



Caring in the Older Population

A Research Brief for Local Authorities

January 2009

ILC-UK

www.ilcuk.org.uk

Founded in 2000 as the International Longevity Centre – UK, the ILC-UK is an independent, non-partisan think-tank dedicated to addressing issues of longevity, ageing and population change. It develops ideas, undertakes research and creates a forum for debate.

The ILC-UK is a registered charity (no. 1080496) incorporated with limited liability in England and Wales (company no. 3798902).

ILC-UK
11 Tufton Street
Westminster
London
SW1P 3QB
Tel: +44 (0)207 340 0440
www.ilcuk.org.uk

This research brief was first published in January 2009.

© ILC-UK 2009

This brief was prepared by James Lloyd of the ILC-UK

jameslloyd@ilcuk.org.uk

About this Research Brief

- This document is for local authorities engaged in developing, planning and delivering services to support older carers.
- The document summarises research published by the ILC-UK and the National Centre for Social Research (NatCen) called *Living and Caring? An Investigation of the Experience of Older Carers*. This research used quantitative statistical analysis to explore differences in the lives of carers and non-carers within the 50+ population. The full report of the *Living and Caring?* research can be downloaded from the website of the ILC-UK.¹

Acknowledgements

The analysis for *Living and Caring? An Investigation of the Experience of Older Carers* was undertaken by Andy Ross, Michael Weinhardt and Hayley Cheshire of NatCen.

This research brief and the research it describes would not have been possible without the generous support of the Nuffield Foundation. The Nuffield Foundation is a charitable trust established by Lord Nuffield. Its widest charitable object is 'the advancement of social well-being'. The Foundation has long had an interest in social welfare and has supported this project to stimulate public discussion and policy development. The views expressed are however those of the author and not necessarily those of the Foundation.

Living and Caring? used data from the *English Longitudinal Study of Ageing* (ELSA), which is a biennial longitudinal survey of a representative sample of around 10,000 individuals aged 50+ in England and Wales, and one of the newest UK surveys providing data that can be generalised to population level. The data analysed in this research was made available through the UK Data Archive (UKDA). ELSA was developed by a team of researchers based at the National Centre for Social Research, University College London and the Institute for Fiscal Studies. The data were collected by the National Centre for Social Research. The funding is provided by the National Institute of Aging in the United States, and a consortium of UK government departments co-ordinated by the Office for National Statistics. The developers and funders of ELSA and the Archive do not bear any responsibility for the analyses or interpretations presented here.

Key Points

- Older carers vary enormously in their age and socioeconomic profile, and in their experience of caring, depending on whom they provide care for and the volume of care provided.
- Spousal carers are typically older, poorer, provide a larger volume of care and experience poorer outcomes than, for example, older carers providing care for a parent.
- Older carers providing moderate to heavy volumes of care (20+ hours per week) report a significantly lower quality of life than comparable non-carers.
- Far more than any other characteristic or impairment, it is the memory functioning of the person receiving care that is most associated with variations in the quality of life of older carers. This suggests that caring for someone with poor memory functioning has a significant effect on the quality of life of an older carer.
- Various factors were found to be associated with variations in the quality of life of older carers. In particular, although few differences in the health of older carers compared to non-carers were found, variations in health status appear to have a stronger association with quality of life than any other factor, underlining the importance of health services to supporting older carers.
- Besides health status, financial hardship and access to medical services were strongly associated with variations in quality of life for older carers.
- Comparing the lives of carers and non-carers, it was found that providers of moderate to heavy care have more difficulty accessing health services and local shops.
- Older carers are more likely than non-carers to wish that they could go to the cinema more often, suggesting that caring responsibilities do constrain aspirations to participate in leisure activities. Spousal carers are less likely to have holidayed in the UK or abroad than non-carers.

Background

Why is caring among the older population on the agenda? 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 compared with 1.2 million in 2006 and around 0.6 million in 1981. 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 increase from 2.3 million in 2002 to 4 million in 2031.ⁱⁱ
- It is widely projected that the majority of long-term care will continue to be provided as unpaid care. 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.ⁱⁱⁱ
- The importance of unpaid carers to the provision of care and support within communities has been increasingly recognised over the last decade. In 2008, the Government published a new carers' strategy,^{iv} which includes commitments to support carer breaks, the piloting of annual health checks for carers and better training for GPs in supporting carers.
- This research brief summarises research published by the ILC-UK and NatCen called *Living and Caring? An Investigation of the Experience of Older Carers*.^v
- *Living and Caring?* used the English Longitudinal Study of Ageing (ELSA) to explore the effect of care provision on the lives of people aged 50+. ELSA provides an excellent resource to study the effect of care provision on the 50+ population since it

contains questions to identify individuals providing care as well a broad range of multi-dimensional variables relating to income, well-being, housing and leisure, etc.

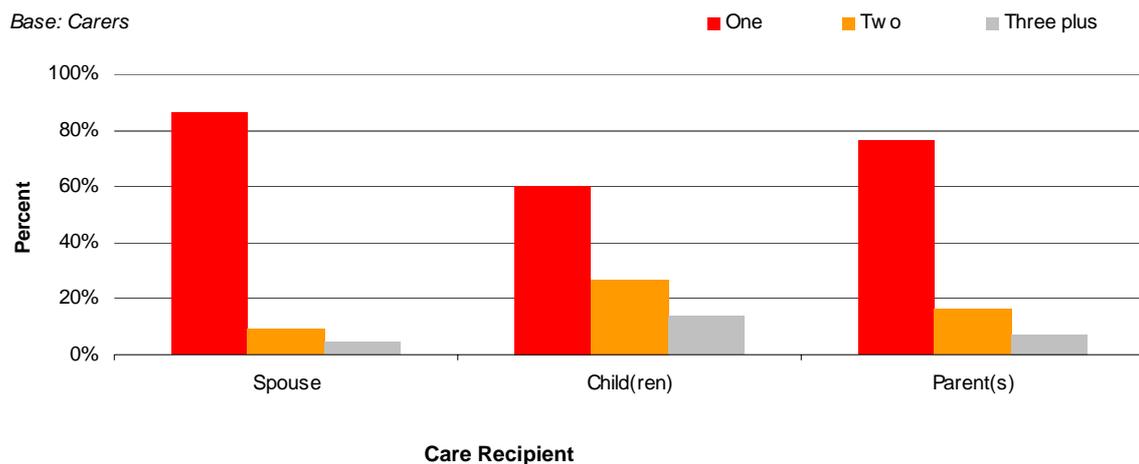
- *Living and Caring?* compared the outcomes older carers and non-carers in different domains directly relevant to local authority policy and service design. The research, which principally used data gathered in 2004, also analysed differences among sub-groups of carers. It distinguished between the *locus* of care, i.e. care for a spouse, for a parent or for an adult child (i.e. not 'childcare'). The research also distinguished carers by the *burden* of care (more than or less than 20 hours of care per week; *light* or *moderate to heavy* care). The analysis controlled for the effects of gender, age, marital status and education, to ensure that differences in these characteristics were not causing the differences between carers and non-carers on the particular factor being examined, e.g. differences in physical mobility might otherwise be explained by differences in age between carers and non-carers.

The Characteristics of Care Provision

Who are older carers? How much care do they provide and who for?

- The most important reason that older carers cite for the provision of care is that “they are needed”. Significant minorities of older carers also cite feeling obliged, wanting to be useful and enjoyment as reasons for providing care.
- The characteristics of carers in the 50+ population vary significantly: by who they care for, their age, gender, social group and the volume of care provided.
- Around 10% of individuals aged 52* and above were providing some form of unpaid care in the year 2004.
- Of these, 39% cared for a spouse or partner, 11% cared for an (adult) child with specific care needs, 34% cared for their parent(s) or parent(s) in law, and 24% for another category of person (and hence were not included in the *Living and Caring?* study). However, individuals frequently care for more than one person:

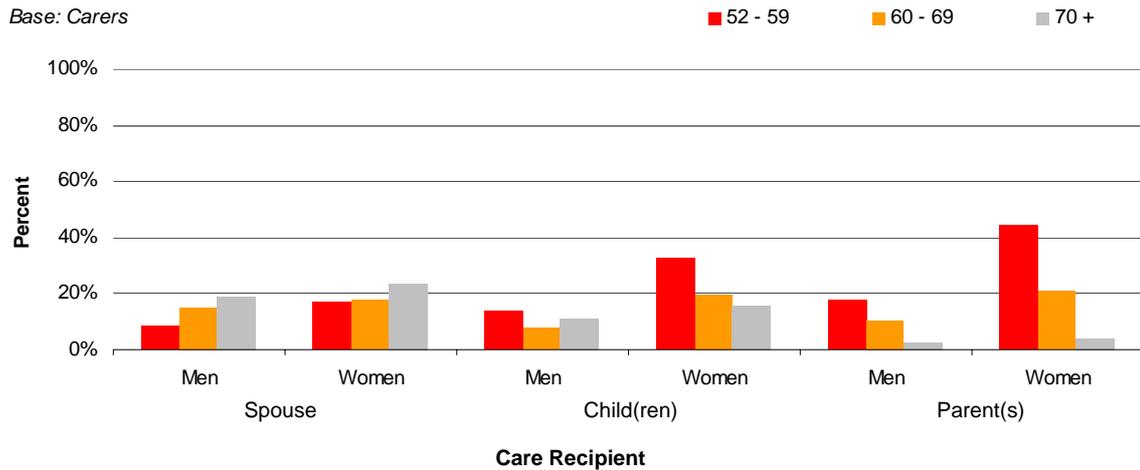
Total number of people cared for by principal care recipient (2004)



- Care provision varies by age, gender and the recipient of care. Women are consistently more likely than men to be carers, and the prevalence of unpaid care declines with age, except for spousal care, the prevalence of which increases with age:

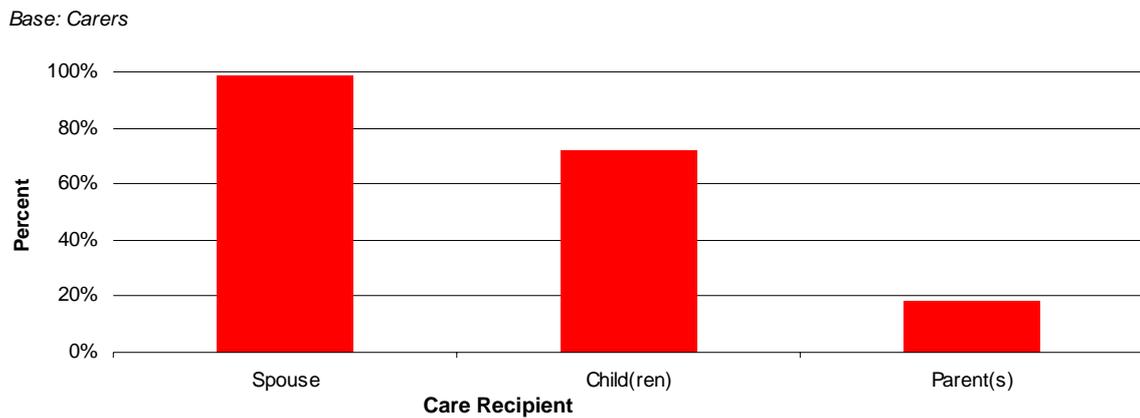
* Data collection for ELSA began in 2002 when survey members were aged 50 or over, data reported for 2004 therefore represents individuals aged 52 and over.

Age and gender of carers by care recipient (2004)



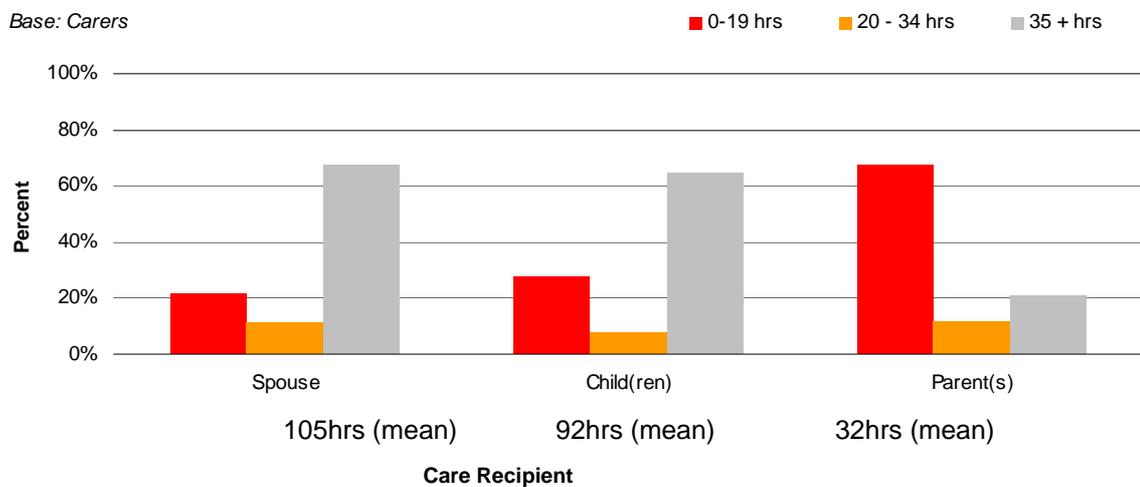
- Relatively few carers providing care to a parent or parent in law live with the person they care for. In contrast, most individuals providing care to a spouse or child do live with the person they care for:

Lived with someone they care for (2004)



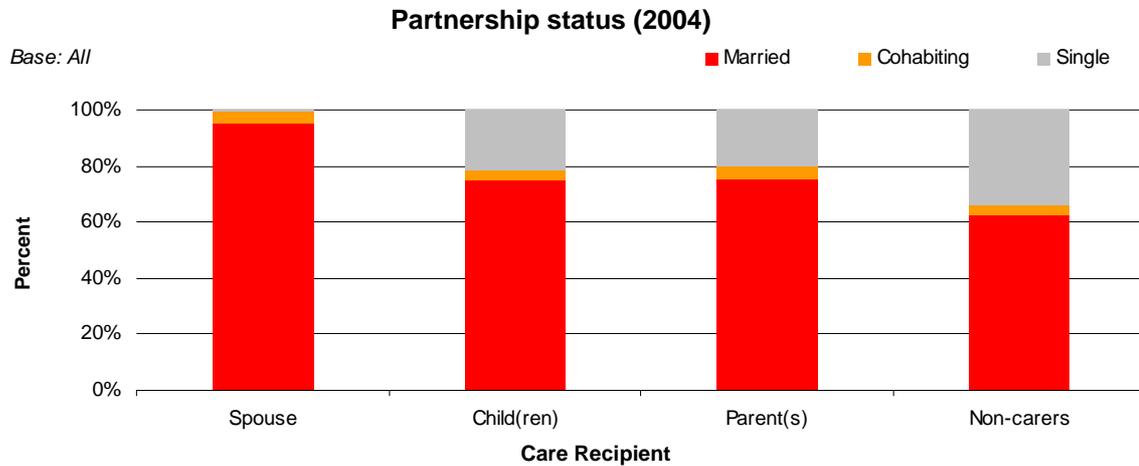
- These variations in co-habitation are reflected in the average number of hours of care provided each week:

Total number of care hours per week (2004)



Caring in the Older Population

- As can be seen above, providers of parental care typically provide far fewer hours of care per week than other types of older carer. Among older carers of spouses and adult children, the situation is reversed: care provision is clearly skewed toward 'heavy care'.
- Finally, carers are more likely to have a partner than non-carers in the 50+ age group:



Access to Services

Mobility and access to services will be particularly important to individuals who are providing care to others. Is there evidence of older carers struggling to access services?

- *Living & Caring?* analysed differences between older carers and equivalent non-carers in relation to access to services (shops, medical services), and in their access to and use of transport.
- Those who provided light care for a spouse were slightly less likely to use public transport than non-carers. Otherwise, no differences between carers and non-carers in terms of their use of public transport were found by the *Living and Caring?* research.
- Those providing light care to a parent or parent in-law were actually 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.
- The *Living & Caring?* research explored whether older carers found it difficult getting to a number of services using their usual form of transport. The research adjusted for whether the individual had access to a car and their level of physical mobility. The analysis was conducted for all carers, but significant differences to non-carers were only found for those providing moderate to heavy care, so only these findings are shown:

Proportion of individuals reporting difficulty in getting to 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%)

- As can be seen above, older people providing moderate to heavy care for a spouse or parent are significantly more likely to report difficulties reaching medical services, such as GPs and hospital. This analysis also controls for whether the person has access to a car or not and their level of physical mobility. These carers are also more likely to report problems accessing local shops and the supermarket.

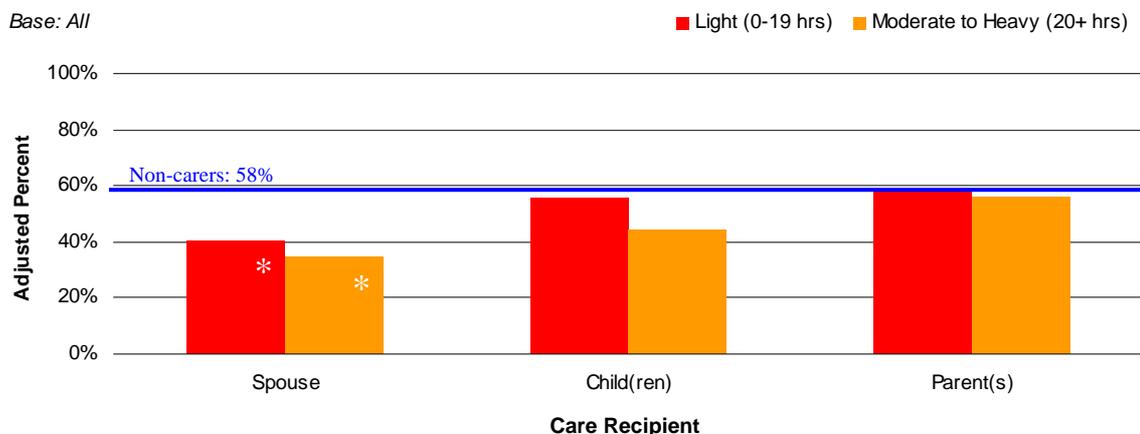
Leisure

Caring responsibilities can limit the scope for carers to participate in leisure activities. To what extent do carers miss out on leisure?

- Living & Caring?* analysed differences between older carers and non-carers in relation to participation in leisure activities.
- Providers of care to a spouse are significantly less likely to have taken a holiday in the last 12 months:

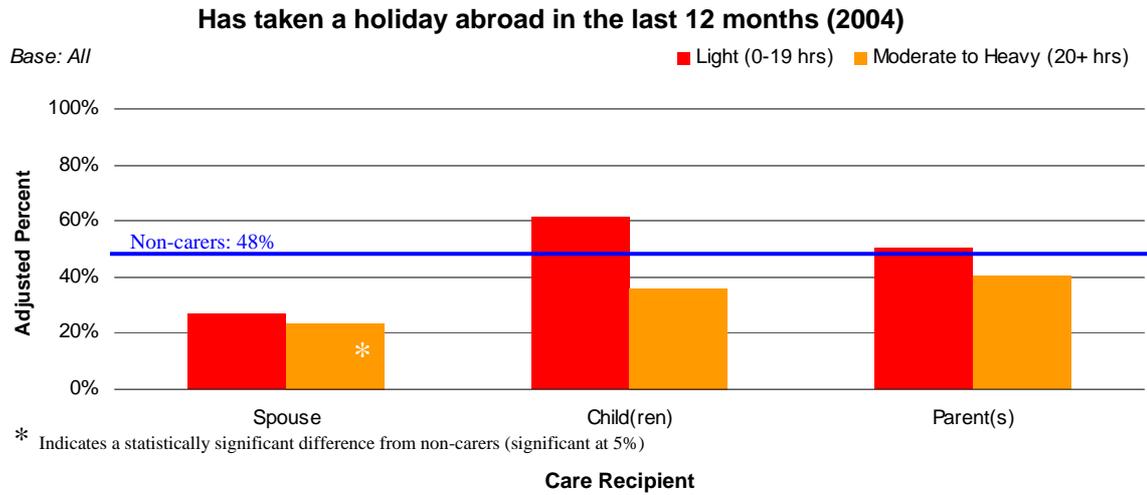
Has taken a holiday in the UK in the last 12 months (2004)

Base: All

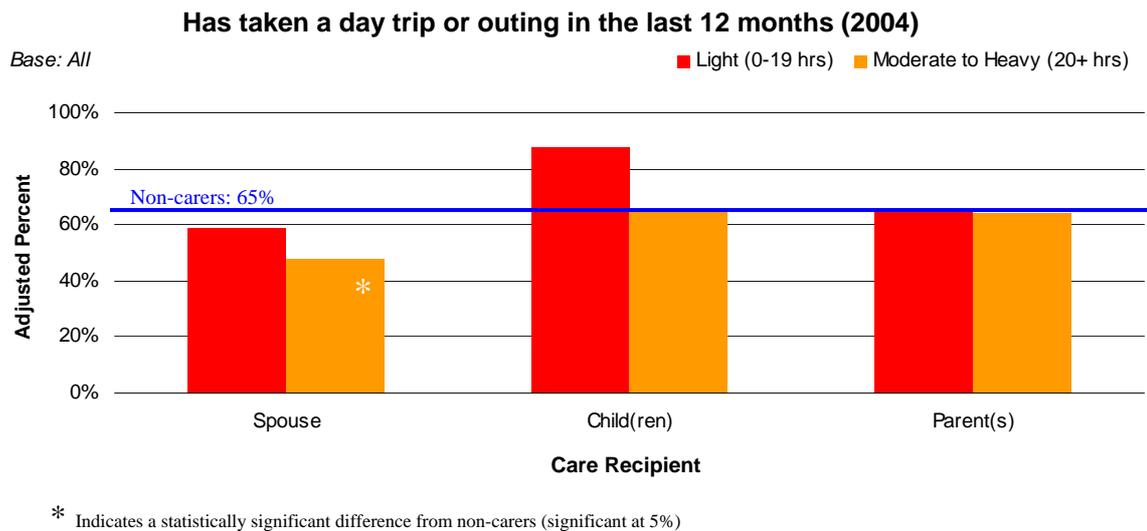


Caring in the Older Population

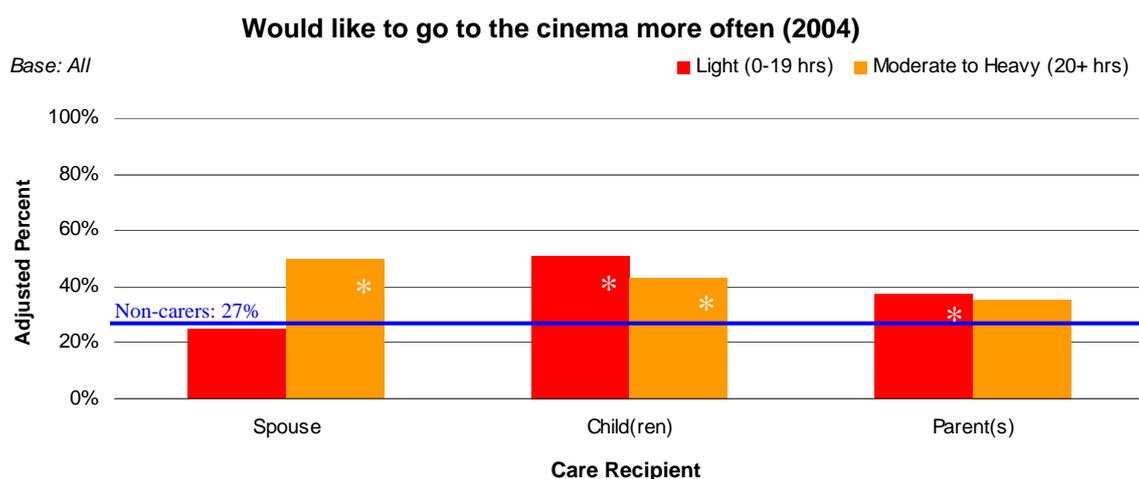
- Providers of moderate to heavy care to a spouse were significantly less likely to have taken a holiday abroad:



- Providers of moderate to heavy care to a spouse were also significantly less likely to have taken a day-trip or outing in the last year:



- Most older carers are significantly more likely to report that they would like to go to the cinema more often than equivalent non-carers:



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

- These and other findings of the *Living and Caring?* research do suggest that older carers participate less in leisure activities than non-carers, and are frustrated by their limited opportunities.

Health

What effect does care provision have on the health of older carers?

- To compare differences in the health of carers and non-carers, *Living and Caring?* looked at a range of subjective and objective measures of health outcomes contained within ELSA. These measures included: subjective general health; experience of chronic pain; physical levels of mobility; the carer's capability to carry out activities associated with daily living and independent living; measures of cognitive ability; upper and lower body strength; and, body mass index (BMI).
- Overall, very few differences were found 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 to experience chronic pain as non-carers.
- 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. 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. However, those who were providing moderate to heavy care to a spouse did report significantly poorer levels of mobility on average than non-carers.
- 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 activities 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. In all cases, carers reported a higher capability for both ADLs and IADLs than non-carers, or showed no difference.

- Previous research into the effects of care provision has identified poorer health outcomes among carers associated with care giving. In contrast, *Living and Caring?* found that carers were typically in better health than non-carers. This result is interesting because the health measures used in ELSA are particularly robust, including both subjective and objective measures of health status. These results may reflect the fact that in many situations, a 'selection effect' occurs, in that from among a 'kinship network' of potential carers, carers provide care because they are relatively healthy and able to do so.

Housing

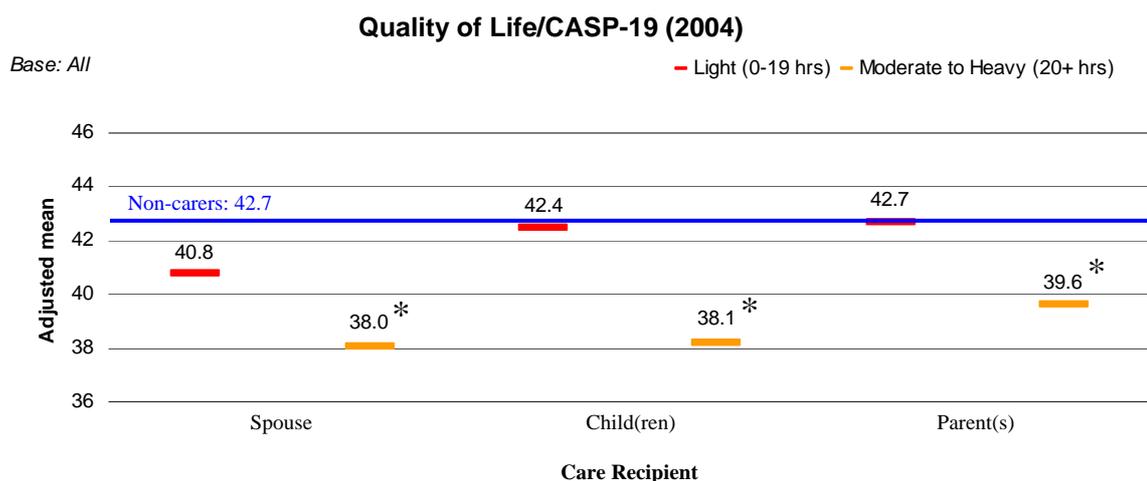
Housing is likely to have a particularly important role in shaping the experience of carers and those receiving care, given that the vast majority of unpaid care provision occurs in the home. What is the typical housing situation of older carers?

- *Living & Caring?* compared older carers and non-carers in relation to their accommodation and housing.
- Providers of care to a spouse were significantly less likely to be an owner-occupier than non-carers.
- Those who were providing moderate to heavy care for a spouse had more housing adaptations associated with a disability, on average, than non-carers. However, there was no similar finding among the other care groups. Those who provided care to a spouse 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.
- 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 who provided moderate or heavy care to a spouse, or a child.
- Similarly, all carers reported a slightly greater experience of noise and pollution than non-carers, although this difference was only statistically significant for those who provided moderate to heavy care. There were no significant differences relating to accommodation problems associated with general upkeep.

Quality of Life

Does care provision have a negative effect on quality of life? What factors are most important for the quality of life of older carers?

- *Living & Caring?* analysed data from a scientifically developed and tested measure of quality of life used in ELSA called 'CASP-19'.^{vi} This is a batch of 19 questions related to control, autonomy, satisfaction and pleasure that produce an overall aggregate score for quality of life.
- *Living & Caring?* found that older carers who provide moderate to heavy care report significantly lower quality of life on average than non-carers:



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

- *Living and Caring?* also explored what influence different factors in a carer's life had on their quality of life, such as access to services, leisure activities and health outcomes.
- The greatest effects on the quality of life of the carers are associated with subjective general health, and level of physical mobility. This suggests that mechanisms to identify older carers experiencing poor health and mobility should be a key part of any strategy to improve outcomes for older carers.
- Reported financial hardship is also among the more important influences on the quality of life of older carers.
- Difficulty in getting to a number of services is also associated with carers' quality of life. Difficulty in reaching a doctor, a hospital, the local shops and supermarket appear to have the greatest influence, even when taking into account their level of physical mobility and access to a car.
- 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. 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.

Quality of Life and Care Recipients

The health status and impairments of the person receiving care will significantly affect an older carer's quality of life. Which of these characteristics of the person receiving care are most important in influencing a carer's quality of life?

- As well as providing data on carers, where the recipient of care is the carer's partner or spouse, ELSA also includes data on the persons receiving care. The *Living and Caring?* research was therefore able to explore those characteristics of the person receiving care that were most associated with variations in the carer's quality of life.
- *Living and Caring?* analysed a range of characteristics of the person receiving care. These characteristics included two measures of care need (ability to carry out

Activities of Daily Living; ability to carry out Instrumental Activities of Daily Living); two additional measures of health (subjective general health and whether they often experience severe levels of pain); and two measures of cognitive ability (memory functioning and executive function).

- The analysis found that far more than any other characteristic, it was the *memory functioning* of the person receiving care that was most important for predicting the quality of life of older carers. Poor memory functioning was associated with poorer levels of quality of life. This suggests that strategies deployed by local authorities to support older carers should seek to identify carers of individuals with impaired memory functioning, and target resources at such carers appropriately.

ⁱ www.ilcuk.org.uk

ⁱⁱ 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

ⁱⁱⁱ 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

^{iv}

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085345

^v Ross A et al. (2008) *Living and Caring? An Investigation of the Experience of Older Carers*, ILC-UK, London

^{vi} Wiggins R et al. (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" in *Social Indicators Research* Vol. 89, No. 1, pp 61-77



ILC-UK
22-26 Albert Embankment
London
SE1 7TJ
Tel. +44 (0)20 7735 7565
www.ilcuk.org.uk