).

In an early exploration of the data we identified very few differences between carers and non-carers when treating carers as a single category of individuals. It was therefore necessary to subdivide the carers groups further into different categories of individuals depending on the person they cared for, and the level of care that was provided. This gave us the following groupings.

Table 1.1 Base samples for Comparative Analysis (weighted)

Caring for	Number of care hours per week	Sample size
A Spouse or Partner	0 – 19	66
A Spouse or Partner	20 +	240
A Child(ren)	0 – 19	23
A Child(ren)	20 +	62
Parent(s) or Parent(s) in-law	0 – 19	189
Parent(s) or Parent(s) in-law	20 +	92

Subdividing the carer group has resulted in some very small sample sizes, severely reducing the power for identifying statistically significant differences between carers and non-carers. This issue is particularly problematic in relation to those providing less than twenty care hours a week to a child, and should be taken into consideration in the interpretation of the findings. A large, although non-significant difference for small samples such as these might be considered tentative, however further analysis with a larger sample would be necessary to confirm the finding.

The weighted base sample for the second stage of the analysis, the longitudinal analysis, was 6640. The sample consisted of individuals who had responded to the first three waves of ELSA (2002, 2004, and 2006). For consistency, all individuals who had reported that they had cared for someone in the last month, but not in the last week in either 2004 or 2006 were removed from the sample. The following groups were constructed for analysis:

Table 1.2 Base samples for Comparative Analysis (weighted)

Carer status in 2004	Carer status in 2006	Sample size
Non-carers	Carers	5668
Carers	Non-carers	319
Carers	Carers	278
Non-carers	Non-carers	376

The weighted base sample for the third stage of the analysis, the Quality of Life analysis – policy domains, was 768. The sample is slightly less than the base sample of carers used for the comparative analysis because fewer respondents completed the self-completion questionnaire

which contained the quality of life questions. The data has been weighted to take account of any sample bias relating to non-completion.

The weighted base sample for the fourth and final stage of the analysis, the Quality of Life and the Cared for, was 320. The sample consisted of all individuals who cared for a spouse, for whom we have interview data for both the person providing the care, and the care receiver.

2 The Demographics and Characteristics of Care

2.1 Demographics

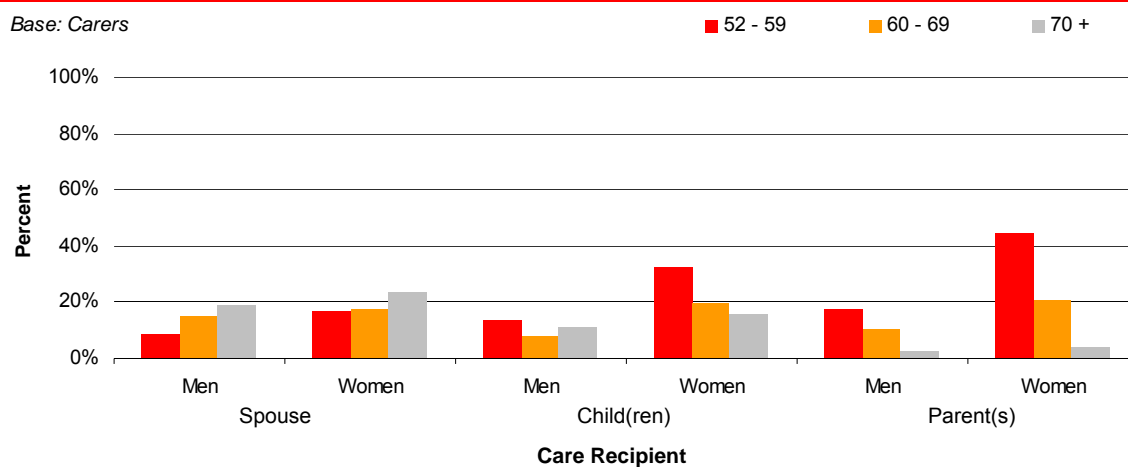
Around 10 per cent of individuals aged fifty-two and above were providing some form of informal care in the year 2004. Of these, 39 per cent cared for a spouse or partner¹³, 11 per cent cared for a child with specific care needs, 34 per cent cared for their parent(s) or parent(s) in-law, and 24 per cent cared for another relative, friend, or someone else.

Figure 2-1 shows the age and gender profile of carers within each care recipient group (the bars within each care recipient groups add up to 100 per cent). More women than men cared for a spouse (57.5 per cent of those caring for a spouse were women compared 42.5 per cent of men). However, this gender difference was more evident among those age 52 to 59 than among those aged 70 or older. On average, those caring for a spouse tended to be much older (68.4 for men, and 67.2 for women).

Similarly, those who provided care for a child were much more likely to be women than men (67.7 per cent of those caring for a child or children are women compared with 32.4 per cent of men). While the proportion of men who cared for a child remains relatively stable at each age category, women who cared for a child are far more likely to be in the younger part of the age spectrum (32.6 per cent of women who care for a child are aged 52 – 59 compared to 15.7 per cent aged 70 or older). Overall, the average age for this care group was 63.9 for men, and 62.7 for women.

There is a sharp decline in the proportions of those caring for a parent or parent in-law with age, which is likely to do with parental mortality. The average age of carers was 60.2 for men, and 58.7 for women. Again, carers were far more likely to be women than men (69 per cent of those who cared for a parent or parent in-law were women, compared to 30.9 per cent of men).

Figure 2-1 Age and gender of carers by care recipient (2004)

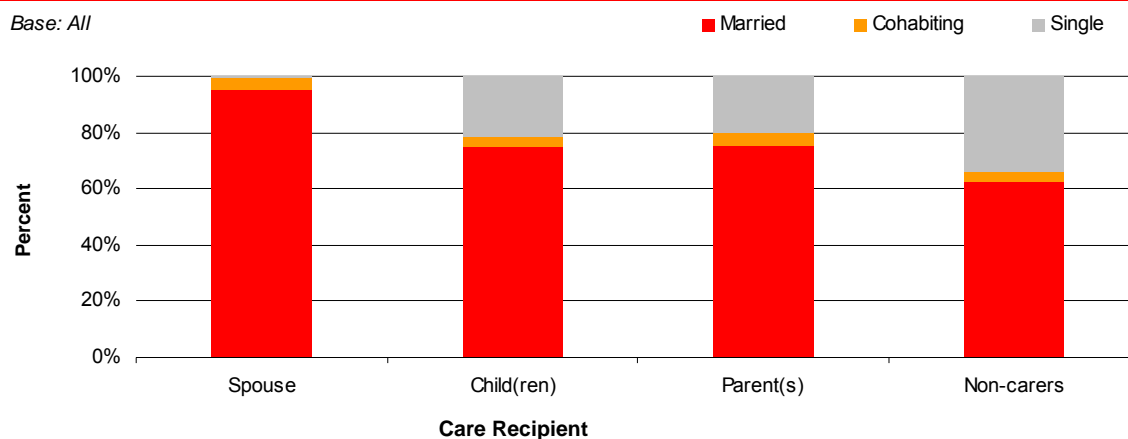


Almost all carers who provided care for a spouse or partner, were married (96 per cent), with 4 per cent cohabiting. Seventy-five per cent of those who cared for a child were married, 3 per cent were cohabiting and 22 per cent were single. These figures are similar to those who provided care for a

¹³ Just 4 per cent were providing care to a partner, so for reasons of brevity both will be referred to as caring for a spouse

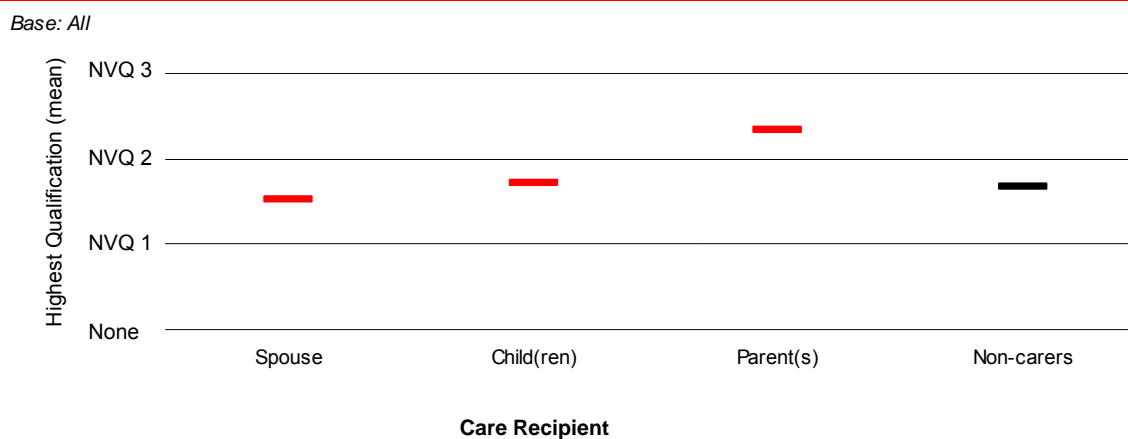
parent or parent in-law: Of these, 75 per cent were married, 5 per cent were cohabiting and 20 per cent were single. Being single was far more prevalent in the non-carers group, with 35 per cent reporting that they were not in a partnership, (Figure 2-2).

Figure 2-2 Partnership status (2004)



Highest qualifications are presented in Figure 2-3 as average NVQ level¹⁴ for each care group. Those who provided care for a spouse had the lowest levels of qualifications on average, with an average NVQ level of 1.5. Those providing care for a child, had slightly higher qualifications (1.7), whereas those who cared for a parent or parent in law tended to hold much higher qualifications on average (2.3), much higher also than the non-carers (1.7).

Figure 2-3 Highest Qualifications (2004)

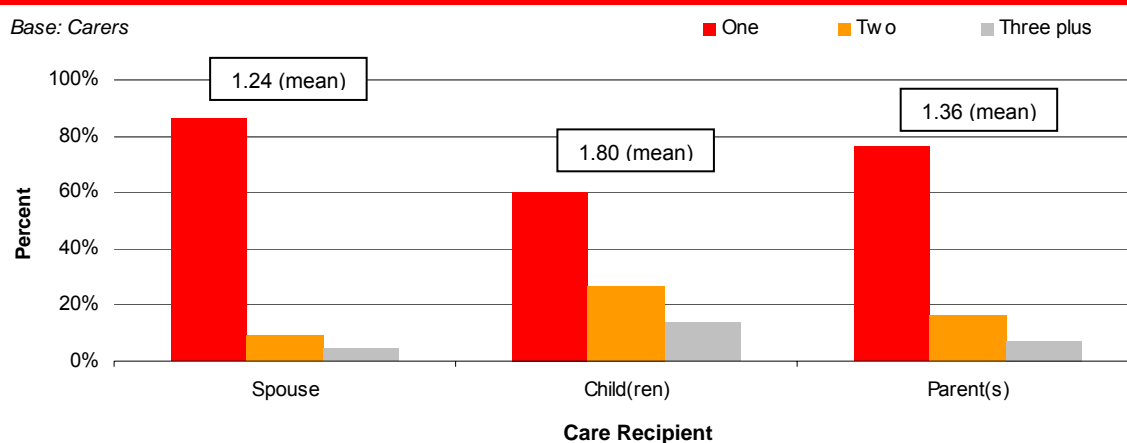


¹⁴ National Vocational Qualifications (NVQ) is a standard scale under which all qualifications (including academic or school qualifications). School leaving qualifications (GCSE, O levels) are recorded as NVQ level 1 – 2, A levels as NVQ level 3, degree level as NVQ 4, and post-degree level as NVQ 5

2.2 Characteristics of Care

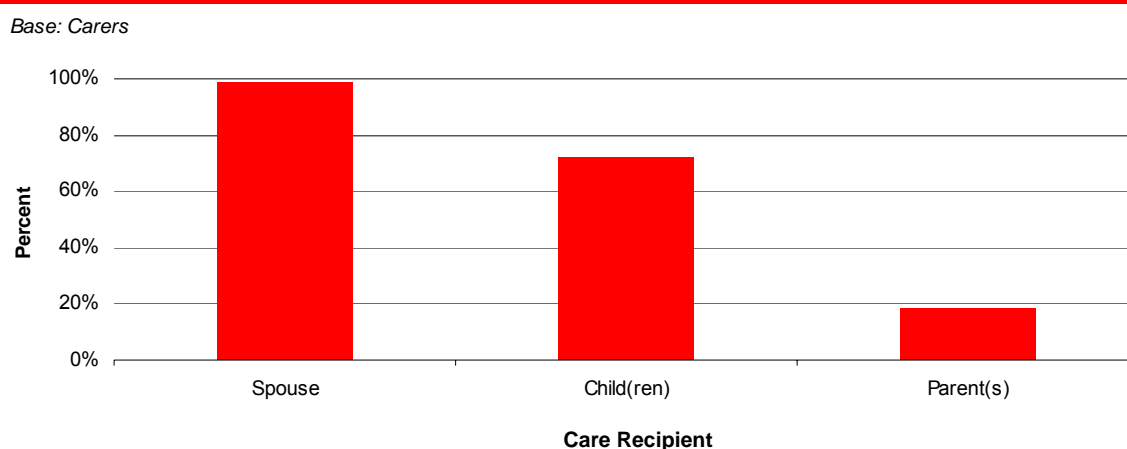
Characteristics of the care experience were quite varied depending on who the care provision was for. The large majority of those who provided care for a spouse were providing care for that one person alone (86.5 per cent). There were more individuals with multiple care roles among those who cared for a parent or parent in-law; of these 16.2 per cent cared for two people and a further 7.5 per cent cared for three or more individuals. Those who cared for a child were even more likely than other carers to care for more than one person, 27.5 per cent cared for two people, and a further 13.6 per cent cared for three or more (Figure 2-4).

Figure 2-4 Total number of people care for (2004)



Unsurprisingly, those who provided care for a spouse, also lived with a person they cared for (98.5 per cent). This was less likely among those who cared for a child, 71.8 per cent, and far less likely among those caring for a parent or parent in-law, 18.4 per cent¹⁵ (Figure 2-5).

Figure 2-5 Lived with someone they care for (2004)

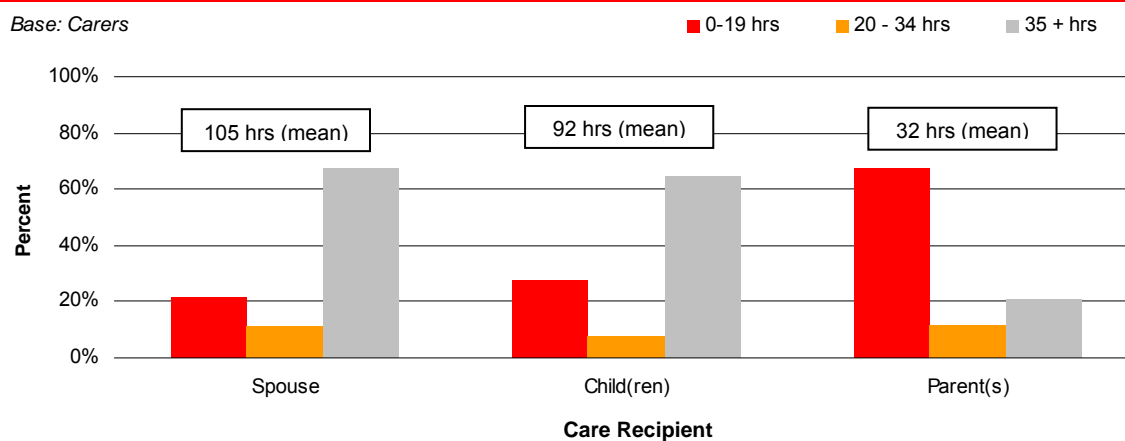


Related to this is the average number of caring hours that a person typically provides each week. Those providing care to a spouse are far more likely to be caring full-time (67.2 per cent provide 35

¹⁵ Unfortunately the question does not identify which care recipient the person is living with.

or more care hours per week). The pattern is similar for those caring for a child, although slightly fewer provide full-time care (64.9 per cent), whereas only 20.8 per cent of those caring for a parent or parent-in-law provide similar levels of care. Instead they are far more likely to provide light levels of care (67.4 per cent provide less than twenty hours a week) (Figure 2-6).

Figure 2-6 Total number of care hours worked per week (2004)



There may be a number of complex and inter-related reasons why people provide unpaid care. In ELSA, individuals are given the option of a range of possible reasons and the answers are presented in Figure 2-7. The most popular reason given for caring was because they were needed; over 80 per cent selected this option (slightly more among those caring for a parent or in-law, 84.7 per cent). This may reflect their experience of a lack of any alternative care provision that could provide the level of care support that is required.

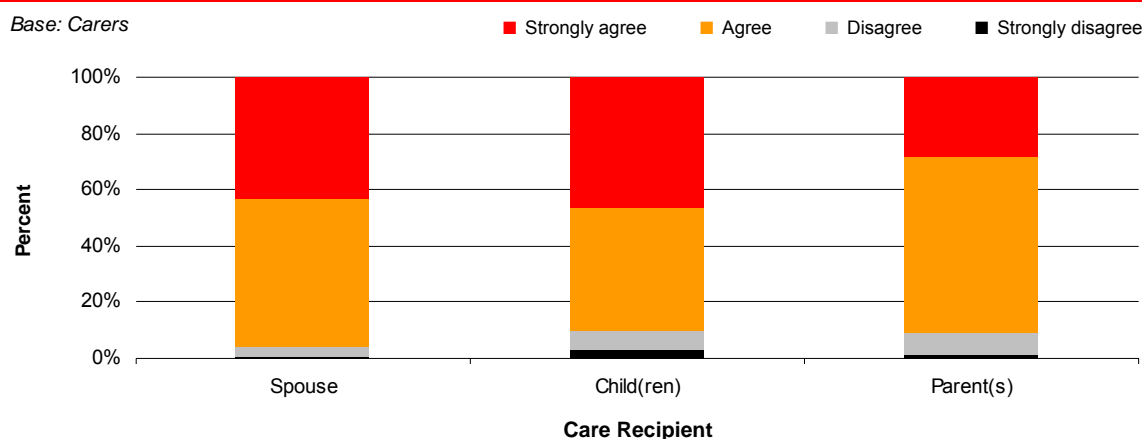
Figure 2-7 Reasons given for caring (2004)

Base: Carers

Reasons given for caring	Caring for a spouse	Caring for a child(ren)	Caring for a parent(s) or in-law(s)
	Per cent	Per cent	Per cent
To meet others	1.6	2.2	2.5
To be useful	10.1	25.7	21.2
For personal achievement	5.7	10.1	2.8
Because I am needed	81.1	80.5	84.7
To earn money	0.2	0.0	0.0
Because I enjoy it	21.6	37.6	30.8
To use my skills	4.5	6.6	5.6
To keep fit	2.4	1.4	1.3
I feel obliged	25.4	32.0	40.6
None of these	8.3	9.5	4.9

The next two most cited reasons were because the carer 'felt obliged', and because they 'enjoyed it'. A feeling of obligation was most heavily felt by those providing care to a parent or parent in-law (40.6 per cent), this was less common among those caring for a child (32.0 per cent), and those caring for a spouse (25.4 per cent), perhaps reflecting expectations attributed to some relationships and not others. Another relatively highly endorsed reason was 'to be useful', particularly among those caring for a child (25.7 per cent) and those caring for a parent or parent in-law (21.2 per cent).

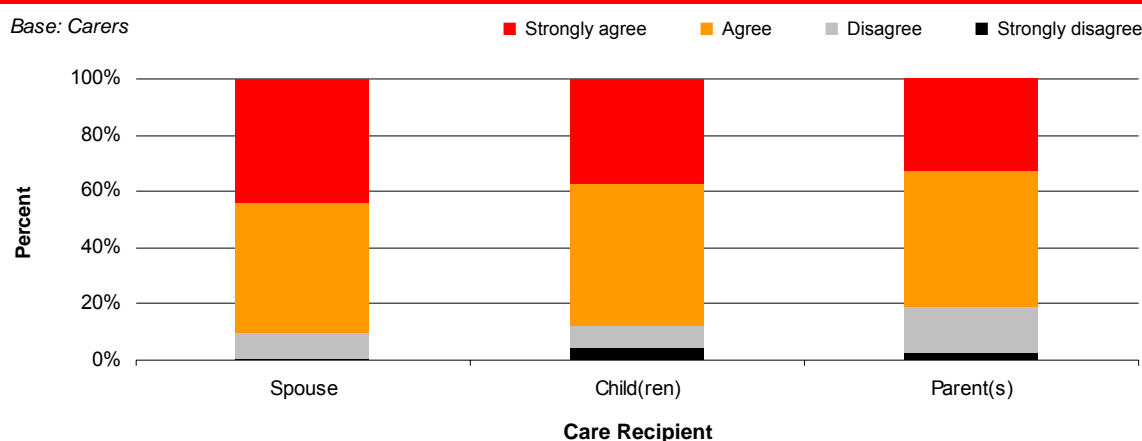
Figure 2-8 'I am fully satisfied with what I have gained so far from caring' (2004)



Finally, carers were also asked about the satisfaction they gained from caring, and whether they felt appreciated. The vast majority of carers agreed with the statement 'considering all the effort I have put into caring for someone, I am fully satisfied with what I have gained so far', with many strongly agreeing with the statement. There was less strong endorsement for the statement among those who cared for a parent or parent in-law. A very small proportion strongly disagreed with this statement, particularly for those caring for a dependent child (Figure 2-8).

A similarly high endorsement was given to the statement 'considering all the effort I have put into caring for someone, I have always received adequate appreciation from others', although this was not quite as high as it was for the statement of satisfaction. Again, those who cared for a spouse were slightly less likely to agree with the statement, and there was a very small proportion who strongly disagreed, particularly among those caring for a dependent child. Overall, the highest endorsement for both questions was among those caring for a spouse (Figure 2-9).

Figure 2-9 'I have always received adequate appreciation from others for caring' (2004)



3 Income and Work

In this chapter we explore differences between carers and non-carers in relation to their income and work. First of all we focus on their experiences in 2004 alone. We distinguish between the type of care provided (whether to a spouse or partner¹⁶, a dependent child with particular care needs, or a parent or parent in-law) and the level of care given (that is, up to 19 hours of personal care a week or twenty hours plus).

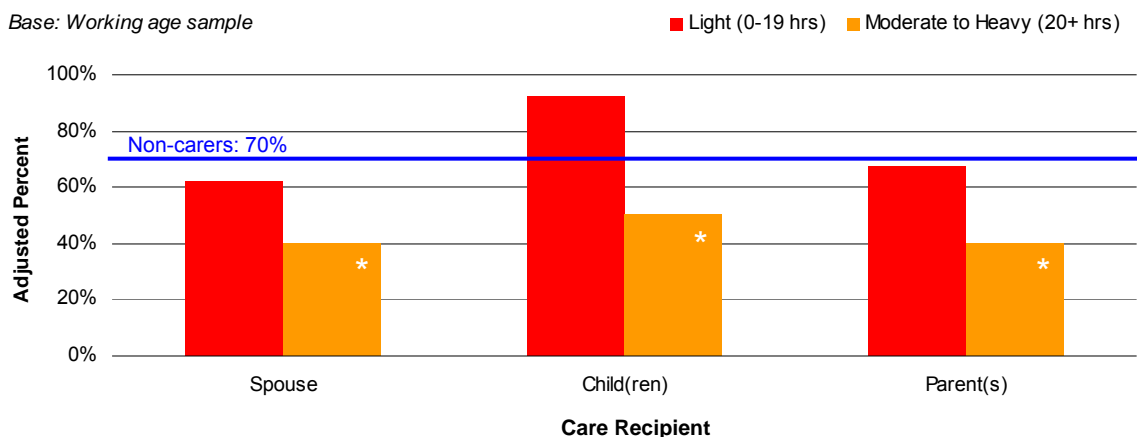
We then explore the propensity of their experiences to change over time, including any change associated with a move into or a move out of a care role. We achieve this by looking at the experiences of four different care groups, those who move into caring between 2004 and 2006, individuals who move out of a care role in that time period, those who remain carers at both time points, and individual who remain non-carers¹⁷. For further details on the analysis strategy used and how to interpret the results please refer to Section 1.3 in the introduction.

3.1 Comparative analysis – comparing carers and non-carers in 2004

There were a number of ways in which we compared the work and incomes of carers and non-carers. First, focusing on those of working age, we explored whether they had carried out any paid work in the last month. Among carers and non-carers who were employed, we also explored the average number of hours they worked each week and their subjective evaluations of their jobs. We then compared the weekly earnings of those in employment and the family weekly earnings of those who worked or those who had a partner who worked. We also looked at total individual income, total family income and total (non-pension) wealth. Finally we explored respondents' subjective evaluations of how they were coping financially.

Those who were providing a moderate to heavy amount of care were far less likely to have engaged in paid work in the last month than non-carers. Forty per cent of those who were providing twenty or more care hours a week to either a spouse, or parent or parent in-law, had engaged in paid work compared to seventy per cent of non-carers. The figure was fifty per cent for those providing care to a child. The differences between those providing less than twenty hours of care and non-carers were not statistically significant (Figure 3-1).

Figure 3-1 Engaged in Paid work in the last month (2004)



* Indicates a statistically significant difference from non-carers (significant at 5%)

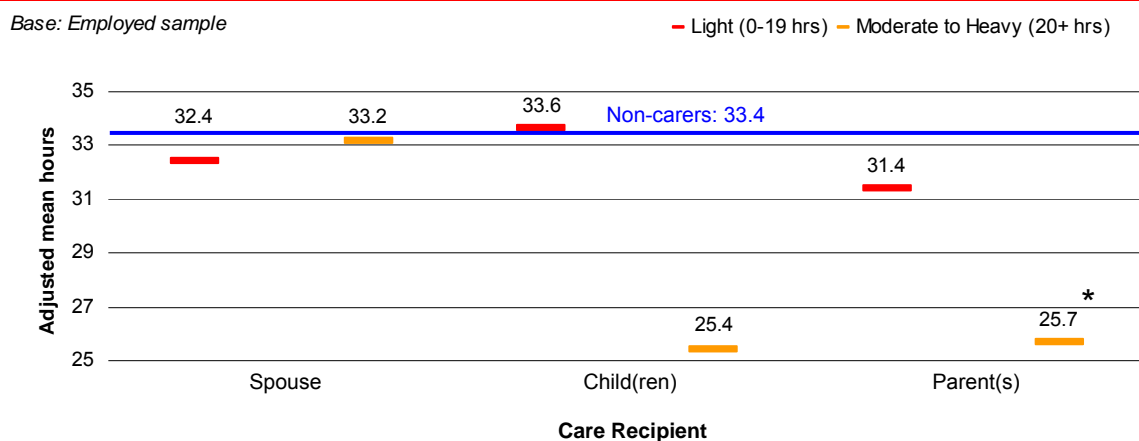
¹⁶ Just 4 per cent were providing care to a partner, so for reasons of brevity both will be referred to as caring for a spouse

¹⁷ These four groups could also include individuals who change carer status more than once between 2004 and 2006.

Unfortunately ELSA does not allow us to identify these individuals

Among those who were employed, only those carers who were providing moderate to heavy care for a parent or parent in-law, worked significantly less hours of paid work a week than non-carers (25.7 hours a week compared to 33.4 hours). Those providing a similar level of care to a child worked just 25.4 hours a week on average. Although this difference was not statistically significant, this may be because of the small sample size associated with this group, and we might therefore consider this finding as indicative. Caring for a spouse appears to make no differences to the number of hours of paid work (Figure 3-2).

Figure 3-2 Working hours (2004)



* Indicates a statistically significant difference from non-carers (significant at 5%)

Individuals who were working were asked to evaluate their jobs subjectively. They were asked to rate their job satisfaction, the demands they faced, the recognition they received, the adequacy of their salary, their job prospects and the support they were given (see appendix A for the full list of statements). There were no significant differences between the evaluations given by carers and non-carers on any of these items.

We also compared income from earnings as well as total income, considering both family and personal income. Whilst someone's personal income may suffer as a result of their caring commitments, they might nevertheless be supported financially by other members of the family. All measures of income have been transformed¹⁸ prior to analysis, and family income has been equalised¹⁹. The income figures given here represent net income.

Apart from those who provided moderate to heavy care for a dependent child, or light care to a parent or parent in-law, all carers lived in families with lower weekly earnings, on average, than non-carers. However, there was no clear relationship between family earnings and the level of care provided. For example, those who provided light care to a spouse lived in families with the lowest earnings (£131 per week)²⁰ and those who provided heavy to moderate care to a parent or parent in-law, lived in families with significantly lower earnings than non-carers (£160 per week). Non-carers lived in families earning an average of £230 per week (Figure 3-3).

¹⁸ As the distribution of income is heavily skewed (i.e. small proportions of individuals receive disproportionately higher levels of income than the vast majority) it is unsuitable for regression analysis. We therefore transformed the measure prior to analysis by taking its natural logarithm.

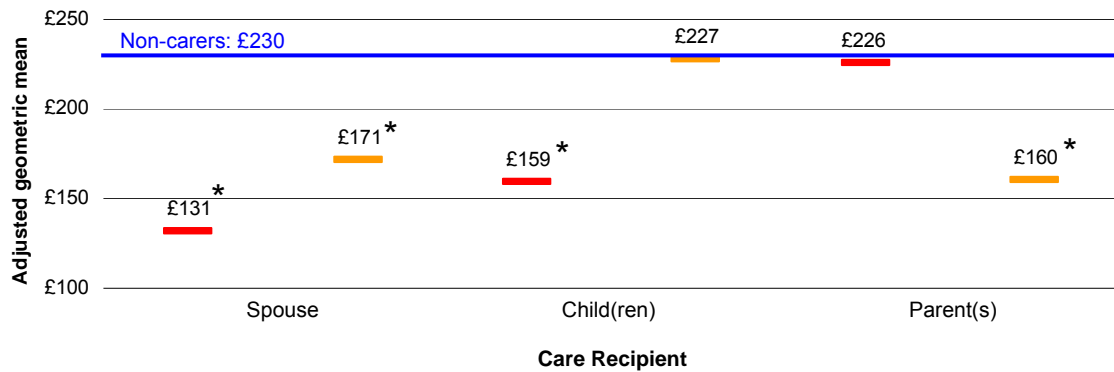
¹⁹ Equalisation takes account of the number, age and relationship status of all individuals in the household so that levels of income are more comparable across households.

²⁰ Figures represent the geometric mean. The geometric mean is what you obtain when you convert coefficients of previously logarithmic transformed data (see note 17) back into a comprehensible form by taking the inverse of its natural logarithm. The geometric mean is very similar to the median

Figure 3-3 Equivalised weekly earnings (family) (2004)

Base: At least one family member in employment

— Light (0-19 hrs) — Moderate to Heavy (20+ hrs)



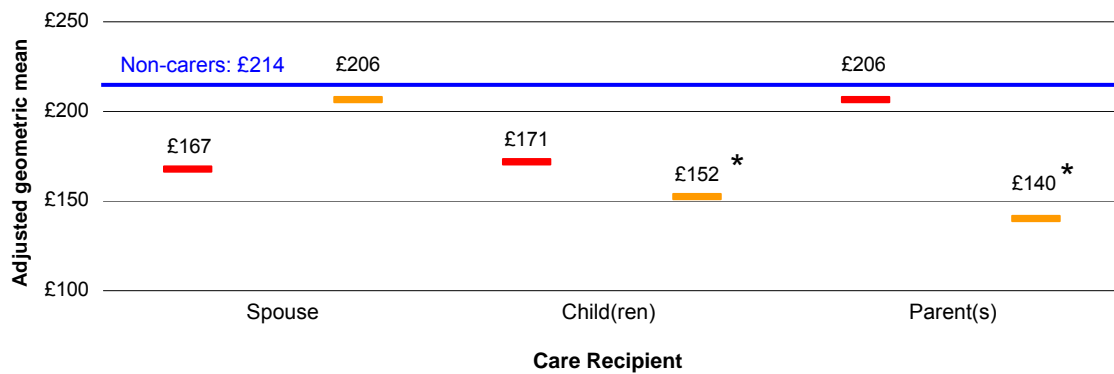
* Indicates a statistically significant difference from non-carers (significant at 5%)

The pattern of earnings is similar for individuals except that differences between non-carers and those who provide care to a spouse are much smaller, and no longer significant. It is also those who provide moderate to heavy care for a child, who earn significantly less than non-carers, as opposed to individuals who provide light care (£152 per week compared to £214 per week for non-carers). Individuals who provide moderate to heavy care to a parent or in-law live in families which earn less than non-carers, and also earn significantly less than non-carers themselves (£140 per week compared to £214) (Figure 3-4).

Figure 3-4 Weekly earnings (individual) (2004)

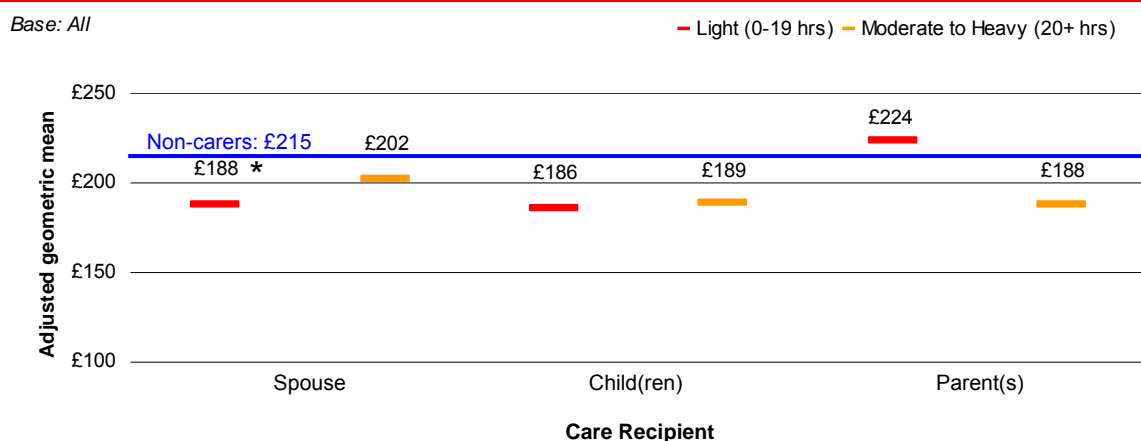
Base: Employed sample

— Light (0-19 hrs) — Moderate to Heavy (20+ hrs)



* Indicates a statistically significant difference from non-carers (significant at 5%)

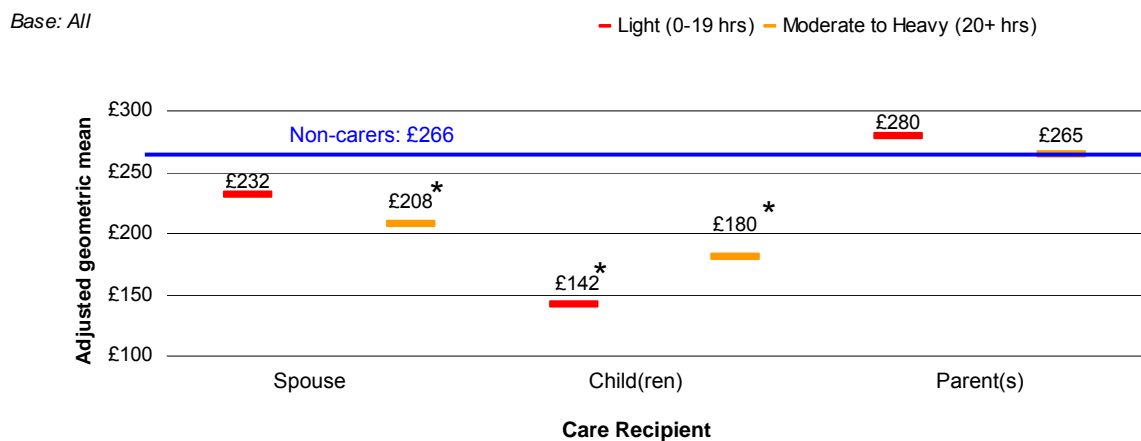
Figure 3-5 Equivalised total weekly income (family) (2004)



* Indicates a statistically significant difference from non-carers (significant at 5%)

Differences in levels of total family income were very small, although generally they suggest that carers live in families with lower incomes than non-carers. The only statistically significant finding was for those providing light care to a spouse. These individuals lived in families with an average income of £188 per week compared to £215 per week for non-carers (Figure 3-5).

Figure 3-6 Total weekly income (individual) (2004)



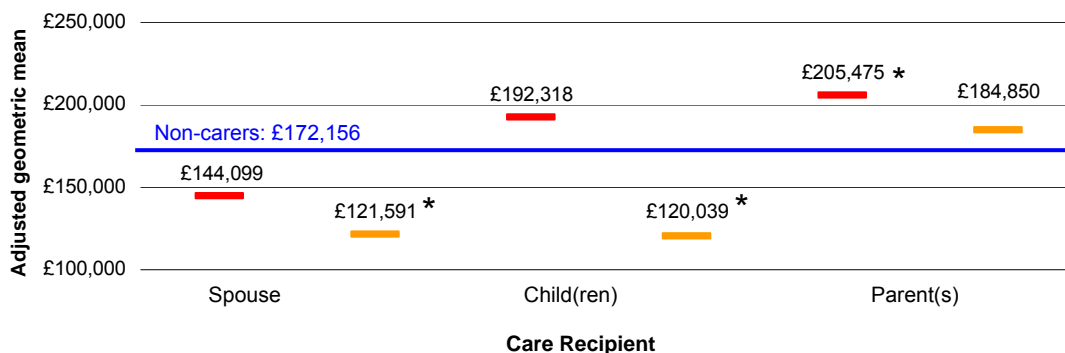
* Indicates a statistically significant difference from non-carers (significant at 5%)

There are much clearer differences relating to individual levels of income. Those who provided care for a dependent child had a much lower level of personal income than non-carers on average, especially those who provided less than twenty hours of care a week (£142 per week compared to £266 per week for non-carers). Those who were providing care for a spouse also had lower levels income, although only those who provided twenty or more care hours a week had incomes significantly lower than non-carers (£208 per week compared to £266) (Figure 3-6).

Figure 3-7 Average equivalised non-pension wealth (family) (2004)

Base: All

— Light (0-19 hrs) — Moderate to Heavy (20+ hrs)



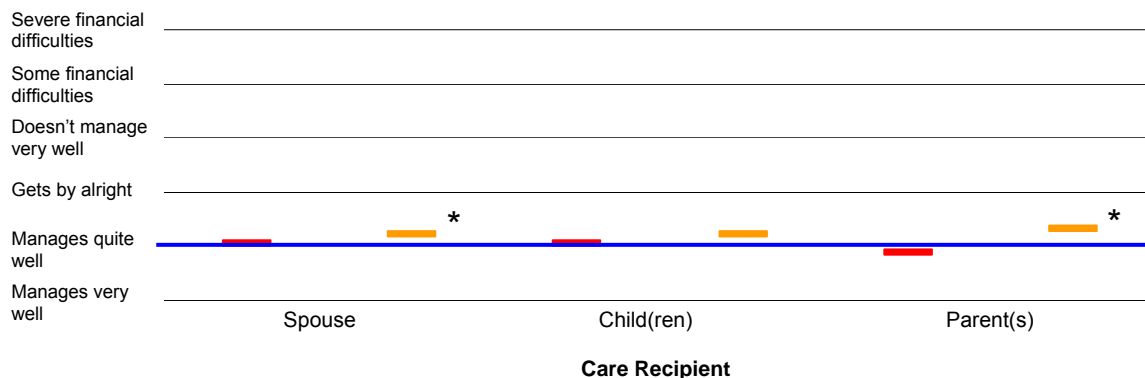
* Indicates a statistically significant difference from non-carers (significant at 5%)

We also looked at levels of family wealth and found that those who were providing moderate to heavy care to a spouse, or to a dependent child, tended to have much lower levels of wealth, on average, than non carers (£121, 591 and £120,039, compared to £172,156 for non-carers). However, those who provided care to a parent or parent in-law tended to have much higher levels of wealth (£205,474 and £184,850), although the finding is only statistically significant for those providing light care to a parent or parent in-law (Figure 3-7).

Figure 3-8 Financial Hardship (2004)

Base: All

— Light (0-19 hrs) — Moderate to Heavy (20+ hrs)



* Indicates a statistically significant difference from non-carers (significant at 5%)

Finally we explored how the individual felt they and their partner, if applicable, were getting on financially. Figure 3-8 shows that on average, the majority of individuals felt they were managing quite well. However, there were some slight fluctuations among the carers, suggesting some individuals within some care groups were not doing quite so well. As a result, the financial hardship felt by those providing moderate to heavy carer for spouse, or for a parent or parent in-law was very slightly higher than that of non-carers.

3.2 Longitudinal analysis – changes in carer status from 2004 to 2006

Between the two time points of 2004 and 2006, there is a fall in the number of people who had engaged in paid work in the previous month. However, those who provided care at both time points were significantly less likely to have engaged in paid work, approximately 45 per cent were in paid work at both time points compared to around 70 per cent of non-carers (Figure 3-9).

There is a general rise in wealth over the time period of approximately £30,000. No doubt this is a reflection of the housing boom that occurred during this period. Those who were providing care at both time points, as well as those who moved into a care role, had much lower levels of wealth, although the difference between those who were carers at both time points, and those who were non-carers is not statistically significant (Figure 3-12).

There was a substantive reduction in the family earnings of all three care groups relative to non-carers. As the differences for all three care groups from non-carers in 2006 is statistically significant when controlling for family earnings in 2004 (indicated in the graph by the symbol '†'), it suggests that this relative change is also statistically significant. Substantively it suggests that those who remain carers, or those who move into a care role, experience a significant reduction in earnings relative to those who remain non-carers. Those who move out of a care role also experience a fall in family earnings, although this is not quite as substantial as for the other two care groups (Figure 3-10).

Those who were non-carers at both time points experienced a rise in personal earnings over the time period, whereas those who moved into caring experienced a fall in earnings: In 2004, the difference in earnings of those who were to become carers, and those who remained non-carers, was not statistically significant. However, in 2006, by which time this former group had become carers, the difference was substantive and statistically significant. In addition, it remains significant when controlling for earnings in 2004, supporting the view that this was more likely to be a causal effect (i.e. one associated with a move into caring), than a selection effect (i.e. individuals who earn less to begin with are more likely to engage in caring). Of course we must always remain cautious when making inferences about causality (see section 1.3 in the introduction). In addition, whilst the personal earnings of those who move out of caring remain significantly lower than that of non-carers, they nevertheless experienced the same, relative rise in earnings over time. Individuals who remain carers at both time points also experiences a fall in earnings, however the difference with non-carers is not statistically significant (Figure 3-13).

The pattern for total family income is similar to that for family earnings. The average family income of non-carers remained relatively stable over the two time points. However, those who moved into caring, and those who moved out of caring, experienced a significant fall in family income relative to non-carers. Individuals who remained carers over the time period also experienced stability in family earnings, however their family earnings were significantly lower than for non-carers (Figure 3-11).

As with individual earnings, non-carers also experienced a rise in total personal income between 2004 and 2006. Those who moved into care did not experience a similar rise in income, a finding which was statistically significant. Those who remained carers at both time points, and those who moved out of caring, also saw a rise in personal income over the time period, however this rise was not as sharp as it was for non-carers (Figure 3-14).

Figure 3-9 In paid employment

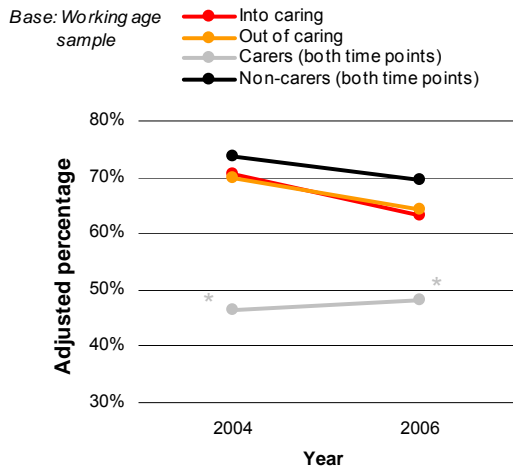


Figure 3-12 Total non-pension wealth

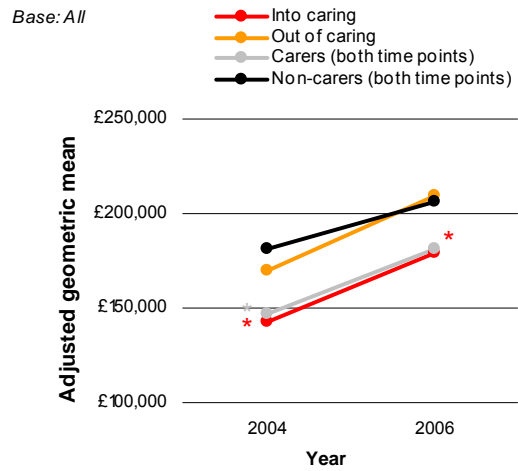


Figure 3-10 Equivalised weekly earnings (family)

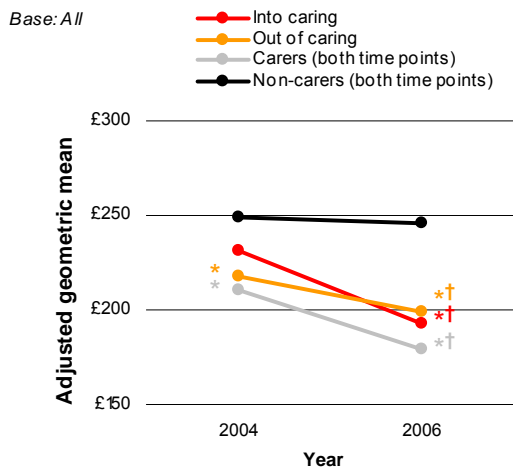


Figure 3-13 Weekly earnings (individual)

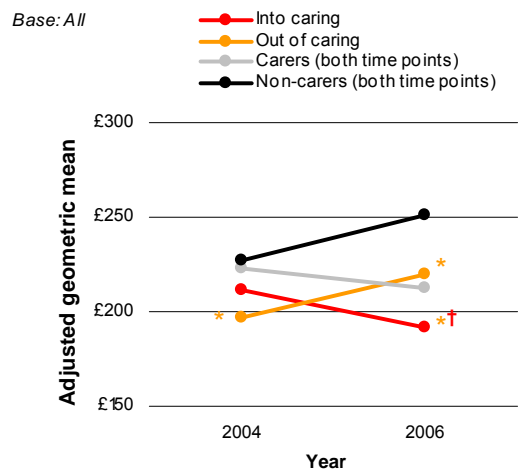


Figure 3-11 Equivalised total weekly income (family)

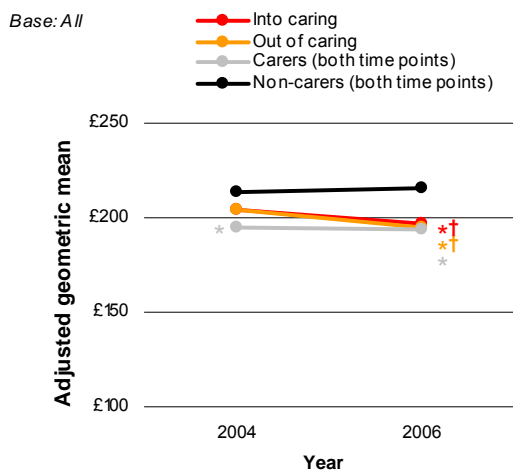
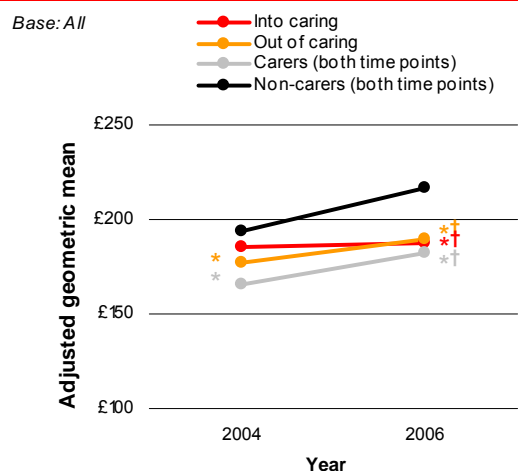


Figure 3-14 Total weekly income (individual)



* Indicates a statistically significant difference from 'non-carers (both time points)' (significant at 5%)

† Indicates a statistically significant difference from 'non-carers (both time points)' in 2006 controlling for differences in 2004 (significant at 5%)

4 Mobility and Access to Services

In this chapter we explore differences between carers and non-carers in relation to their mobility and access to services. First of all we compare their experiences in 2004, and distinguish between the type of care provided (whether to a spouse or partner²¹, a dependent child with particular care needs, or a parent or parent in-law), and the level of care (up to 19 hours of personal care a week or twenty hours plus).

We then explore the propensity of their experiences to change over time, including changes associated with a move into, or a move out of a care role. We achieve this by looking at the experiences of four different care groups, those who move into caring between 2004 and 2006, individuals who move out of a care role, those who remain carers at both time points and individual who remain non-carers²². For further details on the analysis strategy used and how to interpret the results please refer to Section 1.3 in the introduction.

4.1 Comparative analysis – comparing carers and non-carers in 2004

There were a number of different ways in which we compared carers and non-carers mobility and access to services. We considered whether or not they had access to a car, their use of public transport and whether they had any difficulty getting to a number of services. Those providing light care to a parent or parent in-law, were more likely to have access to a car than non-carers (95 per cent of carers compared to 86 per cent for non-carers). However, there were no other differences between carers and non-carers regarding access to a car (results not shown).

We also explored the use of public transport, taking into account whether the individual had access to a car or not. Those who provided light care for a spouse were slightly less likely to use public transport than non-carers (results not shown). Otherwise there were no differences between carers and non-carers in terms of their use of public transport.

Respondents were asked how difficult they found getting to a number of services using their usual form of transport. We also adjusted for whether the individual had access to a car and their level of physical mobility. The analysis was conducted for all carers, however we only report findings for those providing moderate to heavy care, as none of the findings relating to light carers were statistically significant. In addition, we only report findings that are statistically significant.

Of those providing moderate to heavy care to a spouse, a significantly greater number found it difficult to get to services than non-carers. This included getting to a General Practitioner (7.5 per cent compared to 2.1 per cent of non-carers), the hospital (24.8 per cent compared to 9.9 per cent), an optician (5.1 per cent compared to 3.6 per cent) and a supermarket (6.1 compared to 2.9 per cent). Similarly, a significantly greater number of those who were providing moderate to heavy care for a parent or parent in-law found it difficult to get to a General Practitioner (21.3 per cent), the hospital (24.9 per cent), an optician (11.2 per cent), and a supermarket (10.9 per cent). In addition, a significantly greater number found it difficult to get to a shopping centre than non-carers (9.8 per cent compared to 4.3 per cent of carers) (Table 4.1).

²¹ Just 4 per cent were providing care to a partner, so for reasons of brevity both will be referred to as caring for a spouse

²² These four groups could also include individuals who change carer status more than once between 2004 and 2006.

Unfortunately ELSA does not allow us to identify these individuals

Table 4.1 Difficulties accessing services (2004)*Base: All Individuals*

Service	Non-carers	Providing moderate to heavy care to a spouse	Providing moderate to heavy care to a dependent child	Providing moderate to heavy care to a parent or parent in-law
	Adjusted per cent	Adjusted per cent	Adjusted per cent	Adjusted per cent
Bank/cash point	2.8			
Dentist	5.5			
General Practitioner	2.1	7.5		21.3
Hospital	9.9	24.8		24.9
Local Shops	1.7			
Optician	3.6	5.1		11.2
Post office	2.6			
Shopping centre	4.3			9.8
Supermarket	2.9	6.1		10.9

Note: only significant differences reported (significant at 5%)

4.2 Longitudinal analysis – changes in carer status from 2004 to 2006

Unfortunately questions relating to difficulties in accessing services were not asked in ELSA 2006. In addition, whilst they did ask respondents about their use of public transport, the questions were not directly comparable. As a result, we were unable to conduct a longitudinal analysis. We were able to explore the differences in a person's access to a car over time, however we found no differences between the three care groups and non-carers.

5 Leisure and Community Activities

Here we explore differences between carers and non-carers in relation to their leisure and community activities. First of all we compare their experiences in 2004, and distinguish between the type of care provided (whether to a spouse or partner²³, a dependent child with particular care needs, or a parent or parent in-law), and the level of care (whether up to 19 hours of personal care a week or twenty hours plus).

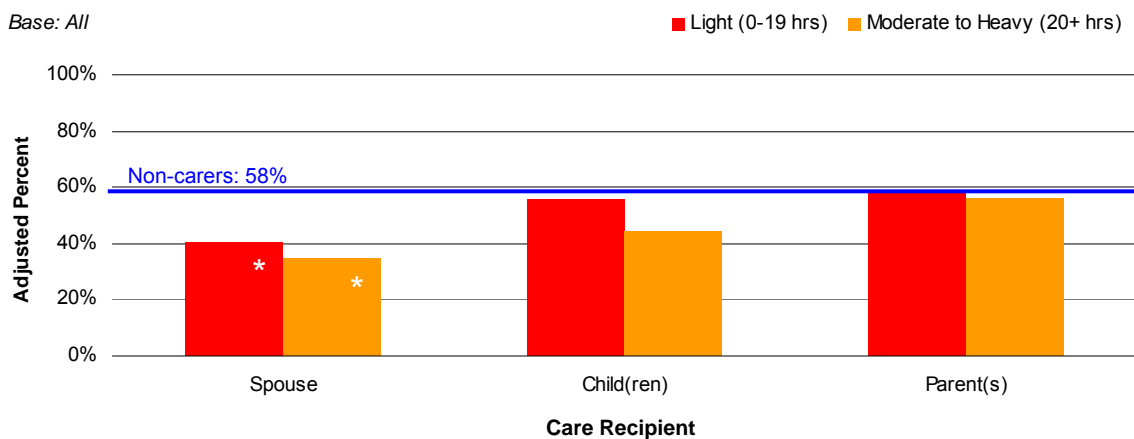
We then explore the propensity of their experiences to change over time, including any change associated with a move into, or a move out of a care role. We achieve this by looking at the experiences of four different care groups, those who move into caring between 2004 and 2006, individuals who move out of a care role, those who remain carers at both time points, and individual who remain non-carers²⁴. For further details on the analysis strategy used and how to interpret the results please refer to Section 1.3 in the introduction.

5.1 Comparative analysis – comparing carers and non-carers in 2004

We examined whether the person has a hobby or pastime, whether they had taken a holiday in the UK, a holiday abroad, or a day trip or an outing within the last 12 months. In addition we considered whether they were a member of an organisation, and the number of organisations they belonged to. They were also asked whether they would like to eat out, or visit a number of places of recreation more often, but felt that, for whatever reason, they were unable to.

There were no differences between carers and non-carers in relation to having a hobby or pastime. However, those who provided care for a spouse were less likely to have taken a holiday in the UK in the last year than non-carers, regardless of whether they provided light, or moderate to heavy care (40 per cent and 34 percent compared to 58 percent of non-carers) (Figure 5-1). Those who provided moderate to heavy care for a spouse were also less likely to have taken a holiday abroad (24 per cent compared to 48 per cent of non-carers) (Figure 5-2), or day trip or outing in the last 12 months (48 per cent compared to 65 per cent of non-carers) (Figure 5-3).

Figure 5-1 Has taken a Holiday in the UK in the last 12 months (2004)



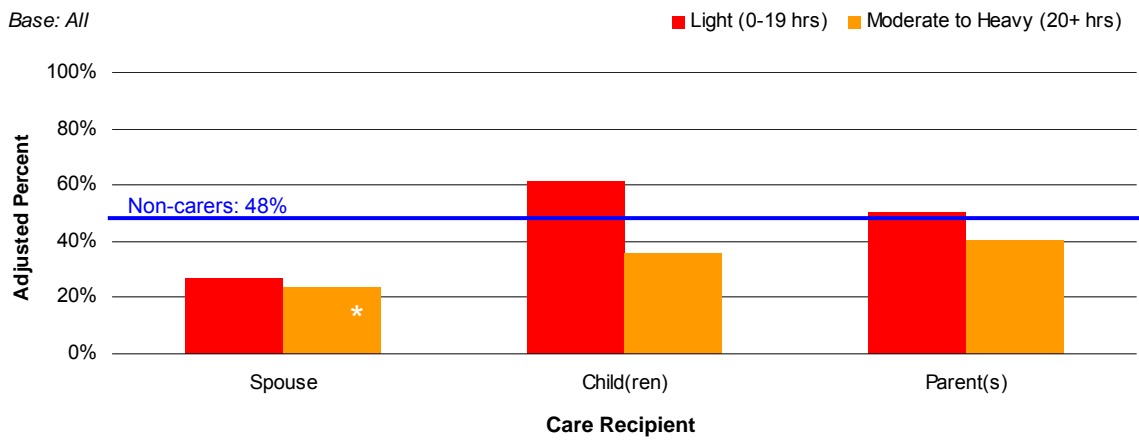
* Indicates a statistically significant difference from non-carers (significant at 5%)

²³ Just 4 per cent were providing care to a partner, so for reasons of brevity both will be referred to as caring for a spouse

²⁴ These four groups could also include individuals who change carer status more than once between 2004 and 2006.

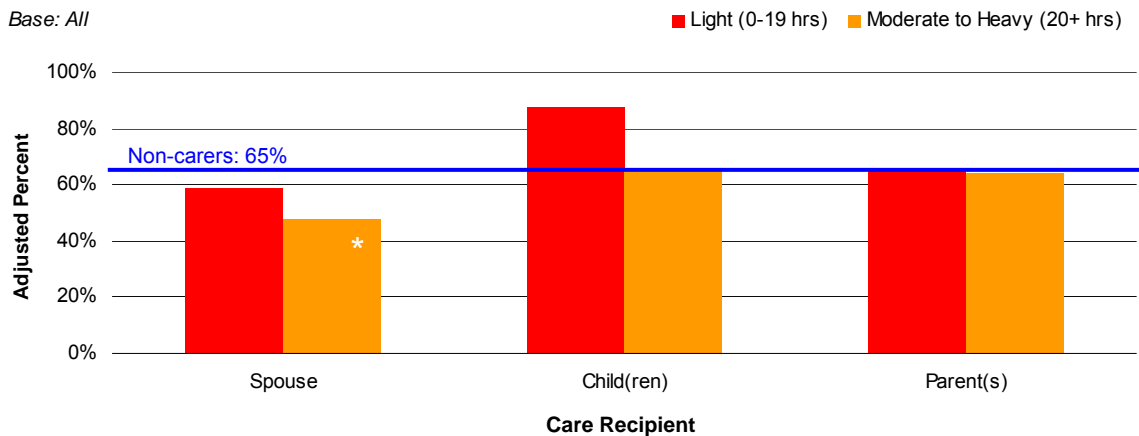
Unfortunately ELSA does not allow us to identify these individuals

Figure 5-2 Has taken a Holiday abroad in the last 12 months (2004)



* Indicates a statistically significant difference from non-carers (significant at 5%)

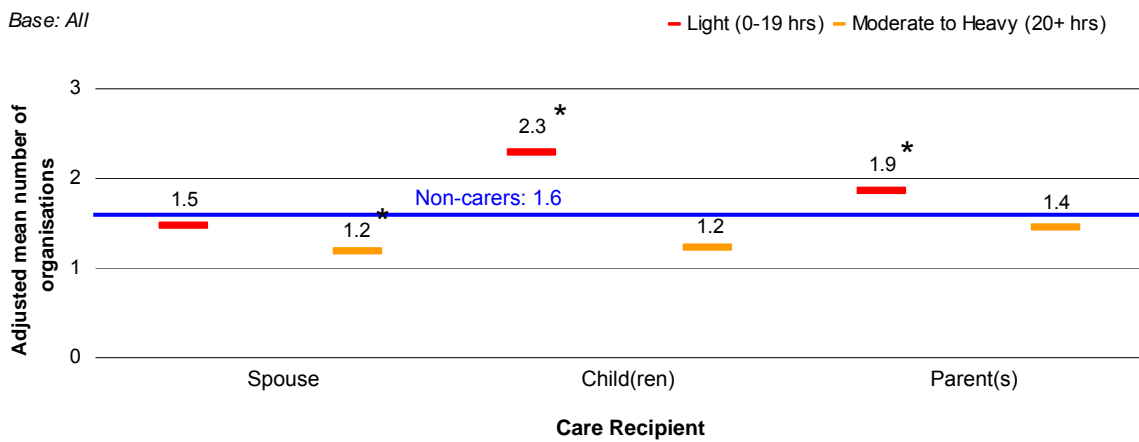
Figure 5-3 Has taken a day trip or outing in the last 12 months (2004)



* Indicates a statistically significant difference from non-carers (significant at 5%)

The provision of care did not effect whether someone belonged to an organisation or not. However, for some care groups, it made a difference to the number of organisations they belonged to. Individuals who were providing moderate to heavy care for a spouse belonged to fewer organisations on average than non-carers (1.2 organisations compared to 1.6). However, those who provided light care for a child, or parent, or parent-in-law, tended to belonged to more organisations on average (2.3 organisations) (Figure 5-4). There are a wide number of possible interpretations and it is impossible to distinguish between them based on this quantitative evidence. Perhaps those individuals who provide informal care also tend to be more inclined to be social, which is something which they can express more readily if their caring roles are less demanding.

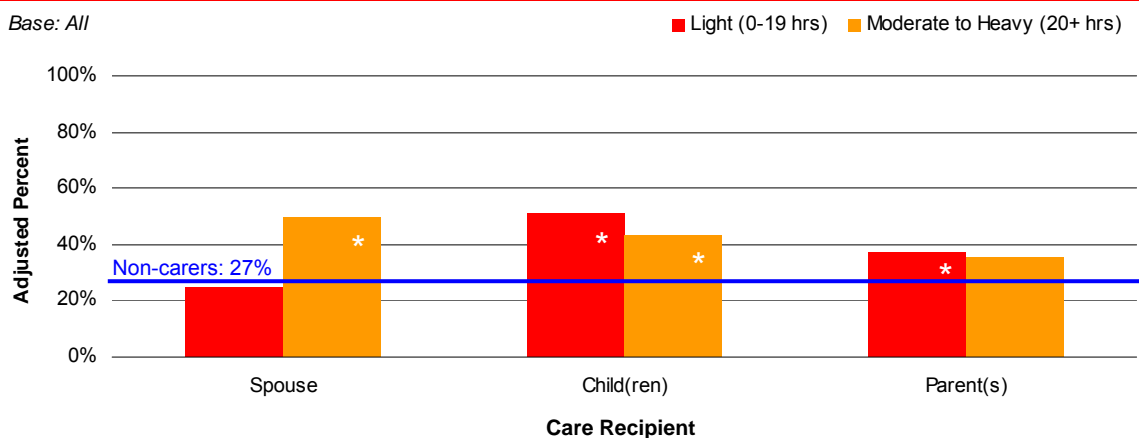
Figure 5-4 Average number of organisation memberships (2004)



* Indicates a statistically significant difference from non-carers (significant at 5%)

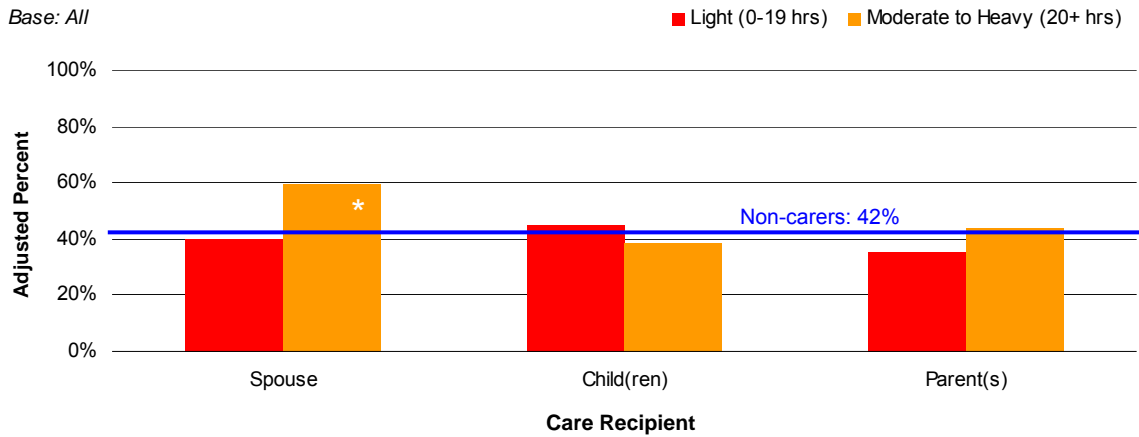
Individuals were also asked whether they would like to eat out, or visit a number of places of recreation more often, but felt that, for whatever reason, they were unable to. Aside from individuals providing light care for a spouse, or heavy care for a parent or parent in-law, all carers said that they would like to go to the cinema more often than non-carers (Figure 5-5). However, only those providing moderate to heavy care to a spouse, also wished they could eat out more often (60 per cent compared to 42 per cent of non-carers) (Figure 5-6).

Figure 5-5 Would like to go to the cinema more often (2004)



* Indicates a statistically significant difference from non-carers (significant at 5%)

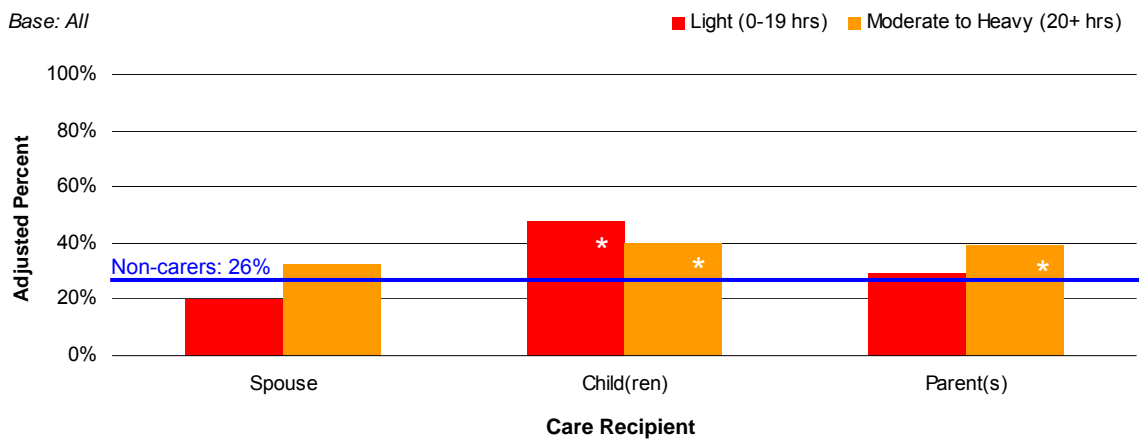
Figure 5-6 Wished they could eat out more often (2004)



* Indicates a statistically significant difference from non-carers (significant at 5%)

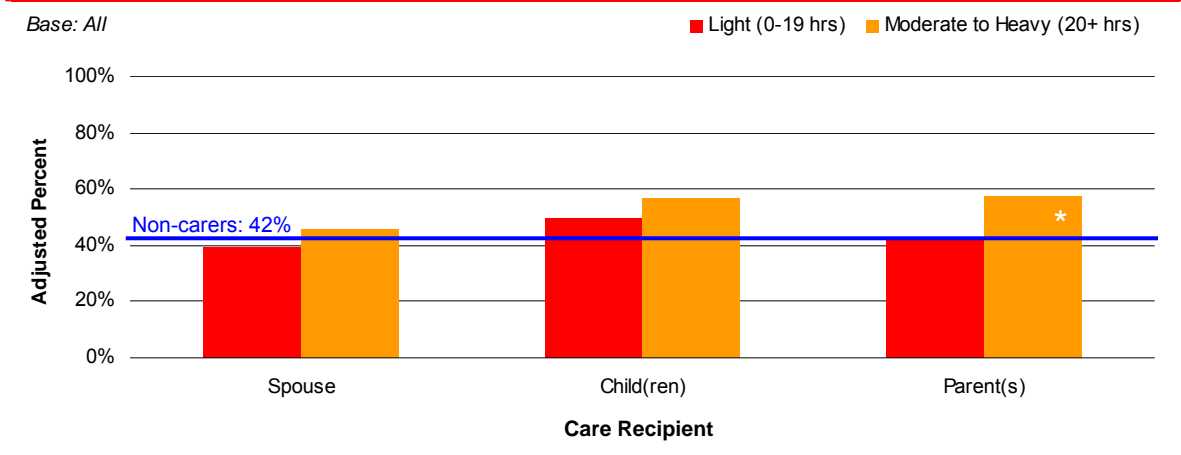
Individuals who were caring for a child, or providing moderate to heavy care to a parent or parent in-law, were more likely than non-carers to want to go to art galleries or museums with greater frequency than they currently could (Figure 5-7). The latter group were also more likely to want to go to the theatre, concerts or opera with greater frequency (58 per cent compared to 42 per cent of non-carers) (Figure 5-8).

Figure 5-7 Would like to go to art galleries/museums more often (2004)



* Indicates a statistically significant difference from non-carers (significant at 5%)

Figure 5-8 Would like to go to the theatre/concerts/opera more often (2004)



* Indicates a statistically significant difference from non-carers (significant at 5%)

5.2 Longitudinal analysis – changes in carer status from 2004 to 2006

There was a small overall reduction in the number of people who had taken a holiday abroad in the last year, between 2004 and 2006. Whilst the difference is only very slight, the reduction among those who cared at both time points, and those who moved out of a caring role, was slightly greater relative to non-carers. However, for those who moved into caring between 2004 and 2006, the reduction relative to non-carers is far more discernable. In 2004 the difference between those who move into caring, and non-carers (the point at which both groups are non-caring groups) is only slight and non-significant. However, in 2006, by which time they have moved into a care role, there is a discernable difference in the proportions who had taken a holiday abroad, 47.4 per cent of non-carers compared to 37.7 of those moving into a care role (Figure 5-9). The result suggests that moving into caring is clearly associated with reduced opportunities for taking foreign holidays.

The findings relating to taking a day trip or an outing in the last 12 months is far less clear. For those moving out of a care role, there appears to have been a slight increase in the proportion taking a day trip or outing, relative to non-carers. However, as the difference between the two groups in 2004 was non-significant, we cannot be certain of this trend. Those who provided care at both time points were less likely to have taken a day trip or outing than non-carers in 2006. There is also suggestion that the situation got slightly worse over time relative to non-carers, however this was not a statistically significant finding (Figure 5-12).

There is little evidence that moving into or out of a care role is associated with a change in the desire to eat out, or visit a number of places of recreation more often. For individuals who care at both time points, there appears to be a reduction in their desire to go to the cinema or eat out more often over time (Figure 5-10 and Figure 5-13). In addition, those who move out of caring wished they could go to art galleries or museums, and the theatre, concerts or opera more often than non-carers at both time points (Figure 5-11 and Figure 5-14).

Figure 5-9 A holiday abroad in the last 12 months

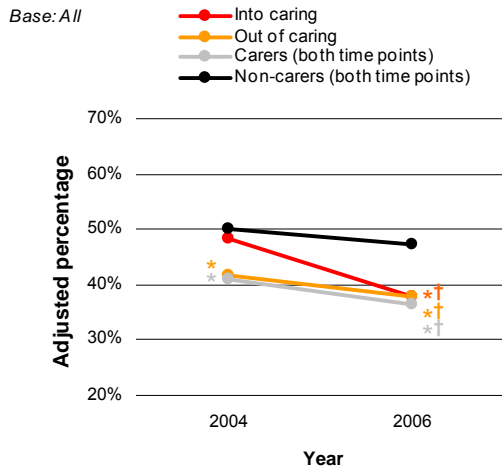


Figure 5-12 Daytrip or outing in last 12 months

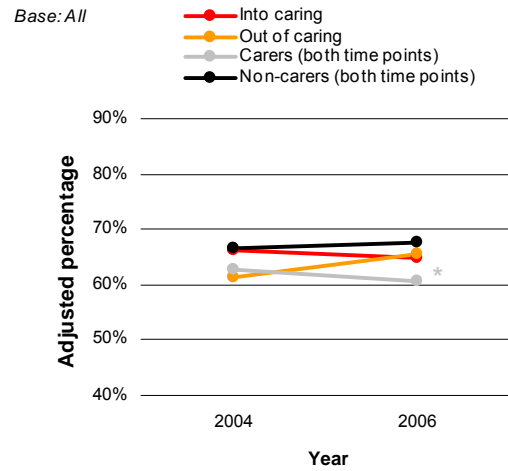


Figure 5-10 Would like to go to the cinema more often

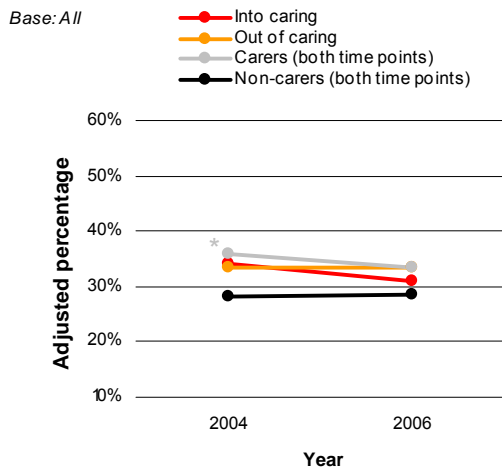


Figure 5-13 Would like to eat out more often

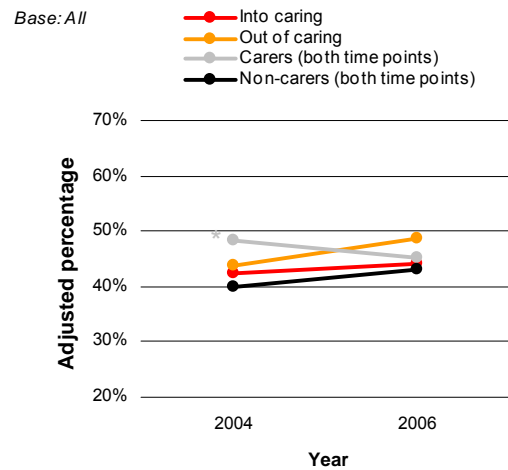


Figure 5-11 Would like to go to art galleries/museums more often

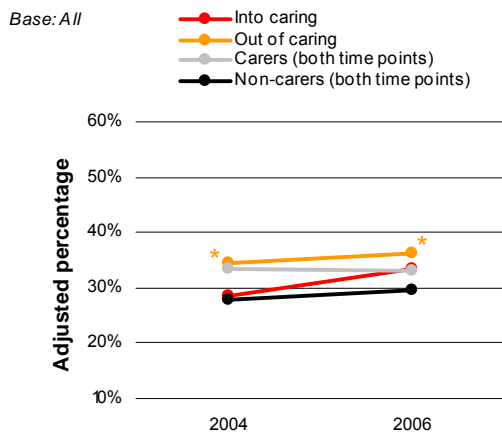
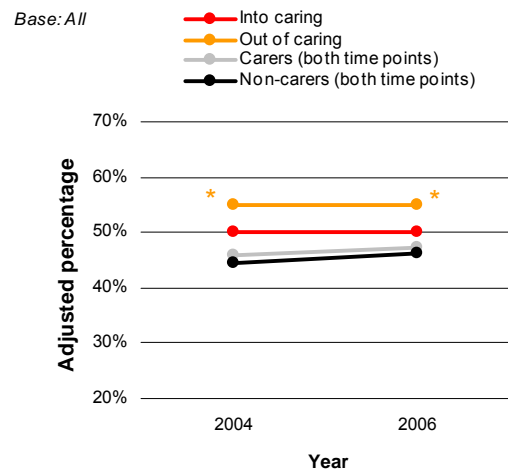


Figure 5-14 Would like to go to the theatre / concerts / opera more often



* Indicates a statistically significant difference from 'non-carers (both time points)' (significant at 5%)

† Indicates a statistically significant difference from 'non-carers (both time points)' in 2006 controlling for differences in 2004 (significant at 5%)

6 Health

Here we explore differences between carers and non-carers level of health. First of all we compare their experiences in 2004, and distinguish between the type of care provided (whether to a spouse or partner²⁵, a dependent child with particular care needs or a parent or parent-in-law) and the level of care (up to 19 hours of personal care a week, or twenty hours plus).

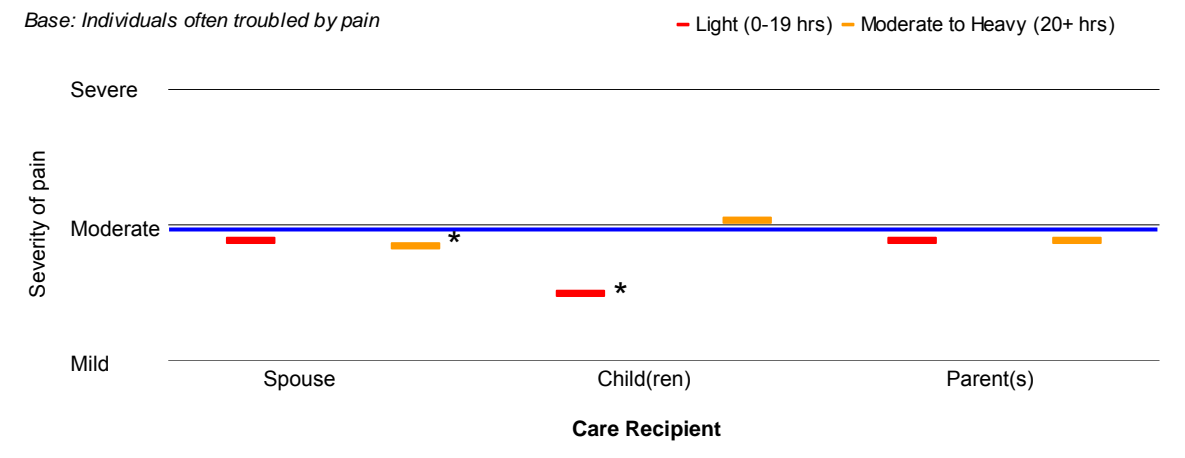
We then explore how their experiences change over time, including any change associated with a move into, or a move out of a care role. We achieve this by looking at the experiences of four different care groups, those who move into caring between 2004 and 2006, individuals who move out of a care role, those who remain carers at both time points and individual who remain non-carers²⁶. For further details on the analysis strategy used and how to interpret the results please refer to Section 1.3 in the introduction.

6.1 Comparative analysis – comparing carers and non-carers in 2004

To compare differences in the health of carers and non-carers we looked at a range of measures covering subjective general health, experiences of chronic pain, physical levels of mobility, the respondent’s capability of carrying out activities associated with daily living and independent living, measures of cognitive ability, upper and lower body strength and body mass index (BMI).

Overall we found very few differences between the health of carers and non-carers. Quite often, where health differences did exist, they tended to show carers were healthier on average than non-carers. Carers and non-carers were just as likely as each other to report having ‘excellent’ or ‘very good’ health (subjective general health). Carers were also just as likely or unlikely to experience chronic pain as non-carers. However, for individuals who did suffer from chronic pain, those who provided moderate to heavy care to a spouse, or light care to a child reported experiencing less chronic pain on average, than non-carers (Figure 6-1).

Figure 6-1 Severity of pain for those often troubled by pain (2004)



* Indicates a statistically significant difference from non-carers (significant at 5%)

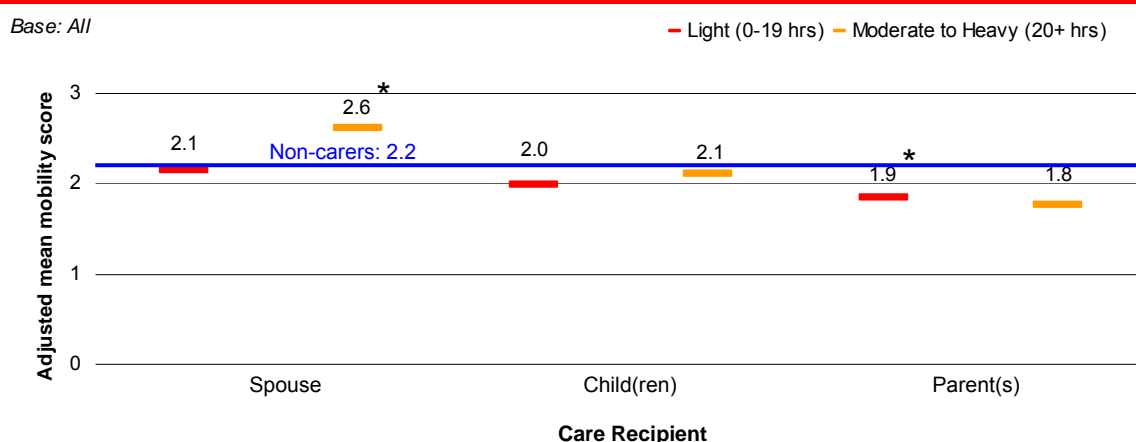
²⁵ Just 4 per cent were providing care to a partner, so for reasons of brevity both will be referred to as caring for a spouse

²⁶ These four groups could also include individuals who change carer status more than once between 2004 and 2006.

Unfortunately ELSA does not allow us to identify these individuals

To assess mobility and arm function, individuals were asked whether they had any difficulties carrying out a range of activities because of a health problem, such as walking, climbing stairs and reaching (see Appendix A for the full list of difficulties).²⁷ Answers to the 10 items were summed to construct a mobility score from 0 to 10, with a high score reflecting poor mobility. Again, there were very few differences between carers and non-carers. Those who provided light care to a spouse were less likely to report poor mobility than non-carers (1.9 compared to 2.2). However, those who were providing moderate to heavy care to a spouse did report significantly poorer levels of mobility on average than non-carers (2.6) (Figure 6-2). This is an important point that should be considered in the provision of services to these older carers.

Figure 6-2 Mobility score: 0 – 10 (*high score = poor mobility*) (2004)

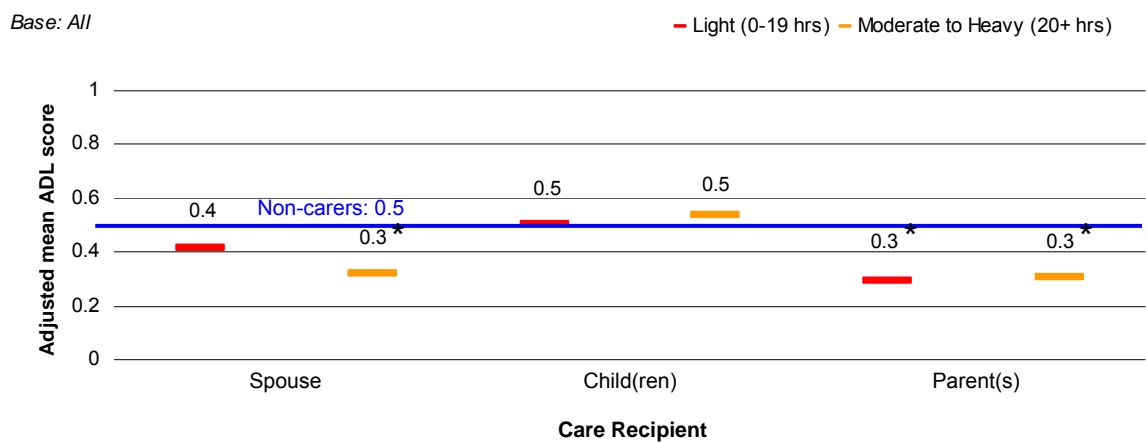


* Indicates a statistically significant difference from non-carers (significant at 5%)

Individuals were also asked whether they had any difficulties performing a number of activities associated with daily living because of a physical, mental, emotional or memory problem. These were subdivided into tasks associated with self care (Activities of Daily Living or ADLs), such as dressing, showering, and eating, and tasks associated with independent living within a community (Instrumental Activities of Daily Living or IADLs), such as preparing a hot meal and managing money (see Appendix A for the full list of difficulties). In all cases, carers reported a higher capability for both ADLs and IADLs than non-carers, or showed no difference.

²⁷ Individuals were told to disregard any temporary difficulties expected to last less than 3 months

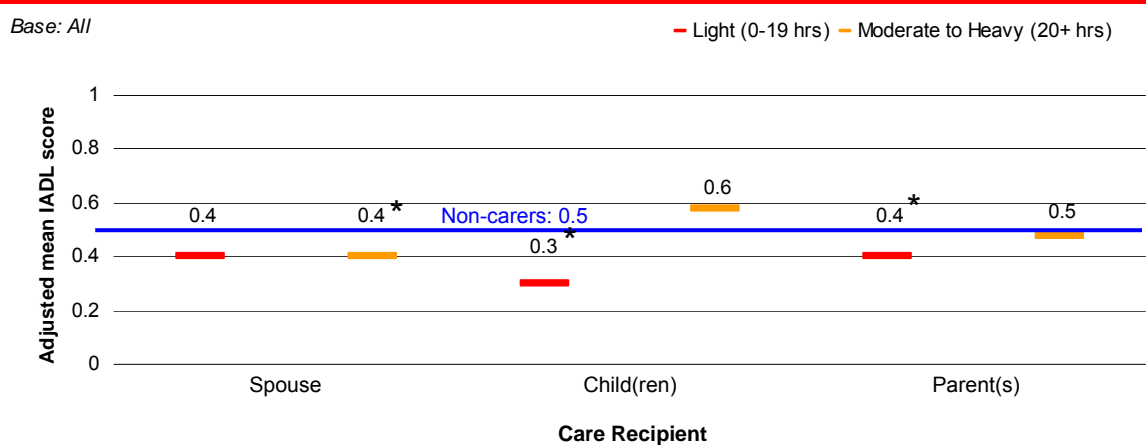
Figure 6-3 Activity of Daily Living score: 0 – 6 (high score = poor capability) (2004)



* Indicates a statistically significant difference from non-carers (significant at 5%)

Those who provided care for a parent or parent in-law, and those who provided moderate care for a spouse, reported significantly less difficulties with self-care than non-carers (0.3 in both instances compared to 0.5 for non-carers) (Figure 6-3). Similarly, those providing moderate to heavy care for a spouse, or light care for either a child, or parent or parent in-law reported significantly less difficulties associated with living independently in the community (Figure 6-4). It would seem, as perhaps would be expected, that good capacity to look after oneself is a prerequisite for caring for others.

Figure 6-4 Instrumental Activity of Daily Living score: 0 – 7 (high score = poor capability) (2004)

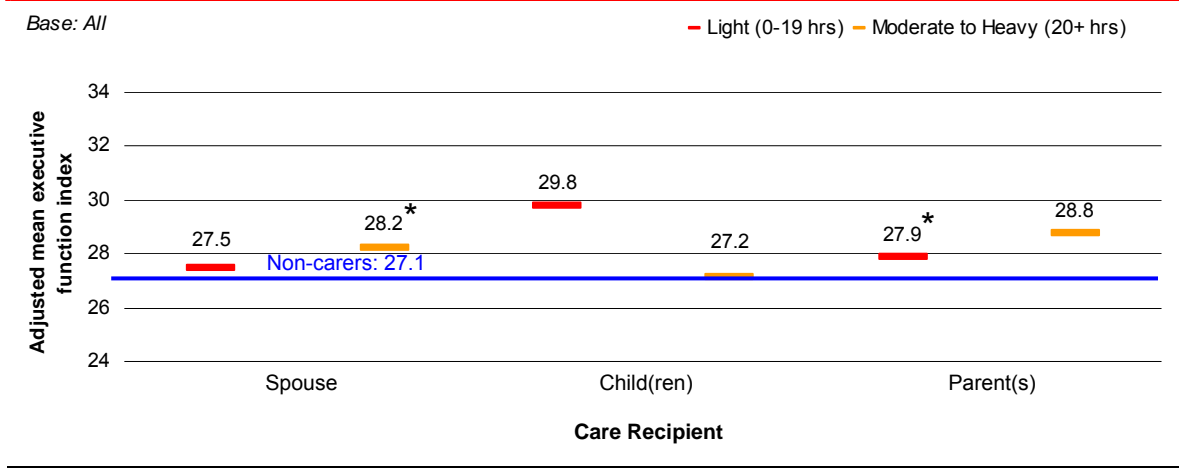


* Indicates a statistically significant difference from non-carers (significant at 5%)

To assess cognitive capability, individuals were asked to perform a number of memory and concentration tasks. Four tests, along with a subjective evaluation, were used to measure memory function, including orientation in time, word recall, and a measure of prospective memory (see Appendix A for full details of this measure). Again, scores were combined to form a memory index ranging from 0 to 30 (good memory function). There were no differences in overall performance between carers and non-carers.

The executive functioning²⁸ index was constructed from four tests covering verbal fluency, attention, visual search and mental speed, and is again measured on a scale from 0 – 30 (good cognitive function) (see Appendix A for full details of this measure). Generally carers perform better overall, although the difference is only statistically significant for those providing moderate to heavy care for a spouse, or light care for a parent or parent in-law (28.2 and 27.9 compared to 27.1 for non-carers) (Figure 6-5).²⁹

Figure 6-5 Executive function index: 0 – 30 (*high score = good cognitive function*) (2004)



* Indicates a statistically significant difference from non-carers (significant at 5%)

We also explored differences in upper body strength (hand grip strength), lower body strength (number of chair rises in a minute) and body mass index. However we found no differences between carers and non-carers.

²⁸ The term 'executive function' refers to a number of cognitive control processes, which include attention, initiation, set-shifting or mental flexibility, organisation, abstraction, planning and problem-solving.
²⁹ It is worth noting that these two groups are much larger in size than the others, which will contribute to the statistical significance.

6.2 Longitudinal analysis – changes in carer status from 2004 to 2006

Looking at changes to health over time we found some interesting results, some of which suggest a change in health may be associated with a change in care status. Self reported health remains consistent over the time period for all four care groups except those who move out of caring. This group sees a rise in the proportion reporting 'poor' health from 3.9 per cent to 7.0 per cent between 2004 and 2006. However, the differences between this group and non-carers is not significant in 2004, therefore we cannot be certain of this finding. Those who provide care at both time points report significantly better health than non-carers both in 2004 and 2006, although only the latter is statistically significant (Figure 6-6).

Among those who experience chronic pain, those who move out of a care role, and those who care at both time points report an increase in the experience of pain by 2006. On the other hand, those who move into caring report stability in the severity of pain they experience which is consistent with the level of pain reported by non-carers (Figure 6-9).

Those who move into a care role report a very similar level of difficulty with self-care (ADLs) as non-carers, which remains fairly low, and stable over the time period (Figure 6-7). They also report a similar level of stability in difficulties associated with living independently (IADLs), however in comparison, non-carers reported a significant increase in difficulties they experienced over time (Figure 6-10).

Those who move out of caring report an increase in the difficulties they experience for self-care and, to a lesser extent, tasks associated with independent living. Whereas those who remain carers throughout the time period report a significant decrease in the difficulties they experience with self-care relative to non-carers (Figure 6-7), however, at the same time they also report a similar level of increase in difficulties associated with living independently to non-carers (although this remains at a significantly lower level) (Figure 6-10).

There were very few, if any differences, in the cognitive ability of the care groups over time. The general experience was a slight decline in capability over the time period. Those who provided care at both time periods experienced a slightly steeper decline in their memory function, however this remained significantly higher than for non-carers (Figure 6-8).

Figure 6-6 Subjective general health (poor)

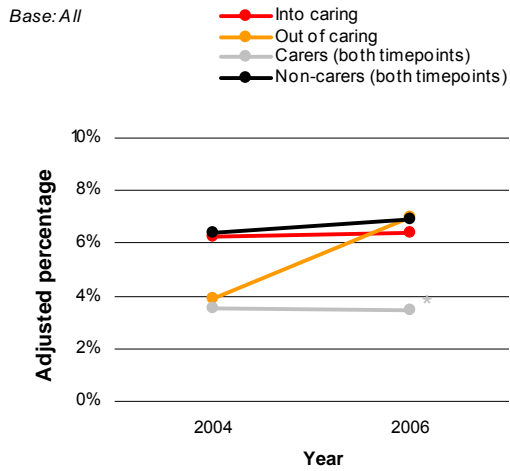


Figure 6-9 Severity of pain for those often troubled by pain

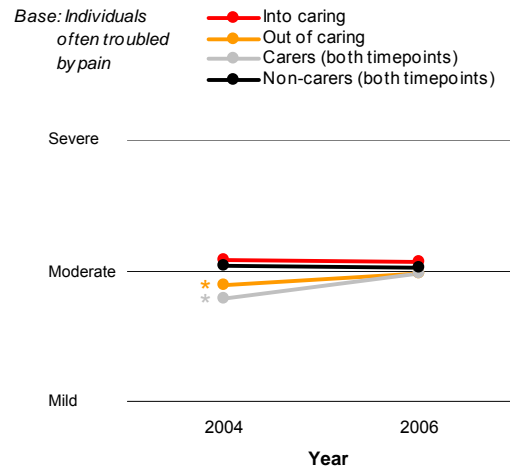


Figure 6-7 Activities of daily living score (0 – 6) (high score = poor capability)

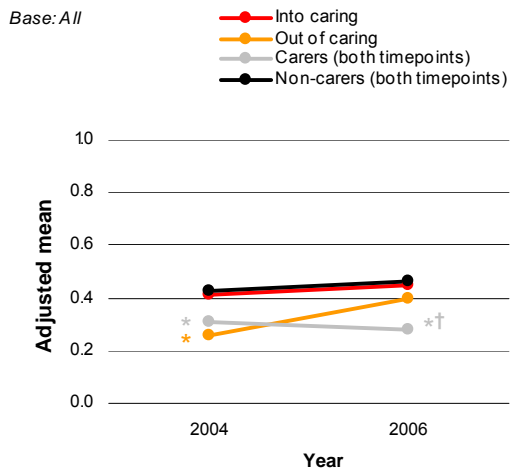


Figure 6-10 Instrumental activities of daily living score (0 – 7) (high score = poor capability)

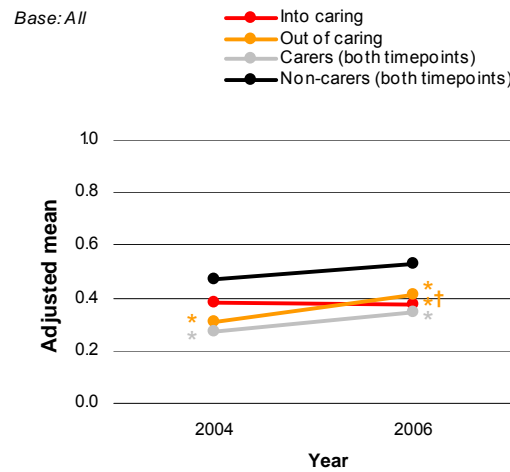


Figure 6-8 Memory function index (0 – 30) (high score = good memory function)

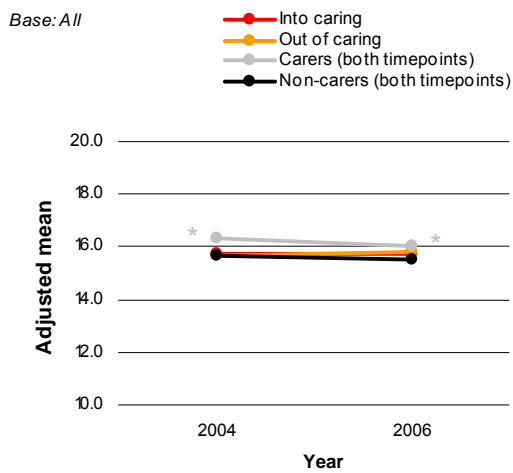
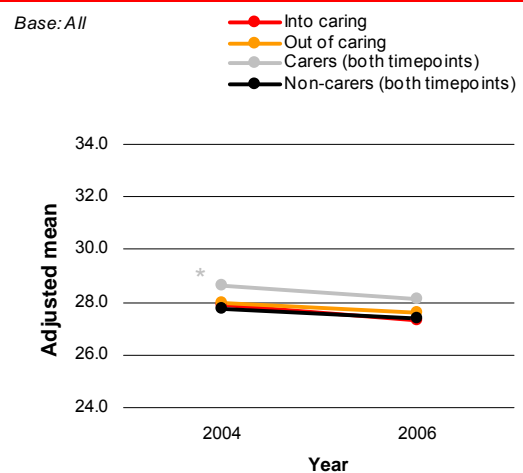


Figure 6-11 Executive function index (0 – 30) (high score = good cognitive function)



* Indicates a statistically significant difference from 'non-carers (both time points)' (significant at 5%)

† Indicates a statistically significant difference from 'non-carers (both time points)' in 2006 controlling for differences in 2004 (significant at 5%)

7 Housing

In this chapter we explore differences between carers and non-carers in relation to their housing experiences. First of all we compare their experiences in 2004, and distinguish between the type of care provided (whether to a spouse or partner³⁰, a dependent child with particular care needs or a parent or parent-in-law) and the level of care (up to 19 hours of personal care a week, or twenty hours plus).

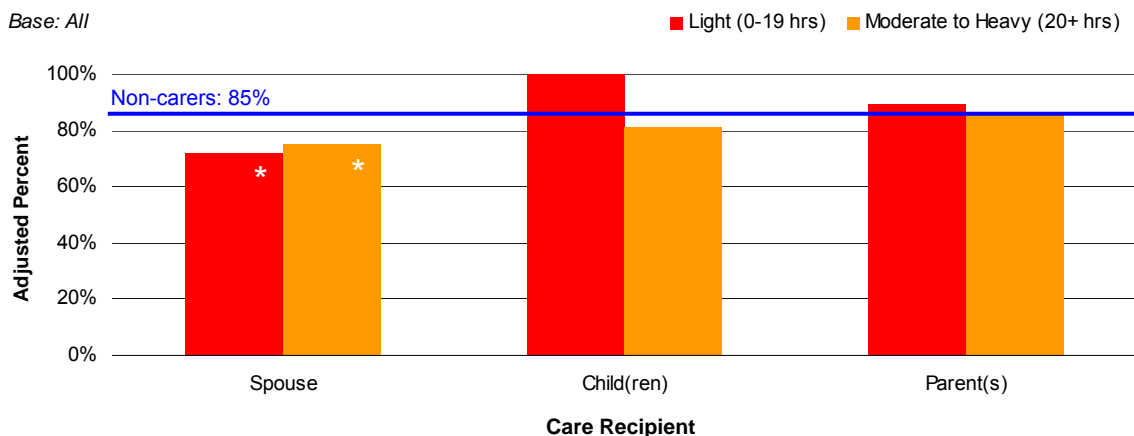
We then explore the extent to which their experiences change over time, including any change associated with a move into, or a move out of a care role. We achieve this by looking at the experiences of four different care groups, those who move into caring between 2004 and 2006, individuals who move out of a care role, those who remain carers at both time points, and individual who remain non-carers³¹. For further details on the analysis strategy used and how to interpret the results please refer to Section 1.3 in the introduction.

7.1 Comparative analysis – comparing carers and non-carers in 2004

In this chapter we compare the experiences of home ownership, the prevalence of housing adaptations we might associate with having a disability or being frail, and housing conditions.

Those who provided care for a spouse were significantly less likely to own their home than non-carers, 72 per cent and 75 per cent compared to 85 per cent of non-carers (Figure 7-1). There were no significant differences among other care groups.

Figure 7-1 Proportion of owner occupiers (2004)



* Indicates a statistically significant difference from non-carers (significant at 5%)

We explored whether individuals had made any special adaptations to their house. There are ten possible adaptations listed in ELSA (the full list of adaptations is reported in Appendix A). Using an

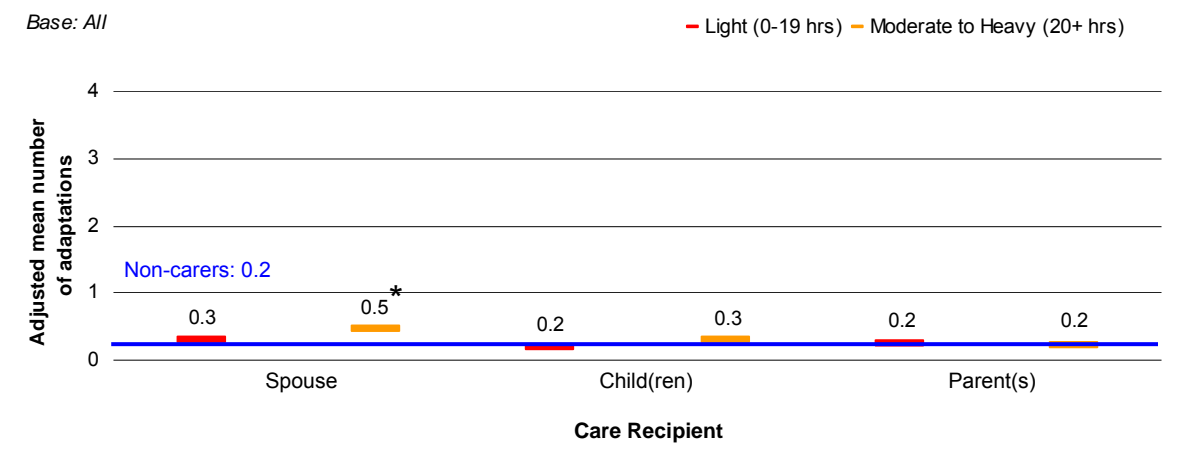
³⁰ Just 4 per cent were providing care to a partner, so for reasons of brevity both will be referred to as caring for a spouse

³¹ These four groups could also include individuals who change carer status more than once between 2004 and 2006.

Unfortunately ELSA does not allow us to identify these individuals

analytical technique³² designed to identify underlying structures in the data, we constructed two strands of adaptations, one associated with adaptations that might indicate disability (i.e. widening doors or fitting ramps) and another associated with adaptations that you might associate with being frail (i.e. hand rails or chair lifts). Given that these adaptations will be need driven, we also controlled for the carers reported level of physical mobility.

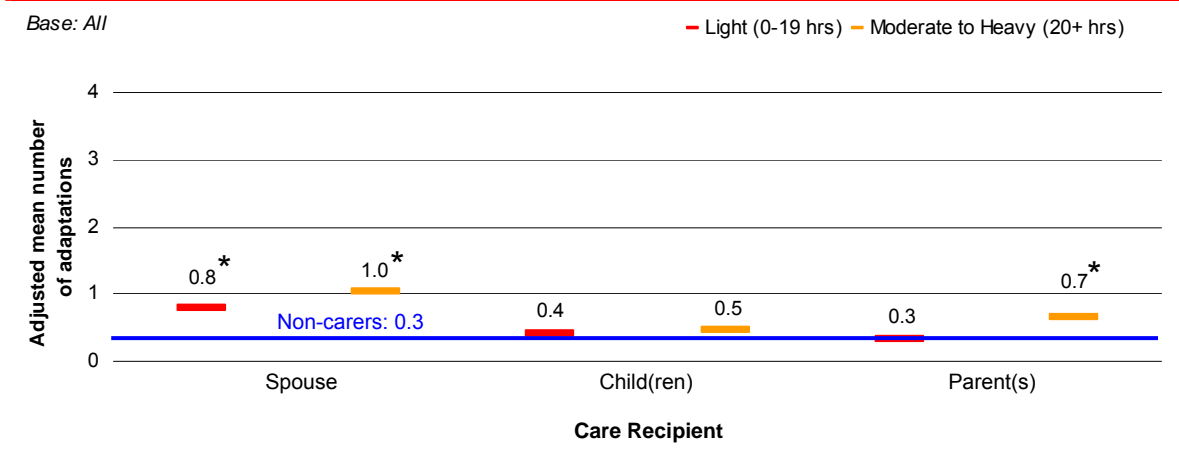
Figure 7-2 Number of housing adaptations: disability (0 – 6) (*adjusted for mobility*) (2004)



* Indicates a statistically significant difference from non-carers (significant at 5%)

Those who were providing moderate to heavy care for a spouse had had more housing adaptations associated with a disability, on average, than non-carers (0.5 compared to 0.2 for non-carers)³³ (Figure 7-2). The association with moderate or heavy care provision is perhaps expected given that someone with a disability is more likely to have a greater care need. However, there was no similar finding among the other care groups. Those who provided care to a spouse had had more housing adaptations on average associated with being frail, as did those individuals providing moderate to heavy care to a parent or parent-in-law (Figure 7-3).

Figure 7-3 Number of housing adaptations: frailty (0 – 4) (*adjusted for mobility*) (2004)



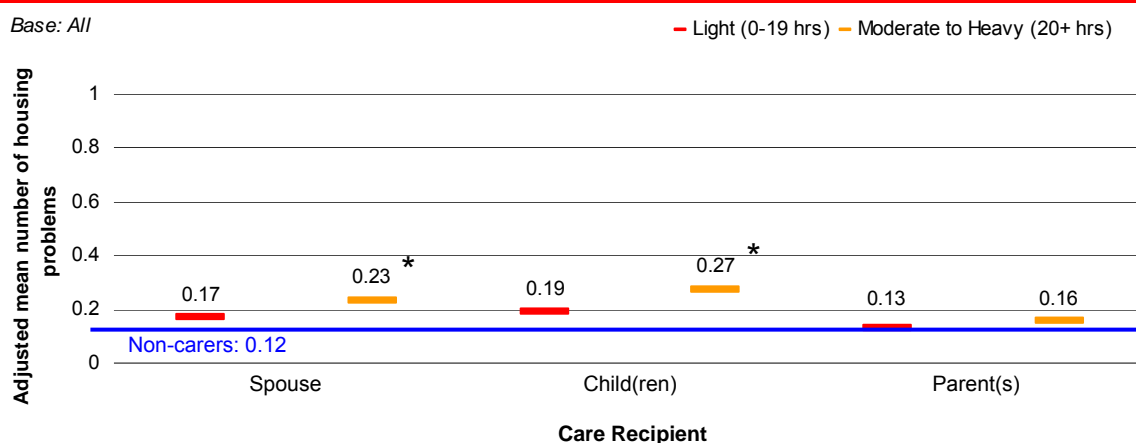
* Indicates a statistically significant difference from non-carers (significant at 5%)

³² We employed a factor analysis to identify these strands in the data. The technique works by identifying responses that, in the data, typically go together. So if an individual answers positively to one, then they are also more likely to answer positively to others in the same strand, suggesting a common underlying concept.

³³ Housing adaptations are fairly rare among the population which explains why the average number of adaptations is below one. We also adjusted for differences in the individuals own levels of physical mobility.

Individuals were also asked whether they had experienced a range of different accommodation problems, including noise from neighbours, rising damp, infestations etc. (for the full list of accommodation problems see Appendix A). Again, we used an analytical technique³² designed to identify underlying structures in the data in order to identify strands of problems which typically go together. We identified three strands, one which included lack of space, darkness and infestations, another associated with pollution (both noise and other environmental pollution) and a third strand associated with poor upkeep, for example rot and decay, wiring and plumbing problems.

Figure 7-4 Number of housing problems 1: *Lack of space, too dark, insects or vermin* (0 – 3) (2004)



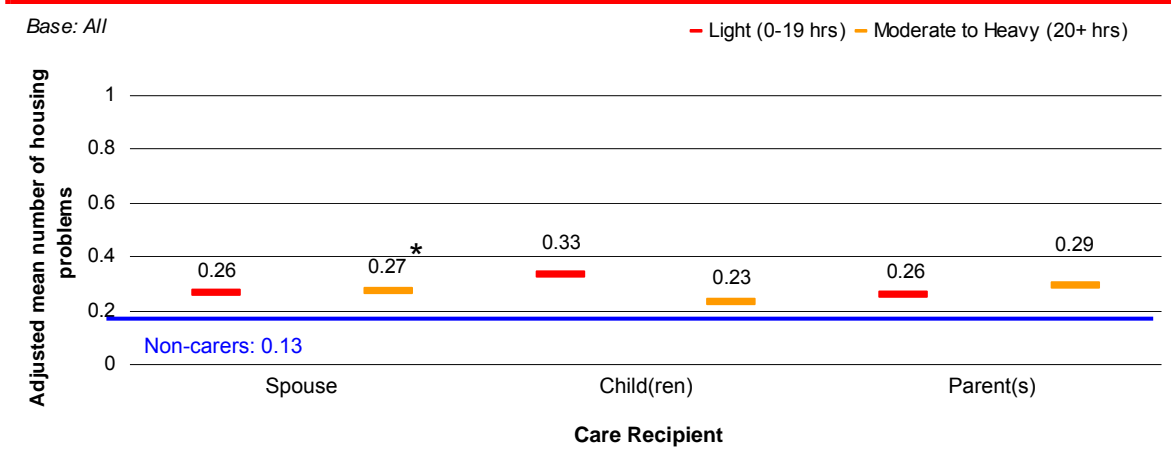
* Indicates a statistically significant difference from non-carers (significant at 5%)

All carers reported slightly more housing problems relating to lack of space, darkness and infestations, on average, than non-carers³⁴. However, the difference was only statistically significant for those who provided moderate or heavy care to a spouse or a child (0.23 and 0.27 compared to 0.12) (Figure 7-4). Similarly, all carers reported a slightly greater experience of pollution than non-carers, although only those who provided heavy care represented a statistically significant difference (0.27 compared to 0.13) (Figure 7-5).³⁵ There were no significant differences relating to accommodation problems associated with general upkeep.

³⁴ Housing problems are fairly rare among the population which explains why the average number of problems is below one. We also adjusted for differences in the individuals own levels of physical mobility.

³⁵ The figure is actually higher for those who provide light care to a child or moderate to heavy care for a parent or in-law. However as these were much smaller samples, it is more difficult to identify a statistically significant finding.

Figure 7-5 Number of housing problems 2: *noise from neighbours, street noise, pollution* (0 – 3) (2004)



* Indicates a statistically significant difference from non-carers (significant at 5%)

7.2 Longitudinal analysis – changes in carer status from 2004 to 2006

There are small fluctuations in the proportion of owner occupiers' between 2004 and 2006, the largest of which is a decrease among those moving into caring (from 78.9 per cent in 2004 to 76.7 per cent in 2006). It could be argued that patterns of ownership are therefore fairly stable over time. However, home ownership remains lower among those who move into caring, and those who remain carers at both time points. In 2006, 76.7 per cent of those who move into caring, and 79.6 per cent of those who remain carers own their own property compared to 85.1 per cent of non-carers (Figure 7-6).

Figure 7-7 shows significant differences in the average number of housing adaptations among the four care groups. Those who care at both time points are more likely to have housing adaptations that could be associated with having a disability, or frailty than non-carers. There is also a significant increase in the number of adaptations over time for this group compared to non-carers. A similar pattern exists for those who move into caring in relation to adaptations associated with frailty, although not in relation to disability. In addition, those who move out of caring are more likely than non carers (at both time points), to have both types of adaptations in 2004 and in 2006 (Figure 7-9).

Figure 7-8 illustrates an increase over time in the experience of housing problems relating to lack of space, darkness, and insects or vermin, for those moving into care relative to non-carers (at both time points). At the same time, the results suggest a decrease in the experience of these problems for those who move out of caring (the difference between this group and the non-carers group is statistically significant in 2004, but reduces, becoming non-significant in 2006). This is quite a novel finding but it is a difficult relationship to interpret. One possibility is that it relates specifically to experiencing a lack of space, with the change in care status associated with the care recipient moving into or out of the property. Further analysis would be needed to test this hypothesis. We found no significant differences relating to the other two strands of housing problems outlined above (Figure 7-10).

Figure 7-6 Owner occupier

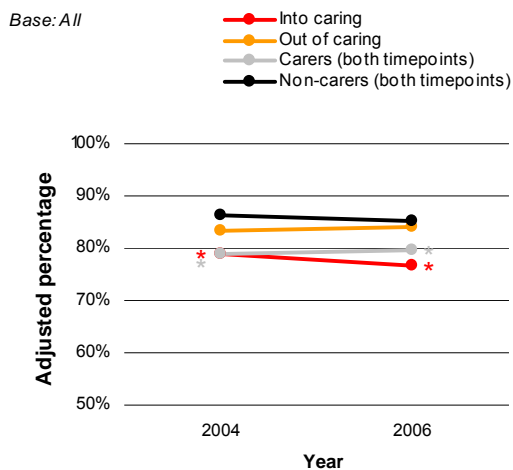


Figure 7-7 Number of housing adaptations: disability (0 – 6) (adjusted for mobility)

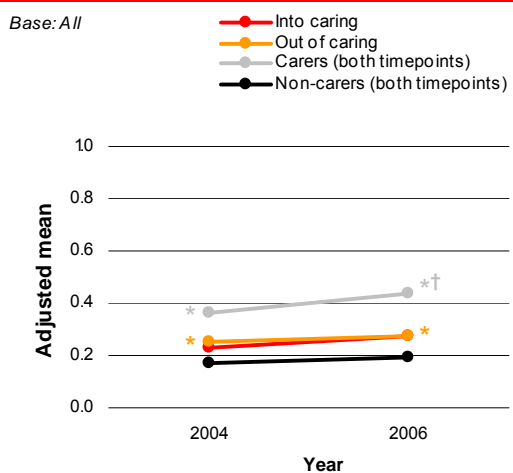


Figure 7-9 Number of housing adaptations: frailty (0 – 4) (adjusted for mobility)

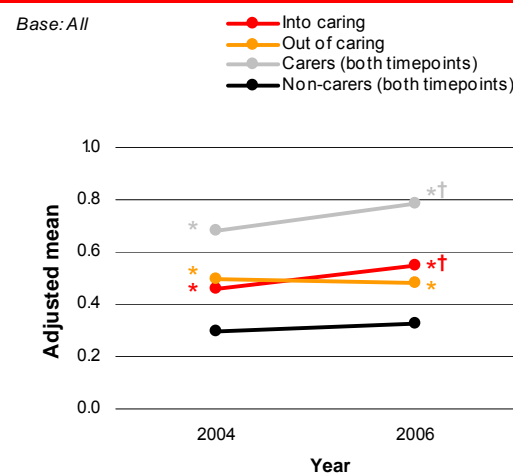


Figure 7-8 Number of housing problems 1: Lack of space, too dark, insects or vermin (0 – 3)

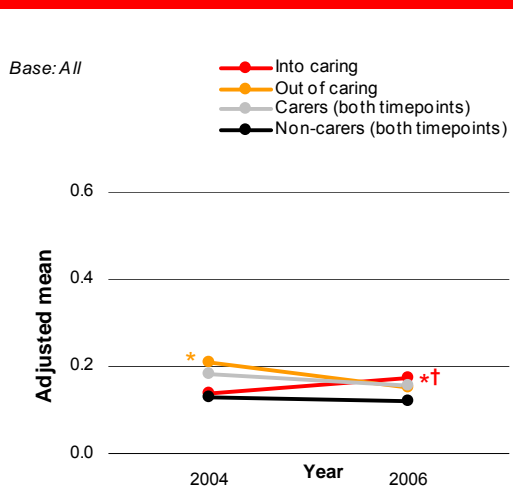
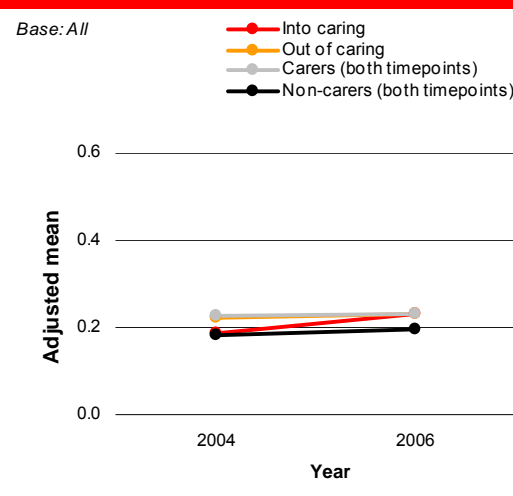


Figure 7-10 Number of housing problems 2: noisy neighbours, street noise, other pollution (0 – 3)



* Indicates a statistically significant difference from 'non-carers (both time points)' (significant at 5%)

† Indicates a statistically significant difference from 'non-carers (both time points)' in 2006 controlling for differences in 2004 (significant at 5%)

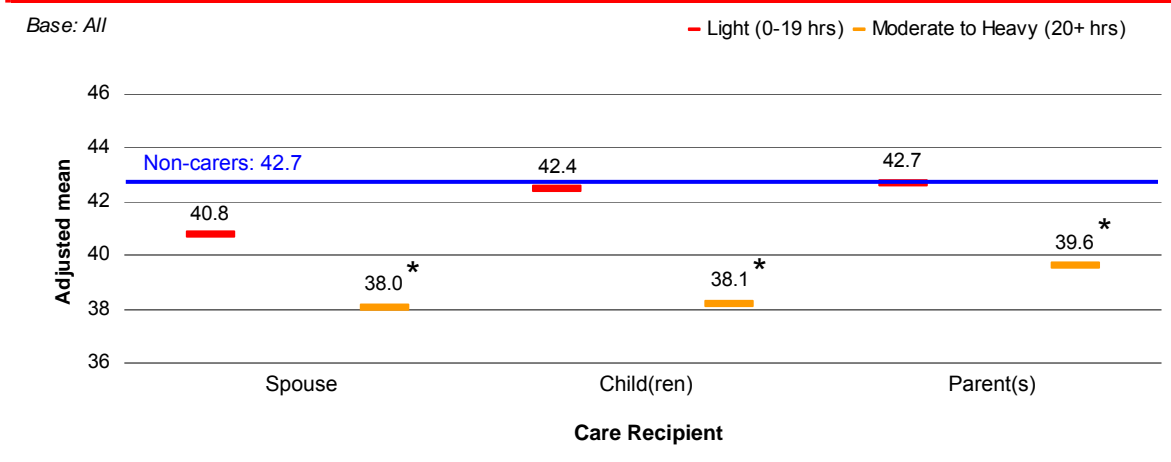
8 Quality of Life and the Policy Domains

In the previous five chapters we established some important differences between carers and non-carers across five key areas of policy. In this chapter, we seek to establish the importance of the factors measured in each of the five policy domains to the quality of life of the carer. In doing so we hope to illustrate where changes to the lives of carers could have the greatest impact on their well-being.

8.1 The quality of life measure (CASP 19)

The measure we used, CASP19, has been designed specifically for measuring the quality of life of older individuals. It is constructed from the responses to nineteen separate questions covering four domains which are considered integral to a persons' well-being. This includes feelings of being in 'control' and having 'autonomy' to pursue personal goals, as well as experiences relating to 'self-realisation' and 'pleasure'. The final measure is given as a score on a scale of 0 – 57, with a high score representing good quality of life. For further details of CASP19, key references and some of the issues involved in measuring quality of life please refer to the introduction.

Figure 8-1 Quality of Life CASP19 (2004)



* Indicates a statistically significant difference from non-carers (significant at 5%)

Figure 8-1 compares the quality of life of carers (measured using CASP19) against the quality of life of non-carers³⁶. There is a clear relationship between the provision of moderate to heavy levels of care and quality of life. Individuals who spend twenty or more hours a week providing informal care report lower levels of quality of life than non-carers, with little variation across caring type. In real terms this difference is relatively small (between 3.1 and 4.7 on a measure with a range of 0 – 57). However, if we consider that the majority of individuals (approximately two-thirds) have a CASP19 score between 33.5 and 51.4, then this small difference might be considered somewhat more significant.

³⁶ The results have been adjusted for differences in gender, age, marital status and level of education

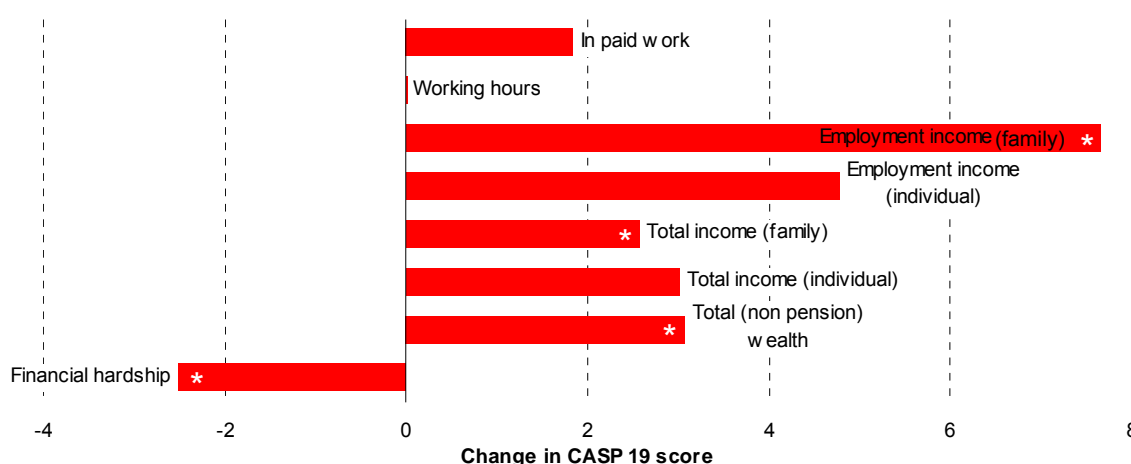
8.2 Quality of life and the policy domains

Our next step is to explore the importance of each factor measured within the five policy domains to the quality of life of carers. As with the longitudinal analysis, we were unable to distinguish between care type or care burden because of issues relating to sample size. The results presented below represent the average effects associated with *all* carers. We adjusted the analysis for gender, age, marital status, level of education, care type, number of care hours, number of people cared for and whether the person lives with a person they care for. Unless otherwise stated we have also adjusted for family income and level of physical mobility³⁷. In other instances, where stated, we have also adjusted for access to a car.

Figure 8-1to Figure 8-6 present the actual change in CASP19 score associated with a one unit change in the factor of interest by means of a bar. In many cases the bar simply represents the difference in CASP19 associated with the factors presence as opposed to it not being present. For example, the effect of having carried out paid work in the last month as against not having carried out any paid work. In other cases, such as with the measure of physical mobility, the reported effect represents the change in CASP19 associated with a single unit change in a score. In the case of physical mobility, the score has a total range of 0 – 10.

These figures are very useful for understanding the actual change in CASP19 associated with a change in, or the presence of a particular factor. However, because of the differences in measurement scale of the different factors, they cannot be used to compare the importance of each factor to the quality of life of carers. Figure 8-7 presents the standardised effects associated with each factor. The bars in this graph represent the relative strength of each factor on the carers' quality of life, and can be used as guide to identify which factors are the most important. Only those factors that had a statistically significant effect on quality of life are reported in this figure.

Figure 8-2 Quality of Life analysis: Income and Work (2004)



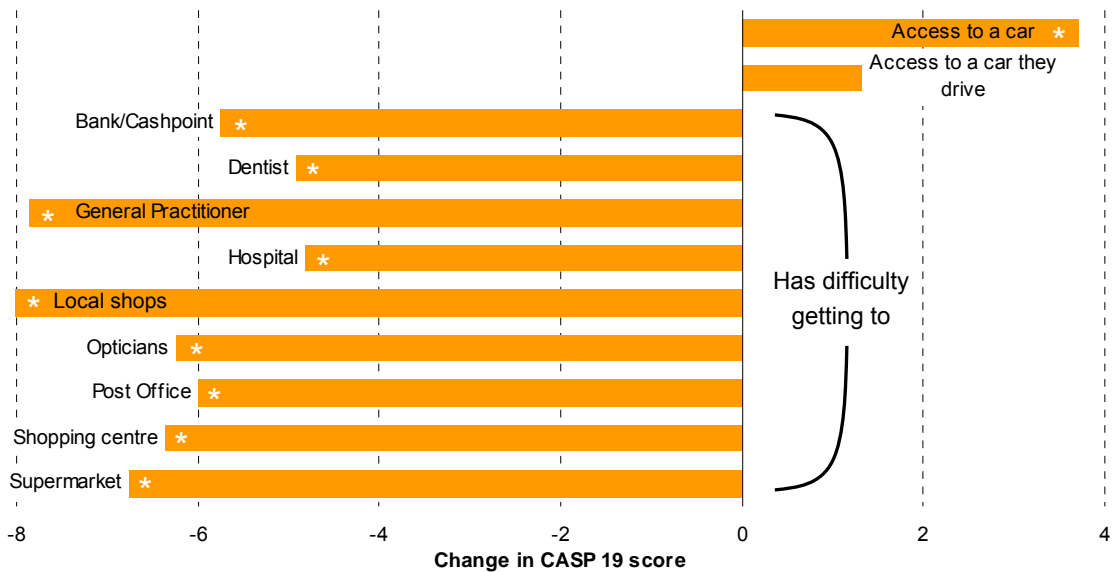
* Indicates a statistically significant effect (significant at 5%)

Note i: all measures of income excluded adjustments for family income

Note ii: a one unit change for all measures of income and wealth is difficult to interpret because it is on a logarithmic scale (see note 19 in chapter 3)

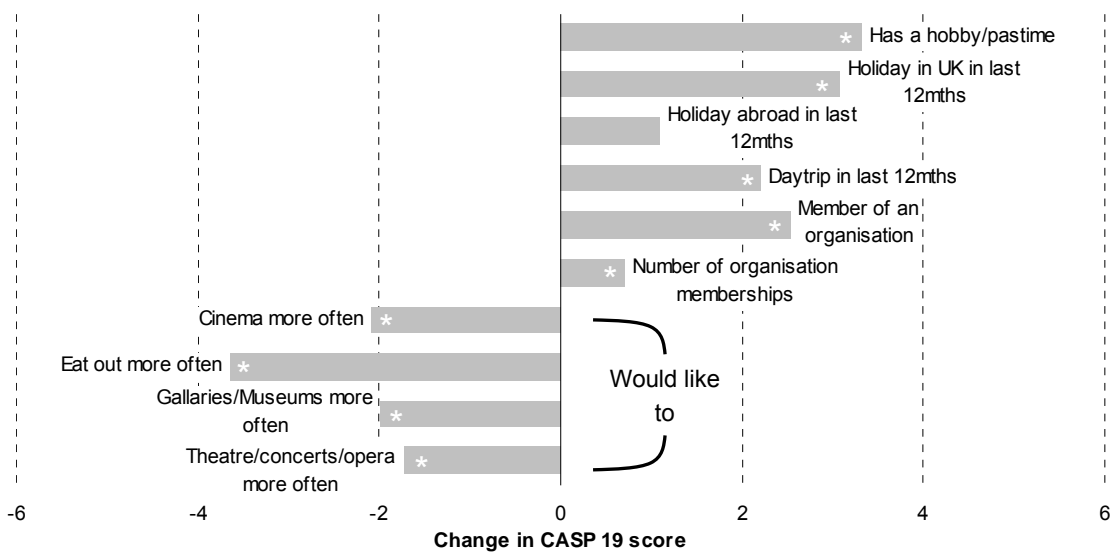
³⁷ Both are strongly related to quality of life, and are also associated with other factors that we are interested in measuring, for example engaging in paid work, and difficulty in getting to services. If we did not adjust for these measures we risk overestimating the relationship of these factors to a person's quality of life.

Figure 8-3 Quality of Life analysis: Mobility and Access to Services (2004)



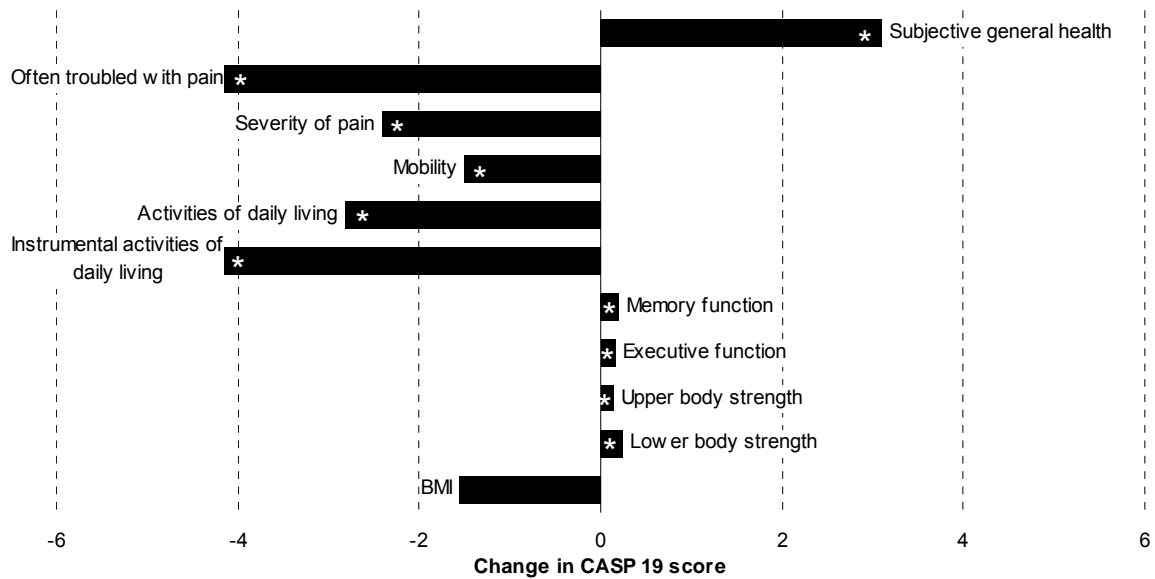
* Indicates a statistically significant effect (significant at 5%)
 Note: Has difficulty in getting to services included adjustments for car access

Figure 8-4 Quality of Life analysis: Leisure and Community activities (2004)



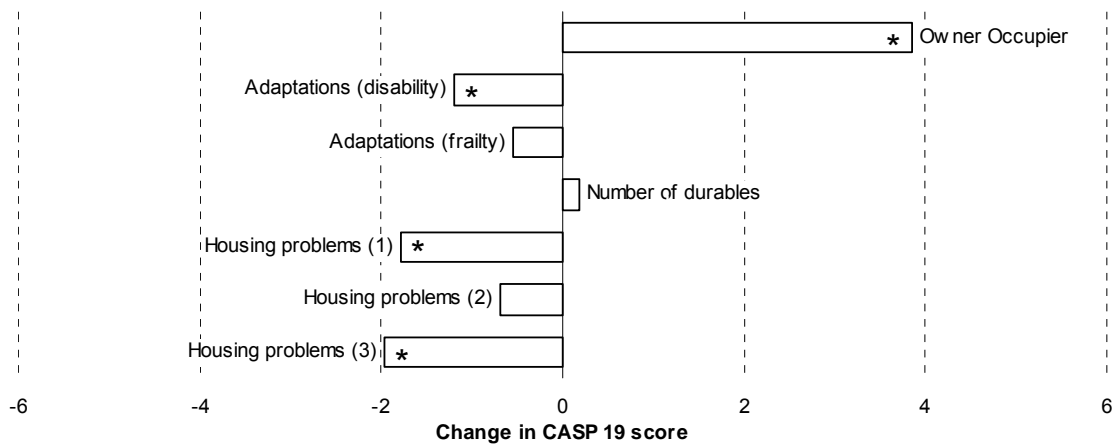
* Indicates a statistically significant effect (significant at 5%)
 Note: all measures included adjustment for car access

Figure 8-5 Quality of Life analysis: Health (2004)



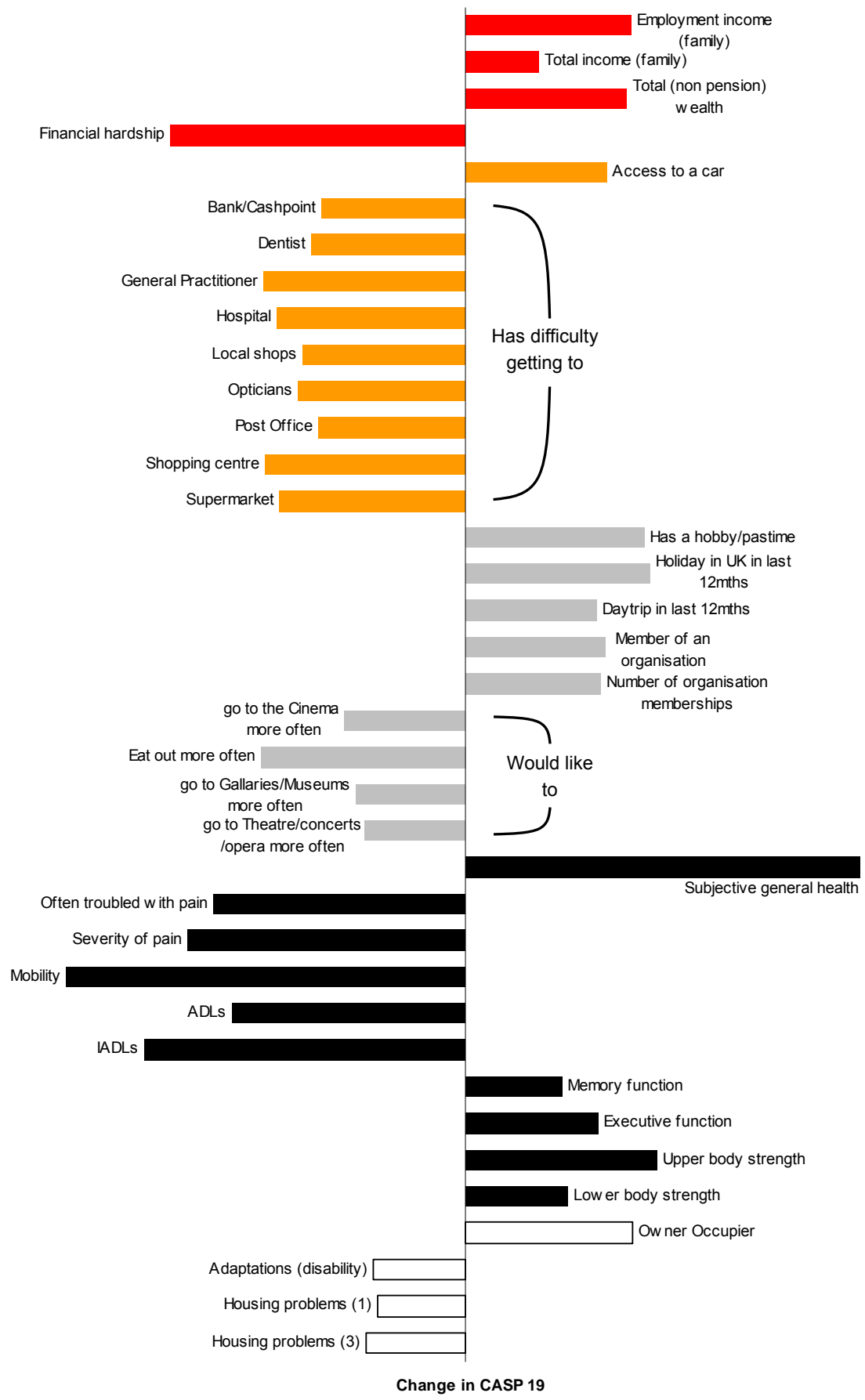
* Indicates a statistically significant effect (significant at 5%)
 Note: all measures of health excluded adjustment of physical mobility

Figure 8-6 Quality of Life analysis: Housing (2004)



* Indicates a statistically significant effect (significant at 5%)

Figure 8-7 Influences on Quality of Life analysis: all significant results (standardised) (2004)



Change in CASP 19

The greatest single effects on the quality of life of the carers are associated with subjective general health, and level of physical mobility (Figure 8-7). The strong effect between global measures of well-being (such as CASP19) and domain specific measures like subjective general health are well documented³⁸. In such cases it is difficult to untangle the direction of effect, i.e. does a higher quality of life lead to reporting a higher level of subjective health, regardless of actual health? As a more objective representation of health, level of physical mobility is perhaps the more useful measure. A single increase in the number of activities relating to physical mobility that the carer has difficulty performing (see Appendix A for a full list of assessed mobility activities) is associated with a decrease of 1.5 in their CASP19 score (Figure 8-5). There are similarly large effects associated with a number of other health measures. However, in a comparative analysis of health (chapter 6), the overall picture for carers is reasonably positive relative to non-carers. There were very few differences between the health of carers and non-carers, and where differences did exist they tended to show carers as healthier on average.

Reported financial hardship is also among the highest influences of quality of life in (Figure 8-7). Again, as with subjective general health there will be an association between CASP19 as a global measure of well-being, and financial hardship as a domain specific measure of well-being, that has nothing to do with the actual experience of financial hardship³⁹. However, along with the significant effects identified for family wealth and income, the results suggest that improvements to wealth do make a significant contribution to the quality of life of carers. Interestingly it is family income that is more important, especially family income from employment. Individual income is not statistically significant. As being in paid work and an increase in work hours are also non-significant, the results seem to suggest that it is the families work status and level of income that is important, rather than the individual carer. This point is doubly important when we consider that in four out of six cases, the average family earnings of carers were significantly lower than non-carers (Figure 3-3 in chapter 3).

Difficulty with getting to a number of services is also associated with carers' quality of life⁴⁰. Difficulty in getting to a doctor, a hospital, the local shops and supermarket appear to have the greatest influence, however the majority services are associated with a four to six point reduction in the quality of life score (Figure 8-3). Getting to these services was particularly problematic for those providing moderate to heavy care to a partner or spouse, or a parent or in-law, so further investigation into alleviating the obstacles that is making it so difficult would certainly benefit these carers lives.

Having a hobby or pastime, taking a holiday abroad and going on a day trip or outing are all important for quality of life, each of which are associated with a 2 to 3 point increase in the quality life score of carers (Figure 8-4). Likewise not being able to go to a number of places of recreation including the cinema, galleries and the theatre, or eating out as often as they would like to, are all associated with a reduction in quality of life. Chapter 5 demonstrates disparity in relation to leisure activities between carers and non-carers, particularly those caring for a spouse. Whilst we cannot be certain of a causal link, it certainly highlights the importance of respite services so that those providing care can take some time out to pursue activities important to quality of life

³⁸ Kahneman, D. Diener, E. and Schwarz, N. (1999) Well-being: The foundations of hedonic psychology, New York, Russell Sage Foundation

³⁹ Kahneman, D. Diener, E. and Schwarz, N. (1999) Well-being: The foundations of hedonic psychology, New York, Russell Sage Foundation

⁴⁰ In addition to the adjustment for physical mobility, we also adjusted for car access.

Finally, owning your own home is associated with positive quality of life, and experiences of housing problems have a small but negative influence on quality of life. Housing problems relating to the lack of space, the accommodation being too dark, and being infested with insects or vermin have been previously shown as more prevalent among those providing moderate to heavy care (Figure 8-7).

There is also a small negative association with housing adaptations that might be associated with disability. Despite the fact that adaptations are designed to alleviate difficulties associated with disability, such as widening doorways, or putting in ramps, this negative effect might stem from the underlying association of caring for someone with severe care needs (the carers own mobility problems have been adjusted for). It is a reminder that whilst we attempt to control for alternative factors that might otherwise explain the relationships we find, we cannot be certain that we have controlled for all important factors.

9 Quality of Life and the Cared for

In a separate, although complementary analysis, we explored how the characteristics of the person being cared for impacts upon the quality of life of the carer. In ELSA 2004, there were about 300 individuals who cared for a partner or spouse, for whom we have interview data for both the person providing the care, and the care receiver. This presents a unique opportunity to explore the relationship between the carers' well-being and the characteristics of their partner or spouse, including their health status, cognitive function and the level of care required.

Again CASP19 was used to measure quality of life, a measure designed specifically for measuring the quality of life of older individuals (for further details of the CASP19 measure please refer to the analysis strategy in the introduction). To capture the level of care required, we counted the number of tasks associated with self care that the person had reported difficulty in performing because of a health or memory problem⁴¹. This included, for example, dressing, showering and eating (also termed 'activities of daily living'). Similarly, we also counted the number of difficulties in performing tasks associated with independent living within a community such as preparing a hot meal, and managing money (also termed 'instrumental activities of daily living'). For a full list of tasks see appendix A.

The care recipient's level of health was measured using a standard subjective measure of general health for which respondents were asked to rate their health as excellent, very good, good, fair or poor. We also included a measure of whether the person had often suffered from severe levels of pain. Finally, two measures of cognitive capability were included, derived from their performance on a number of cognitive tests. Four tests, along with a subjective evaluation, were used to measure memory function, including orientation in time, word recall, and a measure of prospective memory. Scores were combined to form a memory index ranging from 0 to 30 (good memory function). In addition, we included a measure of executive functioning⁴², constructed from four tests covering verbal fluency, attention, visual search and mental speed, again measured on a scale from 0 – 30 (good cognitive function). See Appendix A for full details of these measures.

A regression analysis was conducted in five steps. First we explored the association between the level of care required and the carers' quality of life⁴³. We then included measures relating to the care recipients' health, and thirdly, added measures of the care recipients' cognitive capability. The reason we added the measures in stages like this is because of the issue of shared relationships. If two or more measures share something in common, which they also share with the carers' quality of life, including them both at the same time will mask this shared effect. Instead this effect will be absorbed by one measure alone. As we demonstrate below, including the variables in stages allows you to get a better understanding of these relationships.

In stage four we added further measures relating to the burden of care, including the number of care hours a person undertakes in a week, and the number of people they care for, to see whether this could explain any of the relationships found between the characteristics of a person being cared for and the carers' quality of life. Similarly, in a last step, we adjusted for a person's gender, age, level of education and family income.

⁴¹ Individuals were told to disregard any temporary difficulties expected to last less than 3 months

⁴² The term 'executive function' refers to a number of cognitive control processes, which include attention, initiation, set-shifting or mental flexibility, organisation, abstraction, planning and problem-solving.

⁴³ Linear regression analysis was used to model the effect of the characteristics of the care recipient on the quality of life of the carer. Please refer to the introduction for further details of the methodology used.

Table 9.1 Co-respondent analysis – step 1 (level of care need) (2004)

Characteristics of the persons being cared for	Regression coefficient	Standard error	Standardised regression coefficient	P-value
Activities of Daily Living	-0.205	0.404	-0.045	0.612
Instrumental Activities of Daily Living	-0.980	0.398	-0.206	0.015
Variance explained (R-square)				0.05

Table 9.1 shows the relationship between ‘Activities of Daily Living (ADL)’ and ‘Instrumental Activities of Daily Living (IADL)’ and the quality of life of the carer. The regression coefficient indicates the change in the CASP19 score (the quality of life of the carer) that is associated with one unit change in that particular characteristic of the care recipient. So, on average, for each additional task associated with living independently in the community (Instrumental Activities of Daily Living) which the care recipient has difficulty with, the carers CASP19 score drops by almost 1 unit.

As the measures used throughout this analysis are measured on different scales you cannot use the regression coefficient to compare the importance of different effects. For this purpose we have also included the standardised regression coefficient, which demonstrates the strength of the relationship: the larger the value (negative or positive) the stronger the relationship with the quality of life of the carer. The p-value indicates the statistical significance of an effect, as usual, a p-value of or smaller than 0.05 is considered statistically significant, and has also been highlighted in bold.

The results suggest that difficulties experienced with tasks associated with living independently have a significant impact on the quality of life of the carer. The more difficulties the person experiences, the worse the carers quality of life. The effect of tasks associated with self care (Activities of Daily Living) on the other hand is much smaller and non-significant. One reason for the non-significant effect of the tasks associated with self care is that an ability to perform both types of task rests on a common level of capability, and this common capability has been absorbed in the effect of the former measure. However, we can also draw another tentative conclusion from this result. Tasks associated with living independently in the community (Instrumental Activities of Daily Living) make greater demands on cognitive function than tasks associated with self-care (Activities of Daily Living). As will be demonstrated further below, the cognitive capability of the person being cared for appears to have the greatest impact on the quality of life of the person providing the care.

Table 9.2 Co-respondent analysis – step 2 (plus health measures) (2004)

Characteristics of the persons being cared for	Regression coefficient	Standard error	Standardised regression coefficient	P-value
Activities of Daily Living	-0.023	0.404	-0.005	0.954
Instrumental Activities of Daily Living	-0.825	0.403	-0.174	0.042
Subjective General Health	-1.114	0.644	-0.131	0.085
Often experiences severe pain	-1.178	1.610	-0.060	0.465
Variance explained				0.07

Table 9.2 demonstrates the effect of adding two indicators of health, subjective general health, and whether the person often experiences severe pain. Neither measure has a statistically significant impact on carers' quality of life. The IADL measure remains the only significant effect, and its strength is only slightly reduced by the addition of these two measures.

Table 9.3 Co-respondent analysis – step 3 (plus cognitive measures) (2004)

Characteristics of the persons being cared for	Regression coefficient	Standard error	Standardised regression coefficient	P-value
Activities of Daily Living	-0.278	0.401	-0.061	0.490
Instrumental Activities of Daily Living	-0.310	0.472	-0.065	0.513
Subjective General Health	-0.824	0.632	-0.097	0.193
Often experiences severe pain	-1.197	1.561	-0.061	0.444
Memory function	0.445	0.153	0.246	0.004
Executive function	-0.011	0.092	-0.010	0.904
Variance explained				0.11

In a third step (table 9.3) we introduced measures of memory and executive function. The effect of introducing these two measures is the reduction of the previous effect associated with Instrumental Activities of Daily Living, which becomes non-significant. It appears that a shared cognitive effect between IADLs and memory function is being absorbed by the latter. A one unit improvement in care recipients' memory function is associated with almost half a point increase, on average, in the quality of life of the carer. Considering the measurement scale of memory function is 0 – 30, this represents quite a reasonable effect.

Interestingly care recipients' executive function has no discernable effect at all on the quality of life of carers. Again, there is a reasonable level of shared cognitive ability required to perform tests for both tasks. However the results suggest that it is not so much the broader cognitive ability, but the memory of the care recipient, which is most important for the quality of life of the carer.

Table 9.4 Co-respondent analysis – step 4 (plus measures of care burden) (2004)

Characteristics of the persons being cared for	Regression coefficient	Standard error	Standardised regression coefficient	P-value
Activities of Daily Living	-0.312	0.407	-0.068	0.445
Instrumental Activities of Daily Living	-0.251	0.510	-0.053	0.623
Subjective General Health	-0.752	0.636	-0.088	0.238
Often experiences severe pain	-1.191	1.559	-0.061	0.446
Memory function	0.443	0.152	0.245	0.004
Executive function	-0.013	0.092	-0.012	0.891
Variance explained				0.12

In steps four and five we adjusted the findings, first for additional measures associated with the burden of care (number of care hours, number of care recipients), and then, in addition, for measures of social demographic background (gender, age, education, and family income). It is possible that looking after someone with a poorer memory function requires many more care hours per week, and it is this extra burden of care that explains the relationship of memory with the quality of life of the carer

Table 9.5 Co-respondent analysis – step 5 (social demographic measures) (2004)

Characteristics of the persons being cared for	Regression coefficient	Standard error	Standardised regression coefficient	P-value
Activities of Daily Living	-0.303	0.410	-0.066	0.461
Instrumental Activities of Daily Living	-0.284	0.493	-0.058	0.564
Subjective General Health	0.586	0.602	0.067	0.331
Often experiences severe pain	-1.015	1.524	-0.052	0.506
Memory function	0.437	0.155	0.240	0.005
Executive function	-0.050	0.088	-0.044	0.568
Variance explained				0.16

However, as table 9.4 and 9.5 demonstrate, the adjustments had no real discernable effect on the influence of the care recipients' memory function. To explain this effect we might be immediately drawn to the notion of memory malfunction as a sign of Dementia or Alzheimer's. Clearly, we would expect Dementia and Alzheimer's to have a serious effect on a carers' quality of life. However, respondents were also asked whether they had been diagnosed with Dementia or Alzheimer's and only a very small number of the care recipients we looked at reported a diagnosis with one or the other. Hence, we cannot conclude directly that the strong influence of memory function is caused by either of these two conditions. In addition, all the recipients of care who were included in our analysis were able to respond to the survey questions themselves without the help of a proxy. After the full onset of Dementia or Alzheimer's, it is very unlikely they would be able to take part in a survey like ELSA.

However, it is of course possible that what we are seeing are the very early stages of Dementia or Alzheimer's where the care recipient hasn't yet been diagnosed. It would be quite understandable

why memory has such an effect on the well-being of carers, just because living with a partner who shows such symptoms can be very burdensome and worrying, but also because carers fear that their partner might be diagnosed with either Dementia or Alzheimer's at some point in the near future.

Although tentative, these concluding findings point to some important issues to do with carers and the people they care for. These findings provide a backdrop of detailed evidence which we hope will stimulate debate. The findings are discussed in an associated volume that looks at possible implications for future policy.

10 Appendix A: Measures

Defining carers in ELSA

Did you do any of these activities during the last month, that is since [date a month ago]?

IF YES, PROBE: Which ones?

CODE ALL THAT APPLY.

- 1 Paid work
- 2 Self-employment
- 3 Voluntary work
- 4 Cared for someone
- 5 Looked after home or family
- 6 Attended a formal educational or training course
- 96 None of these

Individuals reporting that they had 'Cared for someone' during the last month were then routed to the following question:

Did you look after anyone in the past week (including your partner or other people in your household)?

INTERVIEWER: By 'look after' we mean the active provision of care.

- 1 Yes
- 2 No

Subjective questions relating to employment

Here are some statements people might use to describe their work. We would like to know how strongly you think that these apply to the paid employment you did in the last month.

Respondents were asked whether they strongly agreed, agreed, disagreed or strongly disagreed with the following statements:

- All things considered I am satisfied with my job
- My job is physically demanding
- I receive the recognition I think I deserve for my work
- My salary is adequate
- My job prospects are poor
- My job security is poor
- I am under constant time pressure due to a heavy work load
- I have very little freedom to decide how I do my work
- I have the opportunity to develop new skills
- I receive adequate support in difficult situations
- At work, I feel I have control over what happens in most situations
- Considering the things I have to do at work, I have to work very fast

Measuring Physical Mobility

We need to understand difficulties people may have with various activities because of a health or physical problem. Please tell me whether you have any difficulty doing each of the everyday activities on this card. Exclude any difficulties that you expect to last less than three months.

Because of a health problem, do you have difficulty doing any of the activities on this card?

PROBE : What others? CODE ALL THAT APPLY

- 1 Walking 100 yards
- 2 Sitting for about two hours
- 3 Getting up from a chair after sitting for long periods
- 4 Climbing several flights of stairs without resting
- 5 Climbing one flight of stairs without resting
- 6 Stooping, kneeling, or crouching
- 7 Reaching or extending your arms above shoulder level
- 8 Pulling or pushing large objects like a living room chair
- 9 Lifting or carrying weights over 10 pounds, like a heavy bag of groceries
- 10 Picking up a 5p coin from a table
- 96 None of these [Exclusive code]

Measuring Activities of Daily Living

Here are a few more everyday activities. Please tell me if you have any difficulty with these because of a physical, mental, emotional or memory problem. Again exclude any difficulties you expect to last less than three months.

Because of a health or memory problem, do you have difficulty doing any of the activities on this card?

PROBE : What others? CODE ALL THAT APPLY

Activities of Daily Living

- 1 Dressing, including putting on shoes and socks
- 2 Walking across a room
- 3 Bathing or showering
- 4 Eating, such as cutting up your food
- 5 Getting in or out of bed
- 6 Using the toilet, including getting up or down

Instrumental Activities of Daily Living

- 7 Using a map to figure out how to get around in a strange place
- 8 Preparing a hot meal
- 9 Shopping for groceries
- 10 Making telephone calls
- 11 Taking medications
- 12 Doing work around the house or garden
- 13 Managing money, such as paying bills and keeping track of expenses
- 96 None of these [Exclusive code]

Measuring Memory Function

The memory function index was constructed from five different components or tests assessing different aspects of memory. The first component was 'Self rated memory' where the participant was asked to rate their memory as excellent, very good, good, fair or poor. The second component assessed orientation in time by asking questions about the date (day, month, year) and the day of the week. The third and fourth component involved word recall: Ten common words were presented aurally and participants were asked to remember them. Word recall was tested both immediately and after a short delay filled with other cognitive tests. Finally, prospective memory was tested. The participant was informed about two actions that they would be asked to carry out at an appropriate later time by the interviewer. The memory index combines all the scores on the objective memory tests and has a range of possible scores from 0 to 30.

Measuring Executive Function

The executive functioning index covers verbal fluency, attention, visual search and mental speed. This index is derived from four components, the first of which was a word-finding task asking the participants to name as many animals as they could think of in one minute. The second test was a letter cancellation task. It tested how many target letters (P and W) the participant could cross out in a page of random letters of the alphabet set out in rows and columns in one minute. The last test was a test of numerical ability. Here, the participant was asked to solve problems requiring simple mental calculations based on real-life situations. The executive function index combines all the scores on the other cognitive tests and also has a range of possible scores from 0 to 30.

Measuring Housing Adaptations

Some homes have special features to assist people who have physical impairments or health problems. Whether you use them or not, does your home have any of the features on this card?

PROBE: What others?

CODE ALL THAT APPLY

Adaptations that might be associated with having a disability:

- 1 Widened doorways or hallways
- 2 Ramps or street level entrances
- 4 Automatic or easy open doors
- 5 Accessible parking or drop off site
- 8 Lift
- 10 Alerting devices, such as button alarms

Adaptations that might be associated with being frail:

- 3 Hand rails
- 6 Bathroom modifications
- 7 Kitchen modifications
- 9 Chair lift or stair glide

95 Any other special features

96 None of these [Exclusive code]

Measuring Housing Problems

Does your accommodation have any of these problems?

PROBE: What others?

CODE ALL THAT APPLY

Housing problems (1)

- 1 Shortage of space
- 4 Too dark, not enough light
- 11 Problems with insects, mice or rats

Housing problems (2)

- 2 Noise from neighbours
- 3 Other street noise, such as traffic, businesses, factories
- 5 Pollution, grime or other environmental problems caused by traffic or industry

Housing problems (3)

- 6 Rising damp in floors and walls
- 7 Water getting in from roof, gutters or windows
- 8 Bad condensation problem
- 9 Problems with electrical wiring or plumbing"
- 10 General rot and decay
- 12 Too cold in winter

95 Other problems

96 None of these [Exclusive code]

Measuring Quality of Life (CASP19)

CASP19

Here is a list of statements that people have used to describe their lives or how they feel.

How often, do you feel like this?

Tick one box on each line (Often, Sometimes, Not Often, Never)

My age prevents me from doing the things I would like to

I feel that what happens to me is out of my control

I feel free to plan for the future

I feel left out of things

I can do the things that I want to do

Family responsibilities prevent me from doing what I want to do

I feel that I can please myself what I do

My health stops me from doing things I want to do

Shortage of money stops me from doing the things I want to do

I look forward to each day

I feel that my life has meaning

I enjoy the things that I do

I enjoy being in the company of others

On balance, I look back on my life with a sense of happiness
I feel full of energy these days
I choose to do things that I have never done before
I feel satisfied with the way my life has turned out
I feel that life is full of opportunities
I feel that the future looks good for me



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