

Care providers, care receivers

A longitudinal perspective

Harriet Young, Emily Grundy and Mark Jitlal

This report analyses the characteristics of people who provide unpaid care to family and friends, and characteristics associated with becoming a caregiver. It also looks at trends in the movement of older people into nursing or residential homes or 'supported' private households.

Unpaid carers play an essential part in supporting people with assistance needs. This report provides information that will inform policy and enable appropriate support of these carers.

The report begins with an overview of caregiving in England and Wales, examines the geographical distribution of caregivers by local authority, and maps poor health and deprivation among carers. It then focuses on:

- family characteristics and education among carers in their 20s
- mid-life carers, examining their employment and health characteristics
- co-resident care for elderly parents
- caregiving among older couple
- characteristics of older people moving to live with relatives or into institutional care.

This study, based on Census data over a thirty-year period, will be of interest to policy makers and practitioners in central and local government, voluntary organisations, employers and researchers.



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Joseph Rowntree Foundation, The Homestead, 40 Water End, York YO30 6WP
Website: www.jrf.org.uk



About the authors

Harriet Young (research fellow) and Emily Grundy (professor) both work at the London School of Hygiene and Tropical Medicine. Mark Jitlal also worked at the London School of Hygiene and Tropical Medicine as a research assistant on this project, and now holds a post as a statistician at University College London.

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Summary

This report presents the results of analyses on unpaid caregiving and on transitions of older people to living in institutional care or with relatives. The question of how to provide and finance long-term care, and the most appropriate balance between institutional care, family-provided co-resident care and mixed care delivered to people at home, has become an important policy issue. The welfare and support of ‘informal’, predominantly family, caregivers is now acknowledged to be a crucial component of this debate, as recognised in recent legislation. The aim of this study is to provide more information on unpaid care providers to inform policy and practice, and enable informed support of care providers.

The main source of data for this analysis was the Office for National Statistics Longitudinal Study, a record-linkage study, which now includes individual-level data from four consecutive Censuses of England and Wales. The large size of the data set meant that, for the first time, it was possible to carry out detailed analyses of caregiving, including geographic analysis by local authority and region, and analyses of sub-groups of the population, for example, young carers aged 20–29, older married carers looking after a spouse, and midlife adult children providing care for a co-resident parent or parent-in-law.

Who provides care? Variations by health, ethnicity and place

Chapter 2 presents results of our analysis of geographic variations in caregiving, including examination of characteristics of caregivers and areas with high proportions of caregivers. In this chapter, we also examine differences between ethnic groups in the proportion of caregivers in the population. In this chapter and throughout the report, we focus particularly on those providing at least 20 hours per week of unpaid care. We refer to this as providing extensive care. We found the following.

- There were clear geographic variations in the proportion of the population providing unpaid care for 20 hours or more per week. Once other factors were controlled for, likelihood of caregiving was highest in Wales and the North of England, and lowest in the South East of England.
- Higher proportions of the population who provided unpaid care for 20 hours or more per week lived in deprived areas. At an individual level, carers were also relatively disadvantaged.

- Higher proportions of these heavily involved caregivers were likely to live in areas with a higher prevalence of poor health, and to be in poor health themselves.
- There were clear ethnic differences in the propensity to provide unpaid extensive care with some geographic variation. Bangladeshis and Pakistanis were more likely to provide care than those from other ethnic groups once age and gender were controlled for. They were twice as likely to provide care than those in the white ethnic group, after control for other factors including socio-economic status.

Young caregivers

The third chapter presents analysis of characteristics of young care providers aged 20–29 in 2001. Caregiving is strongly age-related and the proportion of young people with caregiving responsibilities in 2001 was low (1.3 per cent of those aged 20–29 compared with approximately 5.7 per cent of those aged 40–79). However, if caregiving does lead to reduced opportunities for education and labour market participation, then this scenario may have a lifelong impact on income and socio-economic status for these young carers. Results show the following.

- Among young women aged 20–29, the proportion providing extensive care increased steadily with the number of children they had had since 1991. This suggests that having a child in poor health may be the most usual pathway to becoming a carer among young women.
- Among young people of both genders, the proportions providing extensive care were highest among those with few educational qualifications and those not in the labour force.

Caregiving, employment and health

Chapter 4 presents analysis of correlates of caregiving for those who provided at least 20 hours of care per week in 2001. In this analysis, we focused on midlife carers aged 35–59. We wanted to examine characteristics of these carers that might be indicative of the possible consequences of caregiving, an issue we could not address directly because of the nature of our data. We were therefore not able to conclude that employment and poor health are a consequence of caregiving or a causal factor in care provision. Nevertheless, these findings show that those

providing large amounts of unpaid care have a number of disadvantages that suggest a need for greater support for this group. In particular we found the following.

- Among those employed full-time in 1991, those who were providing extensive care in 2001 were much less likely to be in work than those providing less or no unpaid care.
- For the population aged 35–59 who were employed in 2001, higher proportions of heavy care providers were in poor health than those who provided less or no care.

Caring and co-residence: adult children living with elderly parents

In Chapter 5, we examine the characteristics of midlife adults who provide extensive care for their elderly parents. We focused on adults who were co-resident with elderly parent(s) at 2001. We made the assumption that, if the midlife adult was providing care and the parent had a limiting long-term illness, then this parent would be the recipient of their child's caregiving. We examined the characteristics of the midlife adults in relation to caregiving at 2001 and found the following.

- Midlife adults with a limiting long-term illness at both 1991 and 2001 were less likely to provide extensive care for a co-resident parent than those who did not have a limiting long-term illness at either or both Censuses.
- Midlife adults in full-time employment at both 1991 and 2001 were less likely to provide extensive care for a co-resident parent than those with a history of less employment.
- Being co-resident with the same parent at 1991 was not associated with caregiving status of the midlife adults at 2001. However, being co-resident with the same parent with a limiting long-term illness at 1991 did increase the chance of a midlife adult co-resident with an elderly parent being a caregiver.

Pathways to caregiving: life-course characteristics of caregivers

In Chapter 6, we present the results of analysis of the life-course characteristics of caregivers. We compared the characteristics of caregivers aged 40–79 providing 20 or more hours of care per week in 2001, with those who provided no care or only 1–19 hours per week. Among both men and women aged 40–79 we found differences in the proportions providing 20 or more hours of care per week by a number of current and life-course characteristics. The main results were as follows.

- Among men aged 40–59, the never married were most likely to provide care. Among women in the same age group, the never married and married were equally likely to provide care. Among older men and women aged 60–79, the married were much more likely to provide care than those in other marital status groups.
- Among both genders and age groups, widowed and divorced people were less likely to provide care than those of other marital status groups. This finding is consistent with findings from other studies. Our results also suggest a lower propensity to provide care if divorce or widowhood happened more recently, although this finding would need further investigation.
- Among both men and women, those of lower socio-economic status (using highest educational qualification as an indicator) were most likely to provide care. This association was strong for those aged 40–59, but much less so for those aged 60–74.
- Women were less likely to provide extensive unpaid care if they had a history of strong attachment to the labour market with respect to family commitments.
- Women with a history of employment were more likely to provide unpaid care for 20 hours or more per week in 2001 if they concurrently worked in the public sector or had a history of working in a job with a caregiving element, such as nursing.

Caregiving in older couples

Older people are important providers of care, often to a spouse. In Chapter 7, we examine the characteristics of married older carers aged 65 and over, focusing particularly on those who live just with a spouse and whose spouse has a limiting

long-term illness. We made the assumption that, in these circumstances, the caregiver is most likely to be providing care for their spouse. We found the following.

- Women were marginally more likely to provide extensive care for 20+ hours per week to a spouse than men and propensity to provide extensive care for both genders increased with age. Extensive carers were more likely to have lower levels of education, a limiting long-term illness and poorer self-rated health than others.
- Those who provided extensive unpaid care and who had a spouse with a limiting long-term illness were more likely to be of lower socio-economic status than those providing less or no care and to have the following household characteristics:
 - housing rented from social landlord
 - no car access, especially for women
 - no central heating.

Moving to institutional care in later life

In Chapter 8, we examined the characteristics of older people resident in a private household at 1991 and resident in a communal establishment, such as a residential or nursing home, ten years later. We also examined how the transition to a communal establishment during this period differs from previous decades and looked at characteristics of older people who made a transition to living with relatives. Findings were as follows.

- The probability of moving from a private household in 1991 to a communal establishment in 2001 was higher for those living in rented accommodation (both private and social) in 1991, and for those with a limiting long-term illness in either 1991 or 2001. The probability was also higher for those unmarried at 2001, for women, and for those aged 80 plus. Those living in the North of England in 1991 were more likely to be living in a communal establishment in 2001 than those living in the South East in 1991.
- Childless women were more likely than those with children to make the transition from a private household in 1991 to a communal establishment ten years later.
- The comparison of periods showed that older people were less likely to make the transition to a communal establishment in the period 1991–2001 compared to the previous ten years, but that both these periods had a higher transition proportion compared with 1971–81.

- Among those who lived in 'independent' households in 1991 (mainly people living alone or just with their spouse), the proportion who were living with other relatives by 2001 was much lower than the proportion who were living in a communal establishment by this time.

Conclusions and implications

Unpaid carers are an essential and vitally important component in the system of support for people with assistance needs. Many of those with such needs are older people and much of the help they need is provided by other older people or by those in late middle age. However, there are caregivers of all ages and caregivers are a heterogeneous group. Certain common features can be identified, though, and these include an association between caregiving and disadvantage. In general, people providing care for 20 or more hours per week are more likely to have health problems themselves and to live in poorer areas and in households with fewer resources, and are less likely to have educational qualifications or to be in employment. Supporting caregivers may not only help them with their role but also provide a way of addressing social inequalities.

1 Introduction

Context of the project

Demographic and social changes have led to increasing concerns about the availability of family support for older people who need assistance, and the appropriate balance between family and 'formal' care. On the one hand, the growth in the number and proportion of very old people, who are the most likely to have disabilities, suggests an increase in the population in need of care. However, on the other hand, increases in the proportions of women in employment and changes in family-related behaviour may be associated with decreased availability of family care. The question of how to provide and finance long-term care, and the most appropriate balance between institutional care, family-provided, co-resident care and mixed care delivered to people at home (e.g. a person living at home, attending a day-care setting), has become an important policy issue. The welfare and support of 'informal', predominantly family, caregivers is now acknowledged to be a crucial component of this debate, as recognised in recent legislation.

During the 1980s, use of institutional care increased and the proportion of older people moving to live with children or other relatives decreased (Glaser and Murphy *et al.*, 1997), possibly partly because of changes in the availability of financial help for people entering residential or nursing care (Laing, 1993). Policy and legislative changes in the 1990s sought to halt the former trend, target resources on those with the highest support needs and improve supports for carers. These changes do seem to have resulted in a levelling off in use of residential and nursing care (Laing, 1993) but it is not known how this has impacted on family caregivers, many of whom are themselves older people.

In this report, we present results from a study of caregiving in which we have looked at both providers and assumed recipients of care of different kinds. We examined the life-course characteristics and current circumstances of people providing unpaid care in 2001, with a particular focus on those caring for 20 or more hours per week. We also examined the characteristics of assumed recipients of family care and the characteristics of older people moving to institutional care. Where appropriate, we made comparisons with related work on earlier periods in order to provide an insight to trends. The results provide new information on the characteristics and antecedents of caregivers, on health and employment correlates of caregiving, and on transitions to residential care.

Aims of research

Our first aim was to analyse the current and antecedent characteristics of those who identified themselves as caregivers in the 2001 Census with the target of identifying factors associated with caregiving and its correlates. We focused mainly on unpaid carers who provided at least 20 hours of care per week, which we refer to as extensive care. In particular, we focused on caregiving at different ages and, as far as possible, on different types of caregiving. For example, we aimed to analyse characteristics of older married couples (focusing on extensive caregivers living with a spouse with a limiting long-term illness) and of middle-aged children living with an elderly parent or parent-in-law. Another aim was to analyse transitions made by older people from independent to supported households (institutions, or with relatives or others) between 1991 and 2001, including differentials in these transitions, and to compare results with previous work on such transitions in earlier decades.

Our specific objectives were as follows.

- 1 To describe characteristics of those who identify themselves as caregivers in the 2001 Census, focusing on geographic variation in care provision.
- 2 To examine life-course characteristics of caregivers, including socio-economic status, employment history and highest educational qualification.
- 3 To explore correlates and possible consequences of caregiving by examining changes in health and employment, 1991–2001, among caregivers (only indirect inferences can be drawn).
- 4 To explore characteristics of young carers aged 20–29 and correlates of caregiving in this age group, including educational and employment status.
- 5 For carers assumed to be co-resident with the person they care for, to analyse current and antecedent characteristics of both the caregiver and the person they care for by:
 - focusing on married caregivers aged 65 and over living only with a spouse
 - looking at midlife adult children (35–64) living with elderly parents/in-laws.
- 6 To analyse transitions from ‘independent’ to ‘supported’ environments (institutions or households of relatives) from 1991 to 2001 among older people, and identify demographic and socio-economic factors associated with either type of transition.

Methods

Data source

Our research questions have mainly been addressed using the ONS Longitudinal Study (ONS LS), a record-linkage study of the population of England and Wales. The LS was originally based on a 1 per cent sample of those in the 1971 Census and now includes individual-level data from the 1971, 1981, 1991 and 2001 Censuses. The sample is continuously updated by adding in 1 per cent of new births and immigrants, and so remains representative. At any point in time, the LS includes records from about 550,000 living people (LS members). The data set includes linked information on births to female sample members, deaths of sample members and deaths of sample members' spouses. It also includes census information for those living in the same household as the LS member at each Census. For the first time in 2001, the Census had questions on caregiving, faith, self-rated health, as well as a repeat of the 1991 question on limiting long-standing illness.

Particular strengths of the LS for our purposes are the large sample size, the availability of data spanning a large proportion of sample members' adult lives, the inclusion of information on other people living with sample members and the fact that those living in 'non-private' households (institutions) are also included in the sample. The longitudinal design of the LS enabled us to analyse antecedents and correlates of caregiving, such as employment history and change in health status. The large sample size also allowed us to examine variations in caregiving by individual, household and locational characteristics, about which little is currently known.

Additionally, we used other data from the 2001 Census to analyse geographic variations in care provision in 2001 (objective 1). We accessed census data using CASWEB, a web interface allowing analysis of aggregated census data. For this research, data was downloaded from two Standard Table datasets at the local authority level (unitary authorities and districts). Additionally, we used a Census Table on unpaid care provision and ethnicity at the Government Office Region level, obtained directly from the Office for National Statistics (ONS).

Definitions

In this research, the definitions and questions used in the Census constrain, and to a large extent determine, the variables and definitions we use (although we have also derived a number of additional variables based on information from more than one

census question or more than one Census). Some of the key census questions and definitions are given below.

The information on *caregiving* comes from a question that was included for the first time in the 2001 Census. This asked whether individuals look after, or give any help or support to, family members, friends, neighbours or others because of long-term physical or mental ill health or disability, or problems related to old age. Individuals were asked not to count anything they did as part of paid employment. There were four possible answers to this question: no care provided; or care for one to 19 hours; or care for 20 to 49 hours; or care for 50+ hours per week. Most of our analyses focus on those providing extensive care, which, in line with other studies, is defined as caregiving for 20 hours or more per week (Parker and Lawton, 1994). In all analyses of caregiving, we focus only on those living in private households (i.e. not in communal establishments).

The census question we use to identify caregivers unfortunately does not provide information on whom they were providing care for. However, research using detailed caregiving questions in the smaller, cross-sectional General Household Survey has shown that 75 per cent of those providing 20+ hours of care per week are looking after someone in the same household (Maher and Green, 2002). For analyses examining characteristics of the presumed care recipient (objectives 5 and 6), we make an assumption that care is provided within the household if there is a household member with a limiting long-term illness (see below), who we assume is the care recipient. This will be explained in more detail in the relevant chapters.

We also make use of census information on health status. Both the 1991 and the 2001 Census included a question on *limiting long-term illness* (LLTI). In 1991, individuals were asked whether they had any long-term illness, health problem or handicap that limited their daily activities or the work they could do. People were asked specifically to include problems due to old age. In 2001, the question was the same except that it referred to disability rather than handicap. An additional question in the 2001 Census asked whether people rated their *health* in the last 12 months as good, fairly good, or not good.

Other important definitions are those relating to households. *Communal establishments* (such as residential or nursing homes) were defined in both 1991 and 2001 as establishments providing managed (full-time or part-time supervision) residential accommodation.

Private households are 'ordinary' households in the community and may comprise people living alone or a group of people (not necessarily related) who live at the same address and share a living room and/or share at least one meal a day. Other

more detailed definitions of household composition are given in the appropriate chapters and in Appendix 2.

Analysis

Data preparation initially involved development of data sets. The 2001 Census includes imputed values of many variables. This imputation was carried out when data for an individual were missing, or were incompatible with other individual-level information. We excluded from each analysis LS members who had imputed levels of relevant variables. Therefore the numbers included in different analyses within the same chapter vary slightly due to imputations for different variables.

Methods used include cross-sectional analysis of characteristics of caregivers in 2001 with comparisons of the proportions providing care by each characteristic. Longitudinal analysis involved examination of changes in characteristics over time. We present descriptive analyses, such as cross-tabulations, and also results from multivariate modelling. Multivariate methods are necessary to unpick associations while taking account of relevant factors such as age and gender. In general, we used logistic regression in which the dependent variable is a binary or dichotomised variable (for example, being a caregiver or not) and we present results in the form of odds ratios.

The odds ratio is a measure of association between two factors and compares whether or not the probability of a certain event is similar for two groups. For example, in an examination of gender differences in care provision, an odds ratio of 1.00 for a comparison of caregiving by women compared with men would imply that caregiving is equally likely for both sexes. An odds ratio of 1.40 would imply that women in the sample are 40 per cent more likely to provide care than men, while an odds ratio of less than 1.00 would mean that caregiving is less likely among women than among men.

Note that, unless otherwise specified, the source of all charts and tables is analysis of data from the ONS Longitudinal Study.

Age groups and time periods considered

In each chapter, the analysis considers different age groups of caregivers and variables from different census points, depending on the objective. Table 1 shows this.

Table 1 Age groups and time periods considered

Chapter	Age group	1981	Data from 1991	2001	Title of chapter
2	16+			<input checked="" type="checkbox"/>	Who provides care? Variations by health, ethnicity and place
3	20–29		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Young caregivers
4	35–39		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Caregiving, employment and health
5	35–64		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Caring and co-residence: adult children living with elderly parents
6	40–79	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Pathways to caregiving: life-course characteristics of caregivers
7	65+			<input checked="" type="checkbox"/>	Caregiving in older couples
8	65+	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Moves to institutional care in later life

2 Who provides care? Variations by health, ethnicity and place

Key findings

- There were clear geographic variations in the proportion of the population providing informal care for 20 hours or more per week. Once other factors were controlled for, likelihood of caregiving was highest in Wales and the North of England and lowest in the South East of England. Local authorities with the highest proportion of the population providing unpaid extensive care included Neath Port Talbot, Merthyr Tydfil, Easington and, in London, Barking and Dagenham, Newham and Tower Hamlets.
- There were higher proportions of carers in areas with higher proportions of people with limiting long-term illness. In these areas, individuals were more likely to provide care for given levels of need.
- There were higher proportions of the population providing unpaid care for 20 hours or more per week in deprived areas. Individual disadvantage was also associated with caregiving.
- Higher proportions of these heavily involved caregivers were also likely to live in areas with a higher prevalence of poor health and to be in poor health themselves.
- Both poor health and deprivation were independently associated with increased propensity to provide care.
- There were clear ethnic differences in the propensity to provide extensive unpaid care, with some geographic variation. Bangladeshis and Pakistanis were more likely to provide care than those from other ethnic groups once age and gender were allowed for. They were twice as likely to provide care than those in the white ethnic group, after control for other factors including socio-economic status.

Introduction

This chapter describes the characteristics of those who identify themselves as caregivers in the 2001 Census. We focused on geographic variations in extensive care provision at the local authority and regional levels. The inclusion of a question on caregiving in the 2001 Census meant that, for the first time, it was possible to map the geographic distribution of unpaid carers in England and Wales. Please note that this chapter includes some material previously published in *Population Trends* Volume 120 (Young *et al.*, 2005).

Our specific objectives were to examine the geographic distribution of caregivers throughout England and Wales as follows:

- 1 the proportion of caregivers in each local authority throughout England and Wales and in London
- 2 the association between indicators of need for caregiving and availability of caregivers
- 3 geographic variation in various characteristics of caregivers including health, deprivation and employment
- 4 variations in caregiving by ethnicity.

Several studies have examined regional variations in caregiving but it has not previously been possible to explore these in detail because of small study sample sizes (Maher and Green, 2002). Other research has suggested that unpaid care providers, especially those providing 20 hours or more care per week, are themselves likely to be disadvantaged (Hutton and Hirst, 2000), and so we expected to find associations between both area and individual indicators of disadvantage and caregiving.

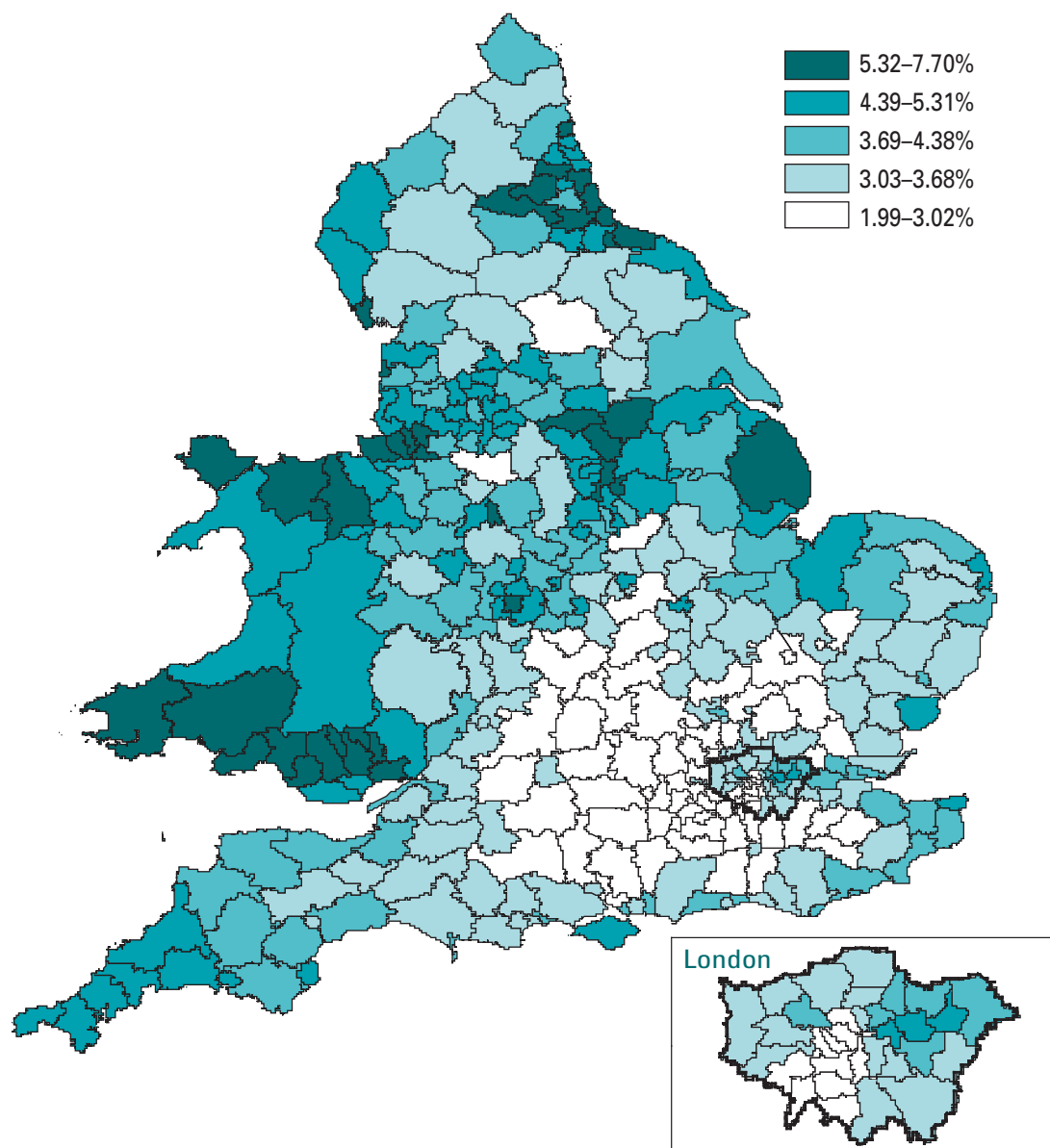
Hutton and Hirst's (2000) analysis of the British Household Panel Survey (BHPS) found that Asians had higher rates of informal care than black Caribbean and white groups, after controlling for household factors. We therefore expected our results to show similar findings. This study, however, has a sample large enough to allow us to examine associations between ethnicity and caregiving in more detail, including looking at regional variations, something not undertaken in previous studies. We paid particular attention to London in our analysis because it has a large proportion of ethnic minorities in the population and there is a lot of diversity between London boroughs.

We focused on the population of England and Wales aged 16 and over in 2001, and examined the proportion of the population providing extensive care of 20 hours or more per week. Our main variables of interest were care provision, presence of a limiting long-term illness and self-rated health, all at the 2001 Census as described in Chapter 1. For the self-rated health variable, we distinguished between those who had good or fairly good health and those who were not in good health. We also used an area-level indicator of deprivation, the Index of Multiple Deprivation (IMD), defined in Appendix 2.

Geographic variation in caregiving

The proportion of the population of England and Wales providing unpaid care for 20 hours or more per week in each local authority (LA) in 2001 is shown in Figure 1. Between 2 and 8 per cent of the population aged 16 and over of each local authority provided extensive care, with an average of 4 per cent. Areas with the largest proportions of the population providing care include Conwy, Denbighshire and the Isle of Anglesey in North Wales; most unitary authorities in South Wales; Merseyside; Durham; Tyne and Wear; and parts of Lincolnshire, South Yorkshire and Derbyshire. The highest prevalences of caregiving were in the local authorities of Neath Port Talbot (7.7 per cent), Merthyr Tydfil (7.4 per cent) and Easington (7.4 per cent). In London, the boroughs with the highest proportion providing extensive care were Barking and Dagenham (5.2 per cent), Newham (4.9 per cent) and Tower Hamlets (4.7 per cent). The smallest proportions of the population providing informal care were in South East Cumbria, North Yorkshire, Northumberland and the South East of England (other than London), although the proportion here was higher in coastal areas.

Figure 1 Proportion of the population aged 16 and over in England and Wales providing unpaid care for 20 hours or more per week in each local authority, 2001



Source: census data in Young *et al.* (2005).

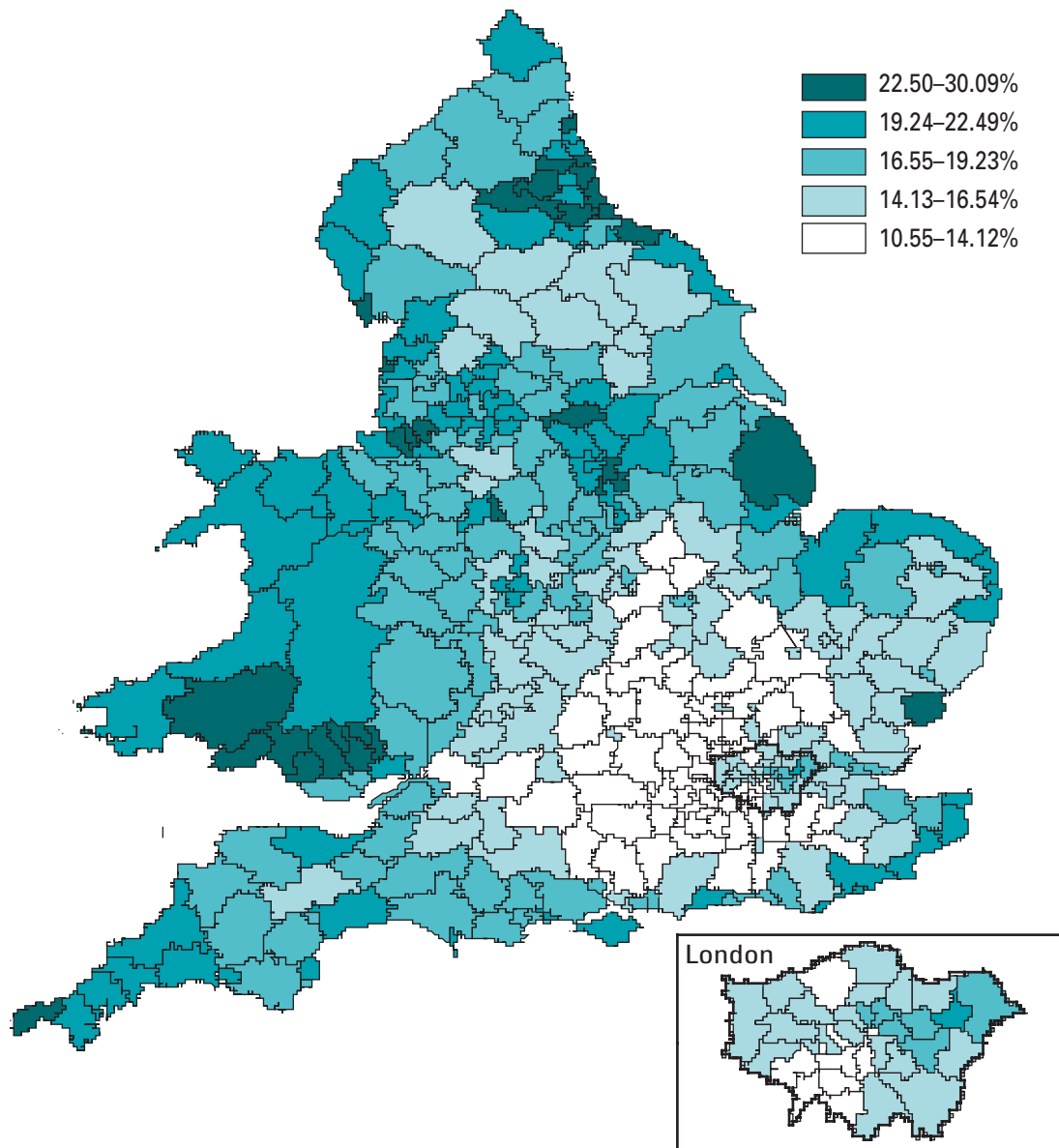
Need for care and availability of caregivers

The proportion of caregivers in an area is likely to reflect both the proportion of the population needing care and the availability of individuals to provide care. First of all, we use the proportion of the population in each LA with a limiting long-term illness (LLTI) as a crude indicator of need for care, although of course only a minority of those with an LLTI will actually need care (Figure 2). Unsurprisingly, a comparison of Figure 1 with Figure 2 suggests that areas with higher proportions of caregivers also had higher proportions of the population with an LLTI.

Next, we assessed the availability of carers by LA. We took the ratio of the number of people in each LA providing care to the number with an LLTI, which gives the number of caregivers per individual with an LLTI. We limited this analysis to caregivers aged 50–59 and those aged 80 years and over with an LLTI, and therefore made the assumption that we were measuring intergenerational care for parents or other older relatives. This ratio (although not necessarily of the correct magnitude owing to the fact that not all individuals with an LLTI need care) gives an indication of differences in availability of carers for a given level of need in each area. Figure 3, showing this ratio by LA, shows a striking similarity in pattern to Figure 1. It indicates that, as might be expected, there were more carers aged 50–59 per individual aged 80+ with an LLTI where prevalence of caregiving was higher. In Merthyr Tydfil and Neath Port Talbot in South Wales, for example, there were approximately three times as many carers aged 50–59 per individual with an LLTI aged 80+ than in Westminster or Hammersmith. Areas with lower numbers of carers per older individual with an LLTI were concentrated in the South East of England. This analysis was also carried out for the ratio of caregivers of all ages to all individuals with an LLTI and showed a similar pattern of results, but a smaller magnitude of difference – the largest ratio was only twice as high as the lowest, compared to three times in this analysis.

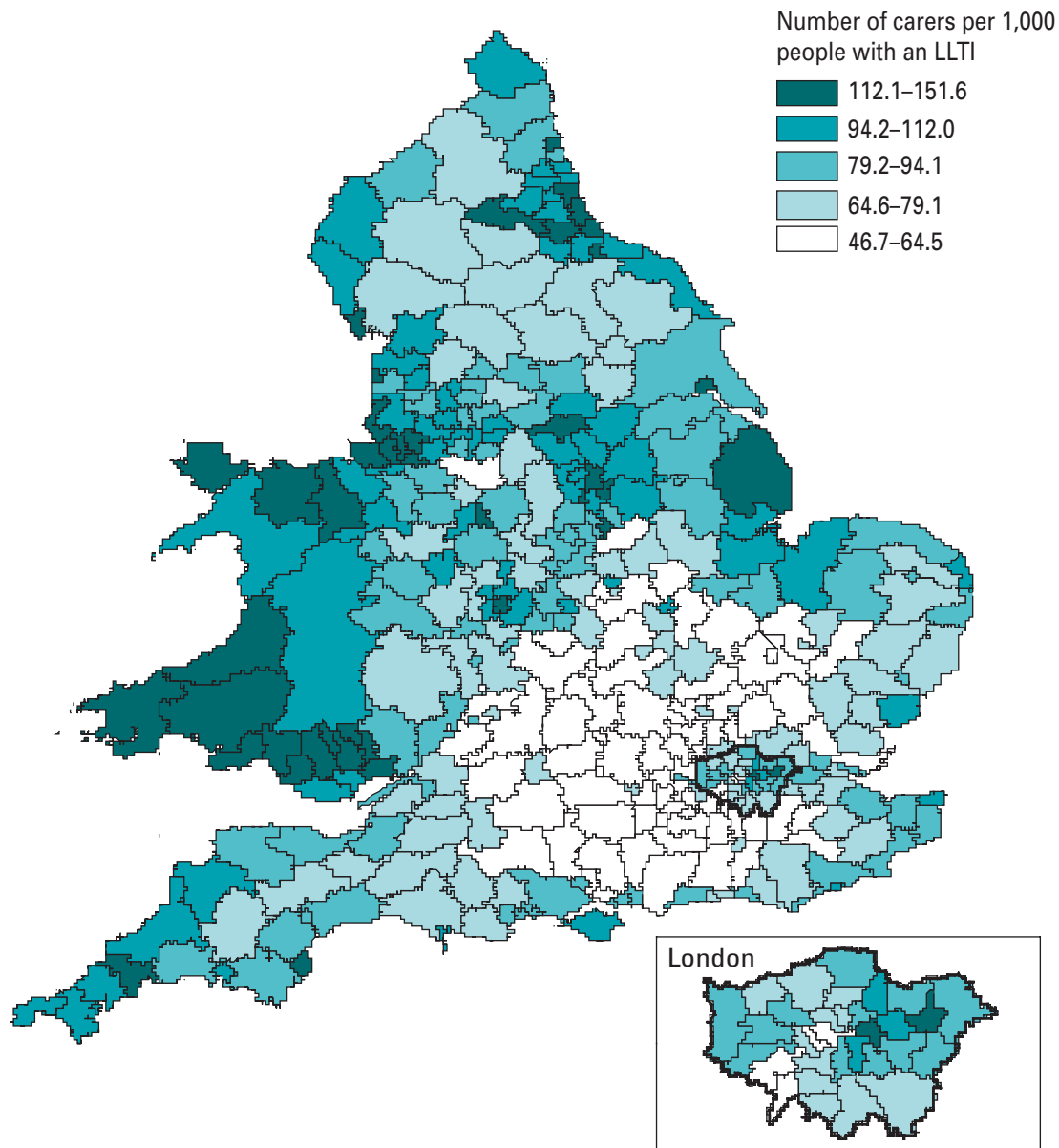
These findings are supported by results from another JRF-funded project (Wheeler *et al.*, 2005), which also showed that areas with high levels of poor health had higher proportions of the population providing unpaid care. This other study showed that, although there was a positive geographic association between poor health and proportions of unpaid carers, the association between poor health and number of health care professionals went the other way, i.e. there were relatively fewer health professionals in areas with above-average rates of poor health (Shaw and Dorling, 2004).

Figure 2 Proportion of the population with a limiting long-term illness in private households in England and Wales, 2001



Source: This map was prepared from standard census table ST016. Census, April 2001, Office for National Statistics. © Crown Copyright.

Figure 3 Ratio of informal caregivers aged 50–59* to people aged 80 and over with a limiting long-term illness by local authority in England and Wales, 2001



* Caregivers providing 20 hours or more care per week.
Source: census data in Young *et al.* (2005).

Caregiver characteristics: health, deprivation and employment

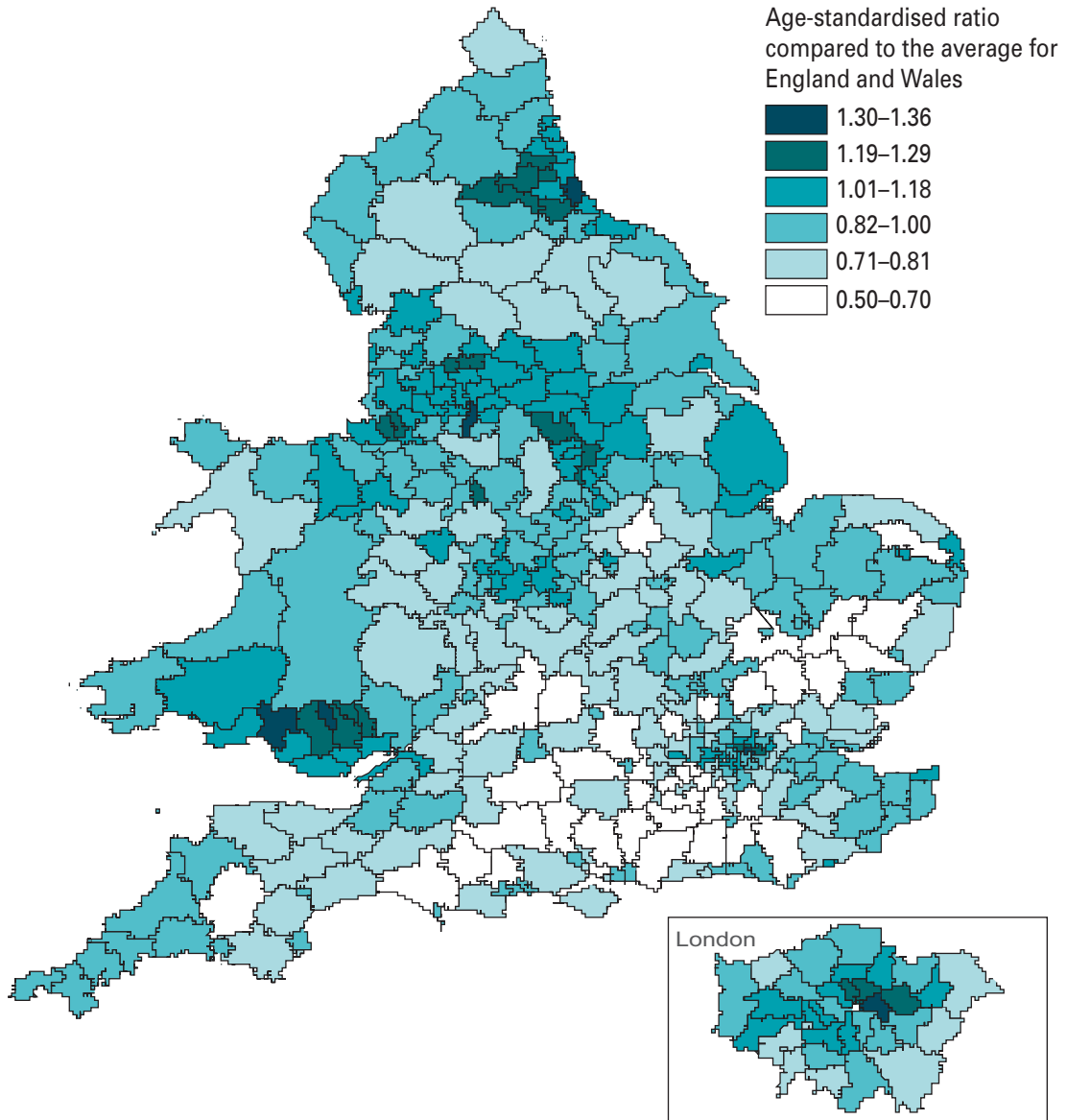
The proportion of informal caregivers with poor self-rated health by LA ranged from 11 to 25 per cent, with a mean of 18 per cent. Male carers were more likely to report poor self-rated health than females (on average, 20 per cent compared with 16 per cent of female carers). One-fifth to a quarter of carers had poor self-rated health in South Wales, Tyne and Wear, parts of Durham, and around Manchester, Leeds and Sheffield (map not shown).

The variation in proportions of the population with poor self-rated health may reflect differing age profiles in different areas because those in older age groups are more likely to be in poor health. For example, in the South of England, carers in coastal areas tend to include higher proportions with poor self-rated health than in other parts of the South of England. Such areas include popular retirement destinations and have older age structures, so, in order to exclude this age effect, we standardised our results by age. This ensures that any associations found were not merely a result of age differences between areas (see Appendix 3 for more information on standardisation).

Figure 4 shows the age-standardised ratios of poor self-rated health among female carers in each LA, compared with the average (of 1.00) for England and Wales. Where the ratio is above 1.00, female carers have higher levels of poor health than the average and, where it is below 1.00 they have lower levels of poor health. Ratios are higher in South Wales, West and South Yorkshire, Derbyshire, Greater Manchester and Merseyside, reflecting that, in these areas, there were larger proportions of carers with poor self-rated health. In London (and the South of England) the highest ratios were in Hammersmith and Fulham, Haringey, Islington, Hackney, Tower Hamlets and Newham. Lowest ratios, reflecting lower rates of poor health among carers after allowance for age-structure differences, were found in the South and East of England. Despite standardisation for age, there still appeared to be higher rates of poor health among carers in coastal areas and towns of South England, in Kent, Cornwall, Brighton, Portsmouth, Poole and Bournemouth. Although the same data for men are not shown, the pattern was similar.

Caregiver health is likely to reflect the health of the general population in an area, so our finding of carers being in poorer health in areas with a higher demand for caregiving is unsurprising. Another possible reason for poor health among caregivers is a positive correlation between health status of cohabittees, due to a shared environment, and lifestyle behaviours (Wilson, 2002).

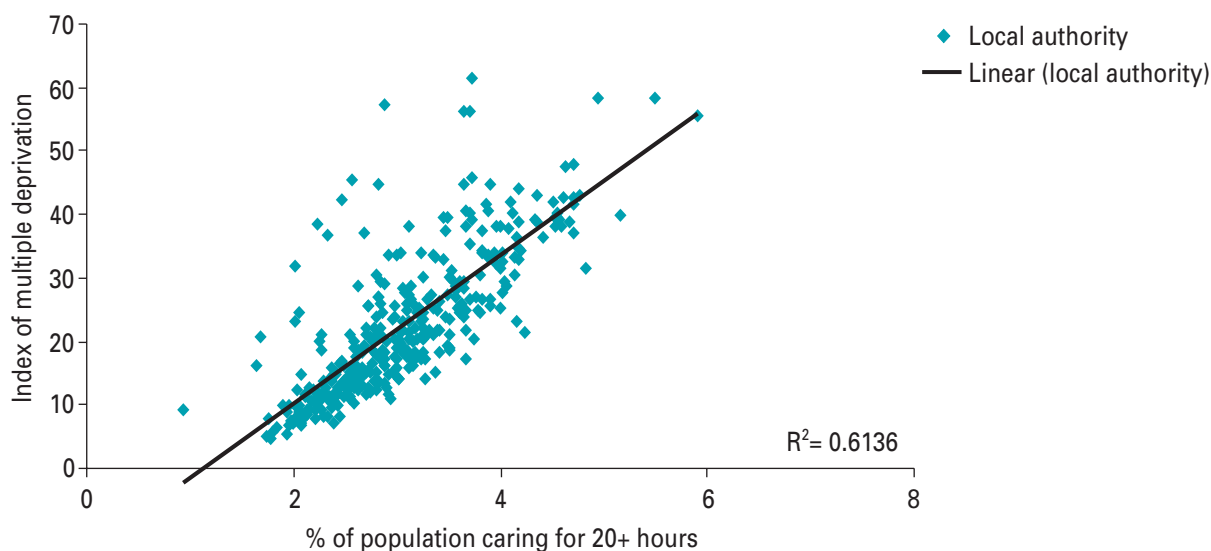
Figure 4 Age-standardised ratios of proportion of female informal caregivers* with poor self-rated health by local authority in England and Wales, 2001



* Caregivers aged 16 and over providing 20 hours of care or more per week.
Source: census data in Young *et al.* (2005).

We used the Index of Multiple Deprivation (IMD) for 2000 as an indicator of area-level deprivation in England and Wales. Figure 5 shows a positive correlation between extensive care provision and area-level deprivation. In other words, LAs with larger proportions of carers in the population were likely to have higher levels of deprivation. Comparison of Figure 1 with Figure 4 indicates that these areas with high proportions of extensive care providers also had higher proportions of carers with poor self-rated health. Local authority populations with larger proportions of caregivers were therefore more likely to be deprived, and to have populations with higher rates of poor self-rated health.

Figure 5 Correlation between deprivation index and proportion of the population providing informal care for 20+ hours per week



Source: 2001 Census, Office for National Statistics. Authors' analysis.

Variations in caregiving by ethnicity

Numbers of caregivers

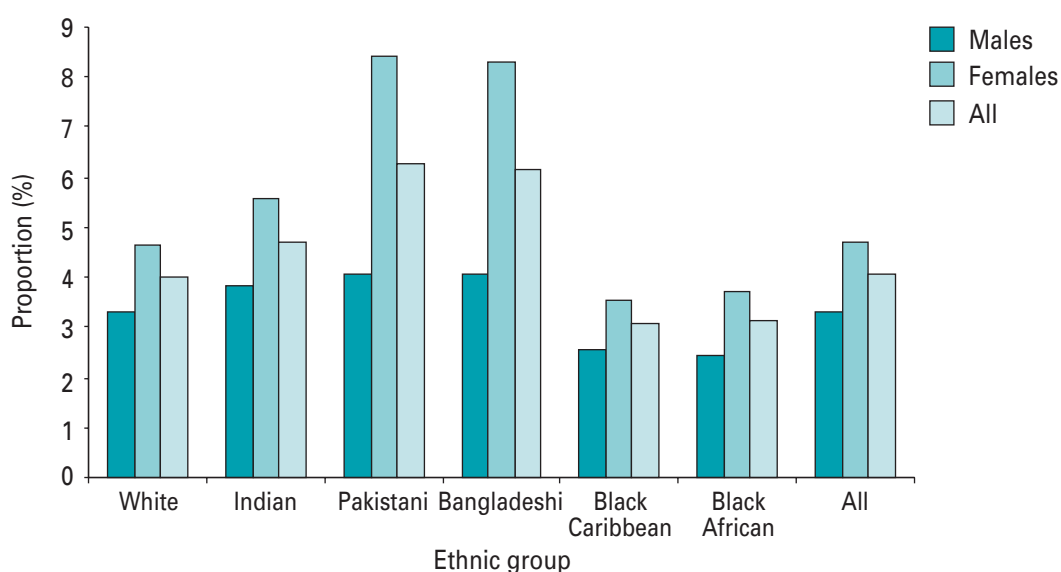
There were approximately 130,000 caregivers (7.8 per cent of all carers) from minority ethnic groups in England and Wales in April 2001 providing care for 20 or more hours per week. Of minority ethnic caregivers, nearly half lived in London, 15 per cent lived in the West Midlands and approximately 9 per cent each lived in the North West, and in Yorkshire and the Humber. There were many fewer minority ethnic caregivers in the North East, South West and Wales, where over 98 per cent of caregivers were white. These figures generally reflect the proportion of the whole population from ethnic minorities in each of these areas.

Prevalence of caregiving by ethnicity

Figure 6 shows the prevalence of caregiving by ethnic group and gender for England and Wales. On average, Bangladeshi and Pakistani men and women were more likely to provide care than those from other ethnic groups. However, an examination of the ratio of numbers of female to male care providers by ethnic group and region indicates that the ratio of female to male care providers was highest among those from Bangladeshi and Pakistani ethnic groups. While, in most ethnic groups, women were 40 per cent more likely to provide care than men, Bangladeshi and Pakistani women were twice as likely to provide care as men from the same ethnic group. This may relate to spousal age differences and differences in gender roles.

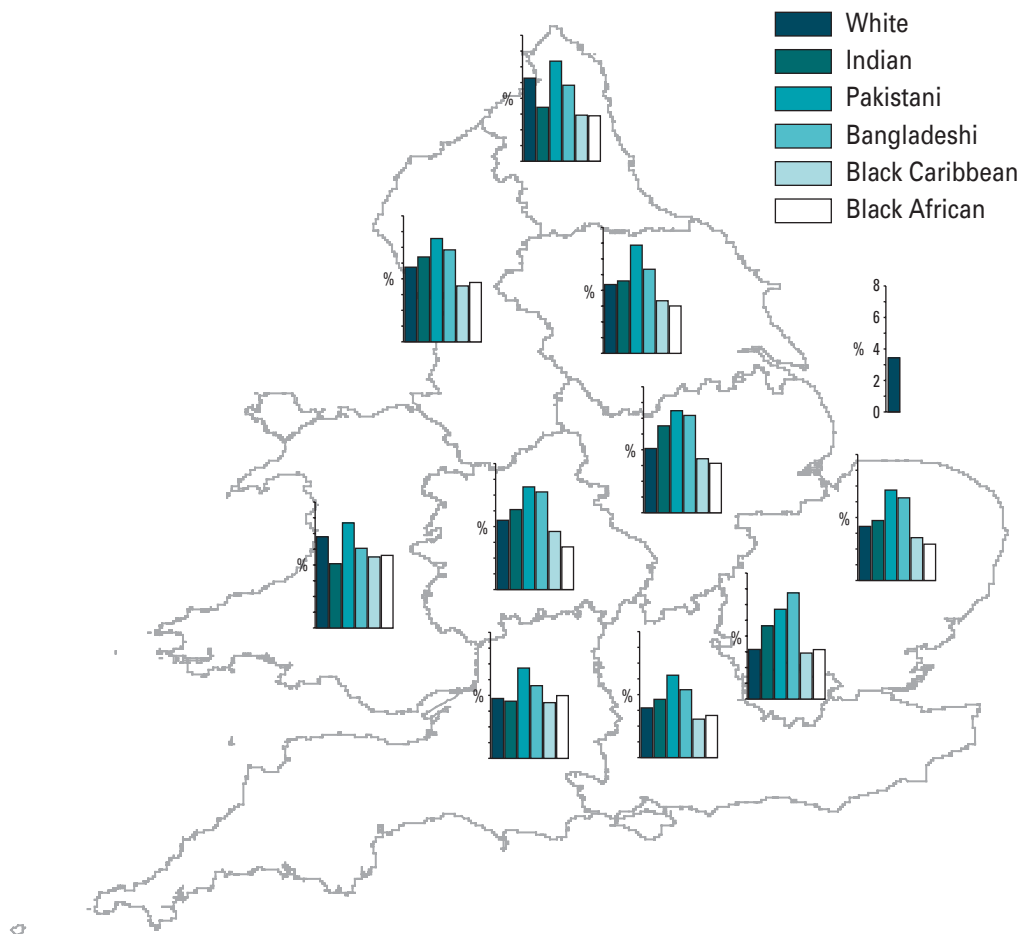
The proportion of the population providing unpaid care by ethnic group and Government Office Region (GOR) at the 2001 Census is shown in Figure 7. This ranged from a low of 2.3 per cent of the black African population providing care for 20 or more hours per week in the East of England, to 6.9 per cent of the Pakistani population providing care in Yorkshire and the Humber. In nearly all GORs, the prevalence of caregiving was highest in the Pakistani population. However, there were regional differences in prevalence of caregiving by ethnic group. For example, in Wales and in the North East, whites were nearly as likely to provide care as Pakistanis, but much less so in other areas.

Figure 6 Proportion of the population aged 16+ providing care for 20+ hours per week by ethnic group and gender



Source: 2001 Census, Office for National Statistics. Authors' analysis.

Figure 7 Proportion of the population providing informal care* by ethnic group and region of England and Wales, 2001



* Population aged 16 and over providing informal care for 20 hours or more per week. This map was prepared from census table M260. Source: Census April 2001, Office for National Statistics. © Crown Copyright.

Prevalence of caregiving standardised by age and gender

The above results do not take account of differing age structures by ethnic group. Table 1 shows age- and gender-standardised ratios of observed numbers of carers to those expected given a standard rate of caregiving, in this case the average for England and Wales (see Appendix 3 for more information on standardisation). Once age and gender were controlled for, differences in caregiving propensity between ethnic groups became clearer and more consistent over the GORs. In all regions of England and Wales, those from Bangladeshi and Pakistani ethnic groups were far more likely than those from any other ethnic groups to provide 20 or more hours of care per week. The Indian ethnic group had the third highest standardised ratio of care provision.

Ethnic group differences in propensity to provide care may be related to factors such as household and family composition, marriage patterns, cultural factors or socio-economic factors.

Table 2 Age- and gender-standardised ratio* of proportion of the population aged 16 and over providing unpaid care for 20+ hours per week by ethnic group in each region of England and Wales, 2001

Region	Ethnic group						Average for region**
	White	Indian	Pakistani	Bangladeshi	Black Caribbean	Black African	
North East	1.29	1.01	2.07	1.72	0.81	0.94	1.29
North West	1.16	1.62	2.20	2.04	0.85	1.17	1.18
Yorkshire and Humber	1.07	1.39	2.34	1.87	0.80	1.00	1.11
East Midlands	0.99	1.54	2.12	2.15	0.83	1.07	1.02
West Midlands	1.07	1.47	2.22	2.15	0.91	0.89	1.12
East	0.83	1.06	1.91	1.85	0.68	0.74	0.84
London	0.82	1.30	1.81	2.34	0.73	0.97	0.91
South East	0.75	1.02	1.67	1.49	0.60	0.86	0.76
South West	0.89	1.06	1.78	1.64	0.84	1.25	0.89
Wales	1.40	1.20	2.06	1.80	1.09	1.32	1.40
Average for ethnic group**	0.98	1.34	2.08	2.15	0.76	0.97	
Number of caregivers	1,513,101	36,907	28,732	10,577	13,561	10,076	1,612,954

* Compared to the value for all groups combined for the whole of England and Wales.

** Averages are weighted according to size of population in each ethnic group/region.

Source: census table M260, Census Program, ONS. Authors' calculations.

Multivariate analysis

We also carried out more complex analysis on data from the ONS Longitudinal Study to complement the findings from the geographic analysis. Using logistic regression, we were able to examine propensity to provide care by the characteristics explored in geographic analysis. Using standardisation, it is possible to control for one or two factors at once, for example age and gender. However, logistic regression enables control for multiple factors at the same time. This analysis supports the findings above and showed that, after control for other factors including age, gender, household size and composition, increased propensity to provide care was associated at the individual level with poorer health, lower socio-economic status, living in the North and Wales, and being from Pakistani, Bangladeshi and Indian ethnic groups.

Conclusions

In this chapter, we analysed geographic variation in care provision for 20+ hours per week for the population aged 16 and over in England and Wales, using data from the 2001 Census. We found that caregiving propensity is not evenly dispersed through the population, either geographically, socio-economically or ethnically (see beginning of chapter for 'Key findings'). The variations in health status and deprivation of caregivers indicate that councils with social service responsibilities are likely to experience differing demands for support from unpaid caregivers depending on area characteristics. Variations in the proportion of caregivers from minority ethnic groups may also have implications for the type of support services needed.

Having examined characteristics of caregivers in 2001 by geographic region, in the next chapter we focus in more depth on young caregivers aged 20–29, before moving on in later chapters to look at midlife and older caregivers, and life-course, health and employment characteristics associated with caregiving.

3 Young caregivers

Key findings

- Among young adults aged 20–29 in 2001, likelihood of caregiving for 20+ hours per week was higher among women than men; higher among 25–29 year olds than those aged 20–24; and higher among those who had lived with one parent rather than two parents in 1991.
- Prevalence of extensive care provision among young women in 2001 increased steadily with the number of children born since 1991. This suggests that, among young women, caregiving may be associated with having a child with special needs.
- Young caregivers, whether men or women, had fewer educational qualifications and included higher proportions out of the labour force than their peers who were not providing extensive unpaid care.

Introduction

This chapter presents analysis of characteristics of young care providers aged 20–29 in 2001. Caregiving is strongly age-related and the proportion of young people providing 20 or more hours of care per week is low (1.3 per cent of the population of this sample compared with 5.7 per cent of the population aged 40–79). However, if caregiving at a young age involves reduced opportunities for education and labour-market participation, these may have lifelong impacts on income and socio-economic status. Knowing more about the characteristics and needs of this group is therefore important. Here we investigate the family characteristics of young people providing extensive amounts of care, and also investigate associations between caregiving, educational attainment and labour market participation.

Our specific objectives are as follows:

- to examine the household and family characteristics of young people providing 20 hours or more care per week in 2001
- to examine differences in educational and employment characteristics of young caregivers providing extensive care, compared with their peers who do not provide care and those who provide only one to 19 hours of care per week.

We chose to focus on the 20–29 year old age group because most people in this age band have completed all or most of their education and have entered the labour market; differences between caregivers and non-caregivers, if they exist, may therefore be detected more clearly than through examination of caregiving among teenagers. We expected that, in fact, there would be differences between caregivers and non-caregivers in this age group, and that caregivers might have fewer educational qualifications and lower labour market involvement, reflecting the competing demands on their time.

We used data from the 1991 and 2001 Census, and also information on number of children born to women in the LS sample between 1991 and 2001 (categorised here into nought, one, two, or three plus children born). We limited the sample to young people who lived with one or both parents in 1991 (when they were aged ten to 19), as we wanted to investigate associations between caregiving and family structure in adolescence. We categorised position in family and family type in 2001 as: child in a two-parent family; child in a one-parent family; living with a partner only; living with a partner and their own children; lone parent; and ‘other’. Other variables investigated were, of course, caregiving status in 2001 (whether or not caring for 20 or more hours per week), highest educational qualification in 2001 (A level, or degree, or equivalent; GCSEs or equivalent; other; none) and employment status in 2001 (not working; part-time employed; full-time employed).

Household and family characteristics of young caregivers

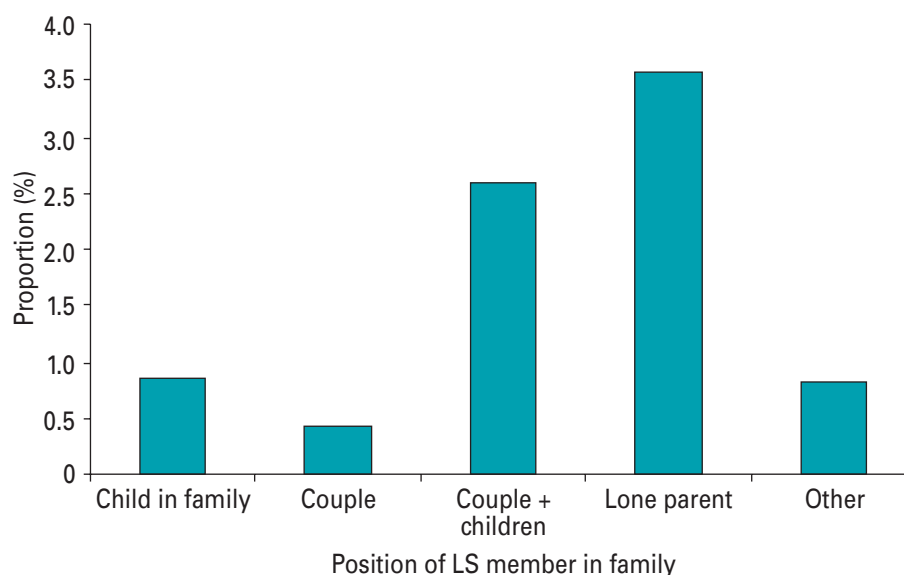
As shown in Table 3, only 1.3 per cent of this sample (547 individuals) were providing care for 20 hours or more per week in 2001. Those who lived in a one-parent family in 1991 were more likely to provide care in 2001. Women were also more likely to be caregivers than men.

We also examined prevalence of care provision by family and household composition in 2001. We distinguished between those who lived as a child in a family with their own parents, and those who lived in households with partners and possibly children. Figure 8 shows that there was a much higher caregiving propensity for those who were living with their own children in 2001 than those who were still living with parents, or living as a couple with no others.

Table 3 Proportion of the population aged 20–29 in 2001 who lived with one or more parent in 1991 providing unpaid care for 20+ hours per week in 2001, England and Wales

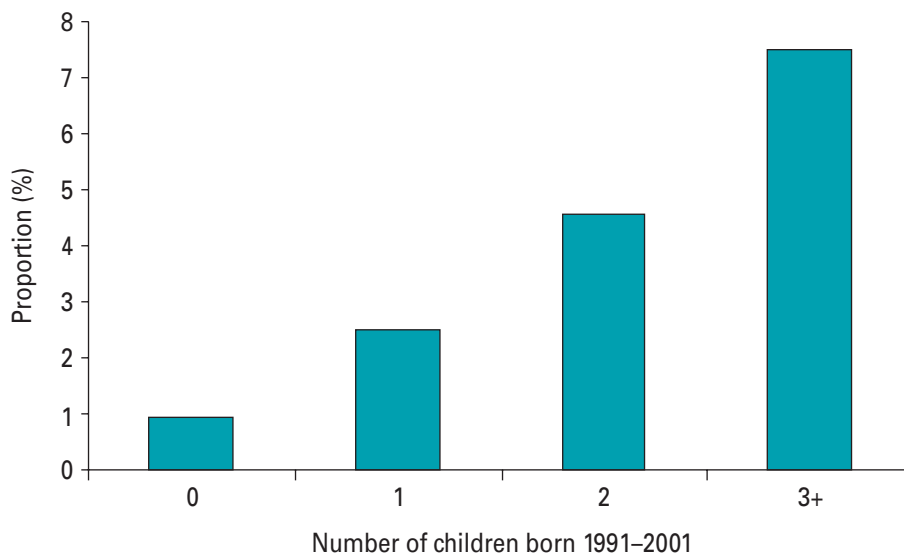
Variable	Category	Proportion (%)	Number of carers
<i>Age</i>	20–24	1.08	227
	25–29	1.43	320
<i>Gender</i>	Male	0.81	174
	Female	1.71	373
<i>Living with parents in 1991</i>	Two parents	1.14	423
	One parent	1.95	124
	<i>Total</i>	<i>1.26</i>	<i>547</i>

Figure 8 Proportion of the population aged 20–29 who lived with one or more parent in 1991 providing care for 20+ hours per week by position in family in 2001, England and Wales



Those with children were the most likely to provide care, so we examined whether the proportion of female caregivers varied with number of children born since 1991 (Figure 9). This shows increasing proportions of caregivers (for 20 or more hours per week) with increasing number of children born. The strength of this association, coupled with the fact that young carers were most likely to provide care if they lived in households with children, implies that many of these young carers may have provided care for a disabled child. This, however, would need to be verified with further research.

Figure 9 Proportion of women aged 20–29 who lived with one or more parent in 1991 providing unpaid care of 20+ hours per week in 2001 by number of children born since 1991, England and Wales



Caregiving at a relatively young age may restrict educational and employment opportunities, so we examined the educational and employment status of carers aged 20–29 in 2001 compared with those not providing care.

Educational status of young caregivers

Figure 10 shows highest educational qualification obtained, by caregiving status. Those providing unpaid care for 20 hours or more per week in 2001 were approximately half as likely to have A levels or a degree than those not providing care, and over twice as likely to have no formal qualifications. This pattern varied little by gender (results not shown).

We also used logistic regression to examine whether educational qualification differed by caregiving status after controlling for other factors that may have influenced this result. These include gender, age group, employment status, housing tenure, marital status, ethnic group and presence of limiting long-term illness, all in 2001. This analysis indicated that those who provided care of 20 hours or more per week were 1.97 times more likely to have no educational qualifications than A levels or a degree (95 per cent confidence interval [CI] 1.43–2.71) and 1.82 times more likely to have GSCEs only rather than A levels or a degree (CI 1.42–2.33).

Figure 10 Highest educational qualification for the population aged 20–29 who lived with one or more parent in 1991 by caregiving status in 2001, England and Wales

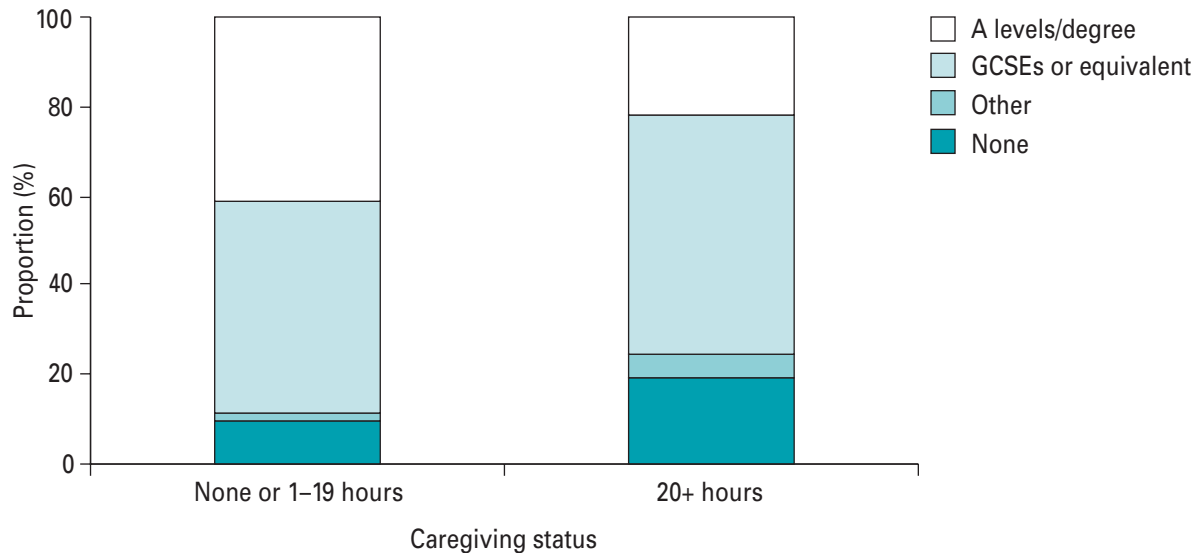
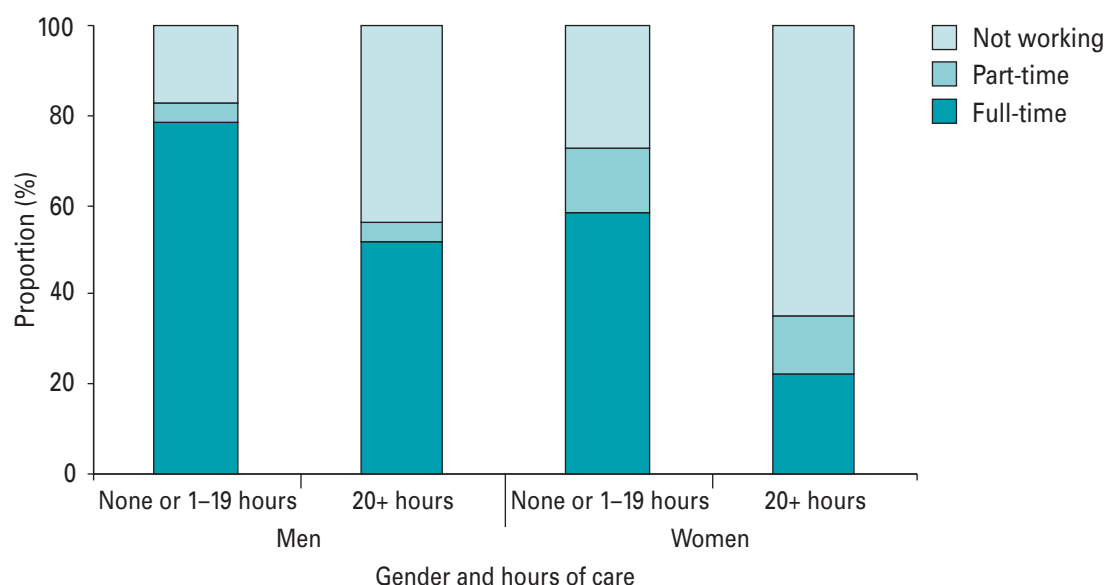


Figure 9 showed that young women were more likely to provide care if they had had children in the previous ten years. However, having children at an early age may itself influence educational outcomes. In order to take account of the effect of this on the association between care provision and educational qualifications, we carried out logistic regression, again for women only, controlling additionally for number of children born. Results indicated that women who provided care were still 1.6 times more likely to have no educational qualifications (CI 1.07–2.38) than A levels or a degree and 1.4 times more likely to have only GCSEs (CI 1.03–1.91). In short, this association between care provision and educational level was weaker, but still significant, after controlling for number of children.

Employment status of young caregivers

Figure 11 shows the distribution of employment status for those aged 20–29 by caregiving status in 2001, for men and for women. For both sexes, those who provided care in 2001 were half as likely to work as those who did not provide care or provided only one to 19 hours of care per week. Men who provided extensive care for 20+ hours per week in 2001 were 34 per cent less likely to work full-time than non-carers or those who provided less care. The equivalent figure for women was 62 per cent. However, caregiving appeared to have no association with part-time work. Proportions working part-time were almost identical for both groups.

Figure 11 Employment status for the population aged 20–29 who lived with one or more parent in 1991 by gender and caregiving status in England and Wales, 2001



As for the analysis of education and caregiving already discussed, we used logistic regression to ascertain whether these associations remained after control for other factors that may have influenced these results. Factors controlled for included age, education, housing tenure, marital status, ethnic group and health status, all in 2001. The results indicate that, for men, those providing extensive care were three times more likely to not work than to work full-time, than those providing less or no care. Women providing care were nearly four times more likely to not work than to work full-time. For women, this may have been associated with the fact that caregiving propensity grows with increasing number of children born, and those with children are less likely to be employed. After control for the number of children born, the strength of the association was smaller but still present – women providing care were now three times more likely to not work than to work full-time.

Conclusions

In this analysis, we focused on family characteristics and educational and employment correlates of caregiving in 2001 for young carers aged 20–29. Results indicate that young people providing 20+ hours of care per week had lower levels of employment than those who provided no care or less care. Results also indicate fewer educational qualifications for young carers than for others. We are unable to make the assumption that these characteristics are an outcome of care provision because the LS does not have data on caregiving before 2001. Instead, the results

may indicate that those of lower socio-economic status (who probably have fewer educational qualifications) are more likely to provide care, or that those with no employment may have more time to provide care. More research using other data sets would need to be carried out to verify that these outcomes are a consequence of care provision. Research to date has shown that care provision can have negative outcomes for employment.

These results do, however, indicate that young extensive carers have lower levels of education and less employment than non-carers of the same age. This is likely to have consequences for the quality of life and future opportunities of young care providers. They therefore may need support to ensure that they are able to develop their life skills and fulfil their potential.

In this chapter, we have looked at relationships between caregiving and employment among young adults. In the following chapter, we examine this association among those aged 35–59, and also look at associations between caregiving and health for this older age group.

4 Caregiving, employment and health

Key findings

- Among those aged 35–59 in 2001 who were in employment, higher proportions of extensive care providers were in poor health than those who provided less or no care.
- We are not able to determine whether employment and poor health are a consequence of caregiving or a causal factor in care provision. Nevertheless, these findings indicate that extensive caregivers are likely to have support needs of their own.

Introduction

This chapter presents analysis of correlates of caregiving for those who provided at least 20 hours of care per week in 2001. This analysis was an attempt to draw indirect inferences about possible consequences of care provision. The fact that census data on caregiving was collected only in 2001 means that we are unable to ascertain when caregiving began and are therefore unable to say with certainty whether, for example, poor health status in 2001 was partly due to the strain of providing care or whether those already in poor health were more likely to become caregivers. In order to limit the possibility of the factors of interest being antecedents rather than consequences of care provision, our study populations included those with similar characteristics in 1991 vis-à-vis our factors of interest in 2001.

Previous studies have suggested that caregiving may have a negative influence on health status and may lead to reduced participation in the labour market (Pavalko and Artis, 1997; Schulz and Beach, 1999; Beach and Schulz *et al.*, 2000; Henz, 2004). We therefore hypothesise that caregiving will be associated with poorer health status and being out of employment. Both of these possibilities are highly relevant to current policy debates about appropriate supports for caregivers and increasing work participation (Arksey and Kemp *et al.*, 2005).

Our specific objectives are as follows.

- For those who were employed full-time in 1991, to examine employment status in 2001 by caregiving status in 2001.

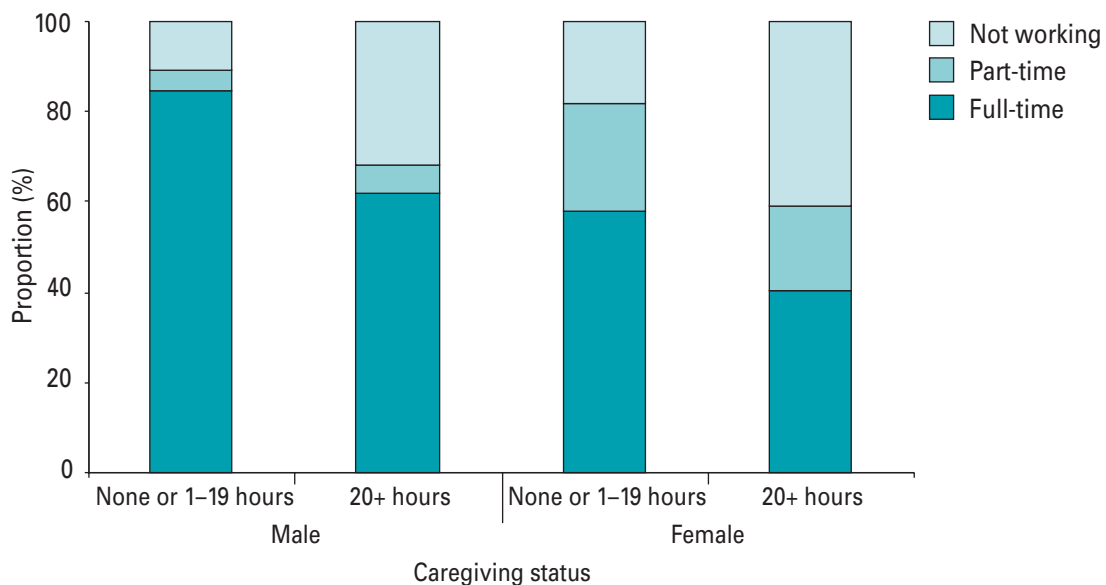
- For those in good health in 1991, to examine change in health status by 2001 for those providing extensive care compared to others in 2001.

In this analysis, our sample consisted of midlife carers aged 35–59 in 2001. We focused on the population under retirement age because we wanted to examine associations between caregiving and employment status in 2001. We used data from the 1991 and 2001 Censuses. In addition to caregiving for 20 hours or more per week in 2001, our main variables of interest were employment status in 2001 (not working, working part-time and working full-time) and presence of limiting long-term illness in 2001 (yes or no) as an indicator of health status. As stated above, for analysis of employment and caregiving, we restricted our analysis to those who were full-time employed in 1991. For analysis of health and caregiving, we restricted our analysis to those with no limiting long-term illness in 1991.

Possible employment consequences of caregiving for midlife adults

For those who were employed full-time in 1991, we examined employment status in 2001 by caregiving status in 2001. Figure 12 presents results of this analysis by gender. Over 80 per cent of men who were not caregivers or who provided care for less than 20 hours per week were in full-time employment in 2001, compared with

Figure 12 Employment status in 2001 for the population aged 35–59 who were employed full-time in 1991 by gender and caregiving status in 2001, England and Wales



only 60 per cent of those providing care for 20 hours per week or more. Among women, just under 60 per cent of the non- or light carers worked full-time in 2001 compared with only 40 per cent of heavy carers.

Comparison of Figure 12 with the equivalent figure for those aged 20–29 (Figure 11) shows that, in both age groups, the association between employment status and care provision was similar. However, in the 20–29 age group, higher proportions of each sub-population were not in work. This may reflect that higher proportions of this age group were still in education, just entering the job market, or looking after young children at home.

We undertook logistic regression analysis to look at the association between being a caregiver (for 20 hours or more per week) in 2001 and economic activity, taking account of other relevant factors including marital status, education, housing tenure, region and health status. This showed that men who were caregivers were 3.4 times (CI 2.96–3.81) more likely to not work than to work full-time in comparison to those not providing care. The equivalent ratio for women was 2.9 (CI 2.49–3.30). These results therefore suggest that, for this population group, reduced employment participation may be a consequence of unpaid extensive care provision, for both men and women. However, as we do not have information on when people became caregivers, it is also possible that the association reflects that people not in employment may be more available to take on caregiving roles. In other words, withdrawal from the labour market may precede rather than be a consequence of caregiving. Either way, the lower levels of economic activity among those providing extensive care clearly have implications for both their current and future income, and need for benefits and other supports.

Possible health consequences of caregiving for midlife adults

For this analysis, we used the study population aged 35–59 in 2001 who did not have a limiting long-term illness (LLTI) in 1991. We analysed the proportion of this population who had developed an LLTI by the 2001 Census, comparing those who provided extensive care in 2001 with those who did not.

Figure 13 shows the proportion of the population who had developed an LLTI by age group and caregiving status in 2001. This shows that the propensity to have an LLTI in 2001 increases with age, as expected. It also shows that, in all age groups, those who provided unpaid care for 20 or more hours per week included a higher proportion with an LLTI than those who provide less or no care. In the 35–44 and

45–54 age groups, those providing 20 hours or more care per week in 2001 were approximately 80 per cent more likely to have an LLTI than those providing less or no care. In the 55–59-year-old age group, the difference was smaller, but still substantial with an increased risk of LLTI for carers of approximately 40 per cent.

Of course, this association between caregiving and development of an LLTI by 2001 could reflect both health status and likelihood of becoming a carer being connected with some other factor, rather than being causally related. For example, poor health might lead some people to withdraw or reduce their labour market activity and, as we have seen, reduced labour market activity 1991–2001 was associated with caregiving in 2001. In order to investigate this, we looked in more detail at the prevalence of LLTI among caregivers by employment status in 2001 (not working, working part-time, working full-time). We found, as shown in Figure 14, that those who were employed either full- or part-time in 2001 were more likely to have an LLTI if they provided extensive care. For those who worked full-time in 2001, extensive caregivers were 77 per cent more likely to have an LLTI and, for those working part-time, the increased likelihood was 51 per cent.

Among those who were not working in 2001, the proportions with an LLTI were much higher. However, among this group, those who were caregivers for 20 or more hours per week were *less* likely to have an LLTI than non- or lighter carers. People who were not in work may have had more serious levels of LLTI, which in some cases may have also constrained their ability to provide care.

We also carried out more complex regression analyses, which allowed us to control for other factors including age, gender, marital status, educational level, housing tenure and region of residence, all in 2001, to investigate these findings further. Results indicated that, among those employed full- or part-time at both 1991 and 2001, those who provided unpaid extensive care were 63 per cent more likely to have developed an LLTI by 2001 (CI 1.44–1.86) than those not providing extensive care. For those not employed at both points in time, those providing care were 28 per cent less likely to have developed an LLTI (CI 0.63–0.82).

For employed people, there were only minimal differences by gender in regression results. For those not working, gender differences were more pronounced. For non-working men, extensive care providers were 62 per cent less likely to have an LLTI than those not providing care or providing less care (CI 0.29–0.51). For non-working women, care providers were only 15 per cent less likely to have an LLTI than those not providing or providing less care (CI 0.74–0.98). This may indicate that non-working women are more likely to provide care irrespective of ill health.

Figure 13 Proportion of the population aged 35–59 with an LLTI in 2001 who did not have one in 1991, by age group and provision of care in 2001, England and Wales

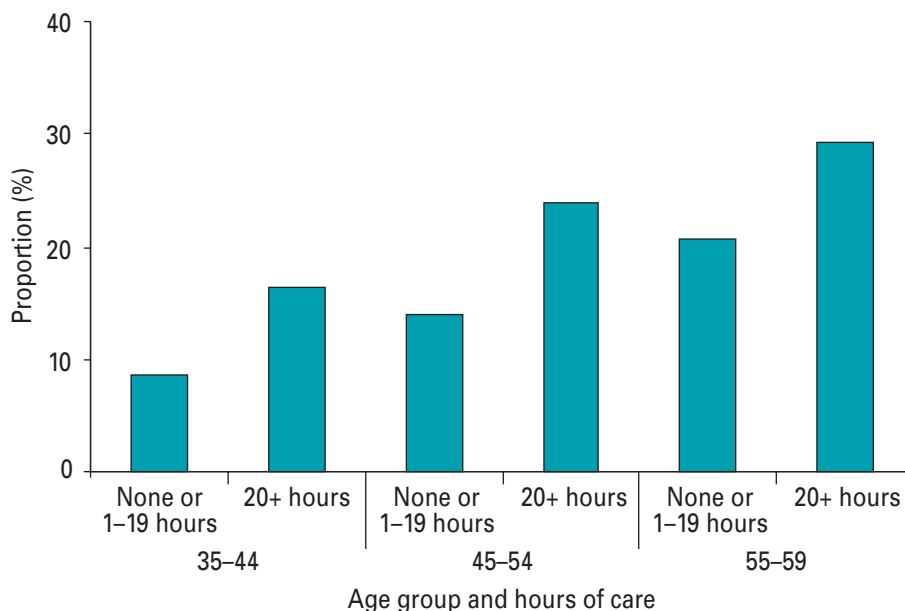
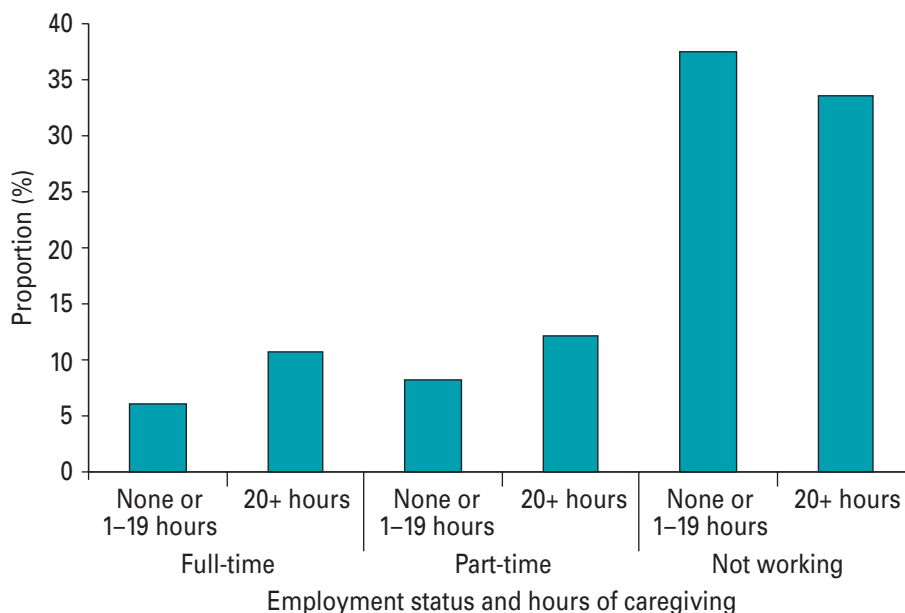


Figure 14 Proportion of the population aged 35–59 with an LLTI in 2001 who did not have one in 1991, by employment status and hours of unpaid caregiving in 2001, England and Wales



This analysis therefore suggests that, for those who are employed, poorer health status may be a consequence of care provision. However, those who are not working are more likely to already be in poor health, in which case health status may influence care provision rather than the other way round.

Conclusions

In this analysis, we focused on possible consequences of heavy care provision for midlife care providers aged 35–59 in 2001. This analysis indicates that midlife caregivers for 20+ hours per week had lower levels of employment than those who provided no care or less care. Results also indicate poorer health for midlife carers in employment. We cannot firmly conclude that these findings are the consequences of unpaid heavy care provision because of the nature of the LS data. Research to date has, however, shown that care provision can have negative outcomes for employment and health. Whatever the case, lower employment rates and poorer health are likely to have consequences for carers' quality of life and future opportunities.

In the next chapter, we examine another aspect of caregiving among midlife adults – caregiving and intergenerational co-residence.

5 Caring and co-residence: adult children living with elderly parents

Key findings

- Midlife adults with a limiting long-term illness at both 1991 and 2001 were less likely to provide extensive care for a co-resident parent than those who did not have a limiting long-term illness at either or both Censuses.
- Midlife adults in full-time employment at both 1991 and 2001 were less likely to be providing extensive care for a co-resident parent than those with a history of less employment.
- Being co-resident with the same parent at 1991 was not associated with caregiving status of the midlife adults at 2001. However, being co-resident with the same parent with an LLTI at 1991 did increase the chance of a midlife adult co-resident with an elderly parent being a caregiver.

Introduction

In this chapter, we examine the proportion of midlife adults living with an elderly parent or parent-in-law in 2001, and the proportion of these children providing care for 20 hours or more per week. We then examine which characteristics of the adult child are associated with increased chance of being co-resident, and of being co-resident and a caregiver.

In Britain, as in other western populations, only a small proportion of midlife adults live with a parent or parent-in-law at any one point in time, although the lifetime chance of such an arrangement is fairly high. Bumpass (1990), for example, estimated that, by the age of 60, a quarter of women in the United States would have had a parent or parent-in-law living with them at some point. This type of arrangement is an important element of the broader spectrum of family care provision. For unmarried people with very extensive care needs, intergenerational co-residence may be the only alternative to institutional care. Understanding more about the factors associated with provision of such care is therefore important for planning purposes. Additionally, intergenerational co-resident carers, whether they are an elderly parent caring for a disabled adult child or an adult child caring for a

frail parent, may have particular needs for carer support services. Previous studies based on the ONS LS have analysed the characteristics of adult children living with elderly parents in 1981 and in 1991 (Grundy and Harrop, 1992; Grundy, 2000). This work showed that unmarried adult children with no children of their own were the most likely to live with a parent; that co-residence was higher among owner-occupiers than tenants; and that, in 1991, married women who were employed were less likely to co-reside with a parent than women not working outside the home. Results also showed a decline in the proportion of midlife adults living with a parent between 1981 and 1991. In this earlier work, inferences about who was supporting whom in intergenerational households had to be drawn indirectly from information about the characteristics of the parties involved. However, the availability of information on caregiving in the 2001 Census means that here it is possible to see what proportion of adult children living with a parent were caregivers and also to look at this in relation to the health of both parent and child.

Our specific objectives are to examine:

- 1 what characteristics of midlife adults are associated with being co-resident with an elderly parent
- 2 among co-resident children, what characteristics are associated with providing 20 or more hours of care per week.

In this chapter, we focus on adults aged 35–64 years at 2001 who were present in the sample in 1991. We first look at what proportion of those in this broad group were living with an elderly parent or parent-in-law and at characteristics associated with this type of co-residence. We also investigate what proportion of those who lived with an elderly parent in 2001 were also living with a parent ten years earlier. We then examine the proportion of these co-resident children who said they were providing care for 20 or more hours per week and how this was associated with characteristics of the parent and the LS sample member.

The main variables used within this chapter relate to the midlife adult at 2001, unless specified otherwise. These include caregiving, presence of LLTI (for both the midlife adult and the parent at 1991 and 2001), economic activity (using a score of economic activity at 1991 and 2001), marital status and housing tenure. We also ascertained whether the midlife adult was living with the same parent at 1991.

Adults aged 35–64 who lived with an elderly parent

Of the 183,187 LS members aged 35–64 in 2001 (who had been in the sample in 1991), 5,203 (2.8 per cent) lived with one or more parents or parents-in-law aged 65 and over. Differences in this proportion by age group, gender and marital status are shown in Table 4. There was little difference between the 35–44 year old and 45–54 year old groups, but the proportion of people co-resident with a parent was much lower among 55–64 year olds, many of whom may not have had a parent still alive (Grundy, 2000; Murphy and Grundy, 2003). Never-married midlife adults, particularly men, were far more likely than the ever-married to live with an elderly parent and the proportions co-residing were lowest among the currently married. Comparison with results from the LS for 1981 and 1991 (Grundy and Harrop, 1992; Grundy, 2000) shows a continuing decline in the proportion of midlife adults living with an elderly parent. For example, in 1981, 42 per cent of never-married men aged 35–44 lived with an elderly parent, by 1991 this had fallen to 30 per cent and, as can be seen in Table 4, in 2001 stood at 21 per cent. Equivalent proportions for never-married women of the same group were 33 per cent in 1981, 23 per cent in 1991 and 13 per cent in 2001.

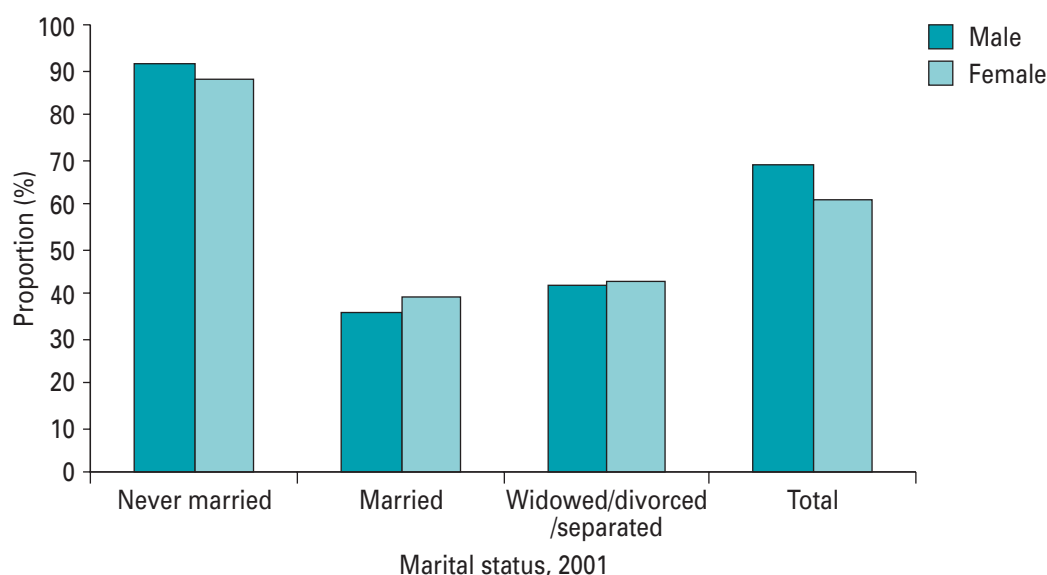
Two-thirds of the adult children who lived with a parent in 2001 had lived with the same parent in 1991, as shown in Figure 15. This proportion varied considerably by the child's marital status. Ninety per cent of never-married children living with a parent in 2001 had co-resided with the same parent in 1991 (and presumably many of these had never left the parental home), compared with 37 per cent of currently

Table 4 Proportion and number of adults aged 35–64 co-resident with a parent aged 65 or over by gender, age and marital status, 2001

Gender and age group, 2001	Marital status						All	
	Never married		Married		Widowed/divorced/separated			
	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>
<i>Men</i>								
35–44	20.5	958	1.1	276	8.0	202	4.6	1,436
45–54	25.0	662	1.4	352	6.2	193	3.9	1,207
55–64	12.0	192	1.1	235	1.9	51	1.9	478
All	20.3	1,812	1.2	863	5.3	446	3.6	3,121
<i>Women</i>								
35–44	13.2	473	1.0	251	2.3	110	2.4	834
45–54	18.5	317	1.4	356	2.7	140	2.5	813
55–64	8.8	93	1.1	220	1.6	90	1.5	403
All	13.9	883	1.2	827	2.2	340	2.2	2,050

married and 42 per cent of formerly married children. In some cases, poor health of the child rather than of the parent may be associated with remaining in the parental home. We investigated characteristics of midlife adults associated with being co-resident with a parent using logistic regression to take account of a range of possible influences. These were: actual age; gender; marital status; limiting long-term illness in both 1991 and 2001; economic activity in 1991 and 2001; and housing tenure. We found that those who were never married at 2001 had nearly 20 times the odds of being co-resident with an elderly parent than those who were married at 2001 (odds ratio 19.8; 95 per cent CI 18.46, 21.22). The results also showed that adults who had a limiting long-term illness in 1991 were more likely to live with a parent than others. Co-residence was also associated with being an owner-occupier (a household rather than individual characteristic).

Figure 15 Proportion of midlife adult children co-resident with a parent at 2001, who were co-resident with the same parent at 1991, by marital status and gender



Characteristics of the co-resident parents

Table 5 summarises the demographic characteristics of the 6,148 parents/parents-in-law living with these 5,203 adult children by child's gender and age group. In cases where there was more than one co-resident parent or parent-in-law, the information on demographic and health characteristics relates to the oldest. As would be expected, given that older children will tend to have older parents, the mean age of co-resident parents increased with age group of the child, as did the proportion of widowed parents, the proportion of female parents and the proportion with a limiting long-term illness.

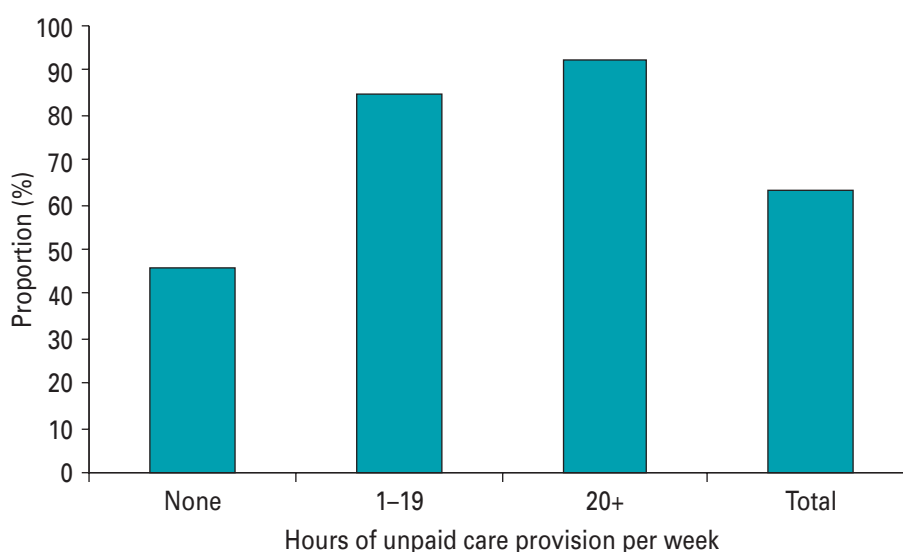
Table 5 Characteristics of elderly parents co-resident with midlife adult child, by gender and age of child at 2001

Gender and age group, 2001	Mean age	% female	% widowed	% with limiting long-term illness	<i>n</i>
<i>Men</i>					
35–44	72.2	52.3	49.1	50.2	1,444
45–54	78.3	67.4	71.9	63.9	1,211
55–64	84.8	80.4	87.9	75.0	480
<i>Women</i>					
35–44	72.8	55.5	54.3	50.9	843
45–54	79.2	70.6	76.4	65.3	820
55–64	86.1	83.4	89.6	84.0	405

Co-resident children who were caregivers

Twenty-one per cent of our sample of midlife adults who lived with an elderly parent reported providing care for 20 hours or more per week. Not surprisingly, provision of care was associated with parent’s health status, as illustrated in Figure 16. This shows that 93 per cent of co-resident children providing 20 hours or more of care per week lived with a parent who had a limiting long-term illness compared with only 46 per cent of children who were not providing care. These results suggest that, although we do not have direct information on who care was provided to, it seems reasonable to assume that, in most cases, co-resident children who said they were providing care for 20 or more hours a week were providing this care to their elderly parent/parent-in-law.

Figure 16 Proportion of co-resident children living with a parent who had a limiting long-term illness, by child’s provision of care, 2001



Demographic and other differences in the proportion of co-resident children who provided 20 or more hours of care per week are shown in Table 6. The proportion of co-resident children who reported providing care for 20 hours per week or more increased with age and, as illustrated in Figure 17, this association was consistent within, as well as between, the broad age groups used. A higher proportion of daughters than sons were caregivers, and further breakdown showed this was particularly the case for married daughters (Figure 18). This is consistent with the literature on gender differences in caregiving and results of other studies, which have shown that unmarried (particularly never-married) children may live with elderly parents because of their own support needs (for example, their own poor health or following divorce or unemployment) whereas, where the child is married, support flows are more often from child to parent (Speare and Avery, 1993).

Table 6 Number and proportion of midlife adults co-resident with an elderly parent who are assumed to provide 20+ hours of care per week for the parent at 2001, by socio-demographic and health characteristics

	<i>n</i>	%
<i>Gender (n = 5,203)</i>		
Male	492	15.7
Female	598	28.9
<i>Age group, 2001 (n = 5,203)</i>		
35–44	251	11.0
45–54	466	22.9
55–64	373	42.1
<i>Marital status, 2001 (n = 5,171)</i>		
Never married	445	16.5
Married	459	27.2
Widowed, divorced or separated	178	22.6
<i>Economic activity</i>		
<i>1991 economic activity (n = 5,203)</i>		
Full-time	655	18.2
Part-time	141	35.3
Not working	294	24.4
<i>2001 economic activity (n = 4,894)</i>		
Full-time	365	12.9
Part-time	158	26.6
Not working	500	34.2
<i>1991–2001 economic activity score (n = 4,894)</i>		
Most work	306	12.4
Some work	425	29.0
Least work	292	30.4

(Continued)

Table 6 Number and proportion of midlife adults co-resident with an elderly parent who are assumed to provide 20+ hours of care per week for the parent at 2001, by socio-demographic and health characteristics (Continued)

	<i>n</i>	%
<i>Lived with same parent in 1991 (n = 5,203)</i>		
No	412	23.0
Yes	678	19.9
<i>Lives with same parent in 1991 and parent then had LLTI (n = 5,203)</i>		
No	788	18.4
Yes	302	32.8
Own health		
<i>1991 health (n = 5,203)</i>		
No LLTI	989	21.2
LLTI	101	18.8
<i>2001 health (n = 5,128)</i>		
No LLTI	798	19.8
LLTI	273	25.1
<i>1991–2001 health score (n = 5,128)</i>		
No LLTI – No LLTI	767	19.5
No LLTI – LLTI	204	30.8
LLTI – No LLTI	31	29.8
LLTI – LLTI	69	16.2
<i>Housing tenure (n = 5,097)</i>		
Owner-occupier	834	20.0
Social rental	178	23.8
Private rental	34	27.4
Other	19	30.2

Figure 17 Proportion of midlife adults co-resident with an elderly parent in 2001 who provided 20+ hrs of unpaid care per week, by age

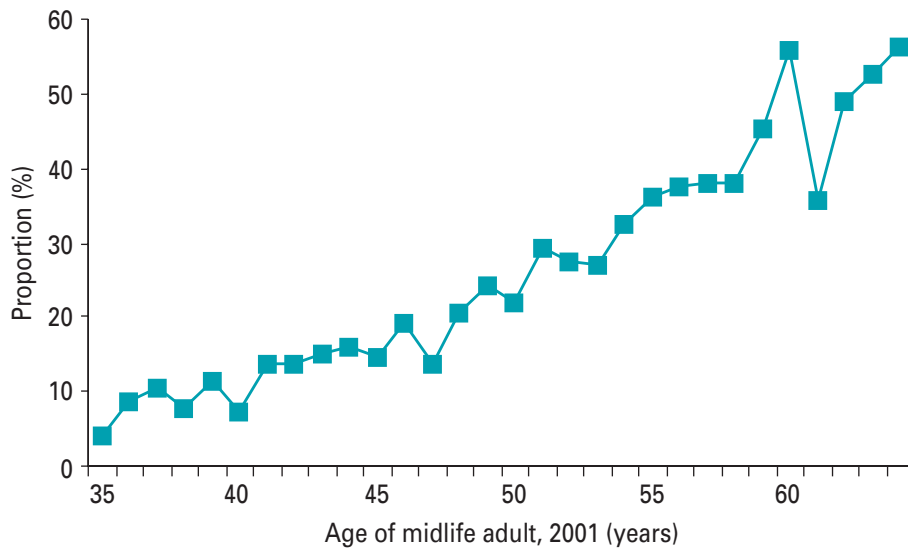
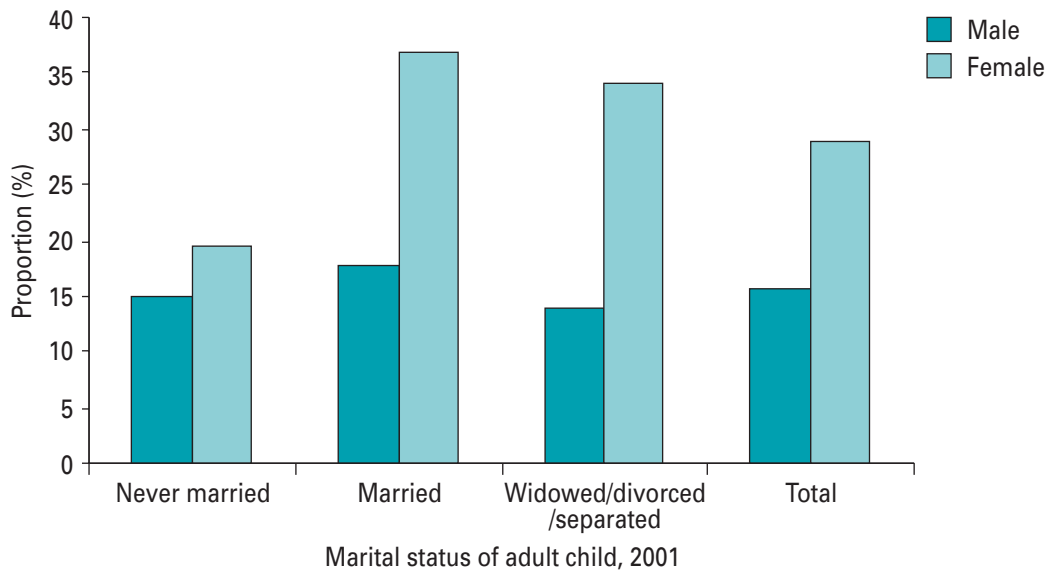


Figure 18 Proportion of midlife adults co-resident with an elderly parent in 2001 who provided 20+ hrs of unpaid care per week, by gender and marital status



In terms of other characteristics of co-resident children associated with providing extensive care, we found that those who had worked full-time in 1991 and were working full-time in 2001 were less likely to provide extensive care. We derived an economic activity score based on employment in both 1991 and 2001 to look at this further. We allocated three points for those employed full-time, two for part-time and one for not employed at each point in time. We aggregated the score for the two census points to obtain a score ranging from 2 to 6. We used this to distinguish a low employment group (score of 2 and 3), intermediate employment group (score of 4 and 5) and high employment group (score of 6) who were employed full-time at both the 1991 and 2001 Censuses. Unsurprisingly, those with least employment were most likely to provide extensive care.

In order to investigate these differences further, we used logistic regression to analyse differences in the proportion of co-resident children who provided 20 or more hours of care per week, taking account of all the factors shown in Table 6. Results showed that, among co-resident children, each of the following factors increased the chance of an individual providing 20 or more hours of care:

- being female
- older age
- being married
- not having an LLTI at one or both Censuses
- not being in full-time employment at both census points of 1991 and 2001.

Parents who were caregivers

We also examined co-resident care involving elderly parents providing care to midlife adult children rather than the other way round. In order to investigate those that were likely to be providing care for a child, we excluded those with a spouse with an LLTI (as in these cases it would be difficult to identify care recipients), leaving a sample of 59,796 older people of whom 7.4 per cent were co-resident with at least one adult child. Of these co-resident elderly parents, only 4.5 per cent provided 20+ hours of unpaid care per week (in comparison with the 21 per cent of adult children discussed in the previous section who lived with a parent and provided 20 or more hours per week of care). The proportion of parents providing this extent of care did not vary

much by parental characteristics, including age, gender, marital status or own health status, but was higher among those living with a never-married child.

Conclusions

In this chapter, we focused on midlife adults, aged 35–64 years at 2001, living with at least one parent (or parent-in-law). First of all we looked at what proportion of adults of this age lived with an elderly parent and what characteristics were associated with this. We found that the proportions living with a parent were low overall, and lower than in 1991, but varied considerably by gender and marital status, and were quite high in some sub-groups. For example, a quarter of never-married men aged 45–54 lived with an elderly parent. Odds of being co-resident with a parent were very much higher for the never married and were also higher overall for men compared with women, and for those in owner-occupied housing compared with rented housing. Two-thirds of these co-resident children had lived with the same parent ten years earlier.

Next, we looked at what proportion of these co-resident children were likely to be providing care for their parent or parents. Overall, 21 per cent of children reported providing care for 20 or more hours a week and nearly all of these lived with a parent who had a limiting long-term illness. Caregiving by co-resident children was associated with being female, being married, being a tenant and not being in full-time employment. We cannot say for certain whether providing care led to reduced employment but, as with the findings reported in Chapter 4, lower full-time employment rates among co-resident children providing extensive care have implications for their living standards and possible needs for support.

In the next chapter, we examine in more detail antecedent characteristics of those who were providing care – whether co-resident or not – in 2001.

6 Pathways to caregiving: life-course characteristics of caregivers

Key findings

- Among men aged 40–59, the never married were most likely to be providing extensive care. Among women of the same age group, the never married and married were equally likely to provide care. Among older men and women aged 60–79, the married were much more likely to provide care than those in other marital status groups.
- For both genders and age groups, the widowed and divorced were less likely to provide care than other marital status groups. This finding is consistent with findings from other studies. Our results also suggest a lower propensity to provide care if divorce or widowhood happened more recently, although this finding would need further investigation.
- For both men and women, those of lower socio-economic status (using highest educational qualification as an indicator) were most likely to provide care. This association was strong for those aged 40–59, but much less so among those who were older.
- Women were less likely to provide unpaid extensive care if they had a history of strong attachment to the labour market with respect to family commitments.
- Women with a history of employment were more likely to provide unpaid care for 20 hours or more per week in 2001 if they concurrently worked in the public sector or had a history of working in a job with a caregiving element, such as nursing.

Introduction

In this chapter, we compare the previous life-course characteristics of people aged 40–79 who were providing 20 or more hours of care per week in 2001, with those who were providing no care or only one to 19 hours of care per week. There is

limited research to date on the prior life-course characteristics of caregivers and this analysis casts light on how propensity to provide care varies in the population.

Our specific objectives were to:

- 1 analyse the association between caregiving in 2001 and marital status, including history of divorce and widowhood, for both men and women
- 2 examine associations between caregiving and socio-economic status
- 3 examine associations between caregiving and both present and previous history of employment
- 4 ascertain whether the following factors are associated with care provision in 2001 for women who have a history of employment:
 - current employment in the public sector, or a history of employment in a caregiving profession
 - history of attachment to the labour market after childbearing.

There is considerable debate as to whether changes in family-related behaviour, such as increases in divorce and changes in the employment patterns of women, may be associated with reductions in the ability or willingness to provide care for family members. We therefore examined associations between marital status and caregiving in order to test the hypothesis that women with more stable marriage patterns may be more willing to undertake caregiving (although the fact that much care is undertaken by spouses for spouses must be taken into account in analysis).

We also examined further associations between socio-economic and educational status and propensity to provide care. This is of interest both to help identify factors that increase or decrease likelihood of becoming a carer, and to see whether caregivers are disadvantaged throughout adulthood. Additionally, in examining relationships between employment history and caregiving, we hypothesised that women with a strong labour market attachment who carried on working when they had a small child might be less likely to become a caregiver later than women who adapted their working life to family circumstances by giving up paid work or moving to part-time employment. We also examined characteristics of employment for women to see whether those whose paid work had included a caring element were more likely to later become unpaid caregivers and also to see whether public sector workers were more likely to have caregiving responsibilities, perhaps because they had conditions of work that made combining these roles easier.

For this analysis, we use data from the 1981, 1991 and 2001 Censuses, and focus on caregivers aged 40–79 in 2001, who were therefore aged 20–59 in 1981. We selected this age range so that all individuals were of working age in 1981 and so that we had sufficient data on their previous life course as adults in 2001. The upper age limit was chosen so that a significant proportion were likely to still be alive in 2001. For employment analyses, we focus only on those below retirement age in 2001, aged 40–59.

We used 2001 census data for information on highest educational qualifications and on marital status. We also used data from the 1981 and 1991 Censuses to obtain information on marital and employment history. For marital history, we developed a variable measuring timing of divorce and widowhood, distinguishing between divorce and widowhood pre- and post- the 1991 Census. We also used a simple measure of employment history for those aged 40–59 in 2001, using data on employment status in 1981 and 1991. We discounted those aged 60–79 because this group was less likely to have been in employment in 1981 and 1991. We used the scoring system described in Chapter 5, allocating three points for those employed full-time, two for part-time and one for not employed at each point in time. We aggregated the score for the two census points to obtain a score ranging from 2 to 6. We used this to distinguish a low employment group (score of 2 and 3), intermediate employment group (score of 4 and 5) and high employment group (score of 6) who were employed full-time at both the 1981 and 1991 Censuses.

Sample characteristics

Our sample consisted of 185,959 individuals, including 10,357 people providing care for 20 hours or more per week. The propensity to provide care differed between men and women and by age, as shown in Table 7. Caregiving prevalence was higher for women than men at all ages except the oldest age group. Caregiving prevalence increased with age for men, but for women it increased and then decreased in the oldest age group considered.

Table 7 Numbers and proportion of the population aged 40–79 providing unpaid care for 20+ hours per week by gender and age group in England and Wales, 2001

Age group	Women		Men	
	Prevalence (%)	Number of carers	Prevalence (%)	Number of carers
40–49	5.45	1,530	3.42	887
50–59	7.19	2,092	4.18	1,144
60–69	7.38	1,613	5.26	1,102
70–79	5.58	1,006	6.71	983
<i>Total</i>	<i>6.43</i>	<i>6,241</i>	<i>4.63</i>	<i>4,116</i>

Caregiving and marital status

Figures 19 and 20 show the prevalence of extensive caregiving by marital status and age in 2001 for women and men, respectively. These figures show that there were different patterns of caregiving by marital status between the sexes and age groups. In all marital status categories and both age groups, women were more likely to be care providers than men.

Figure 19 Proportion of women providing unpaid care for 20+ hours per week by age and marital status, England and Wales, 2001

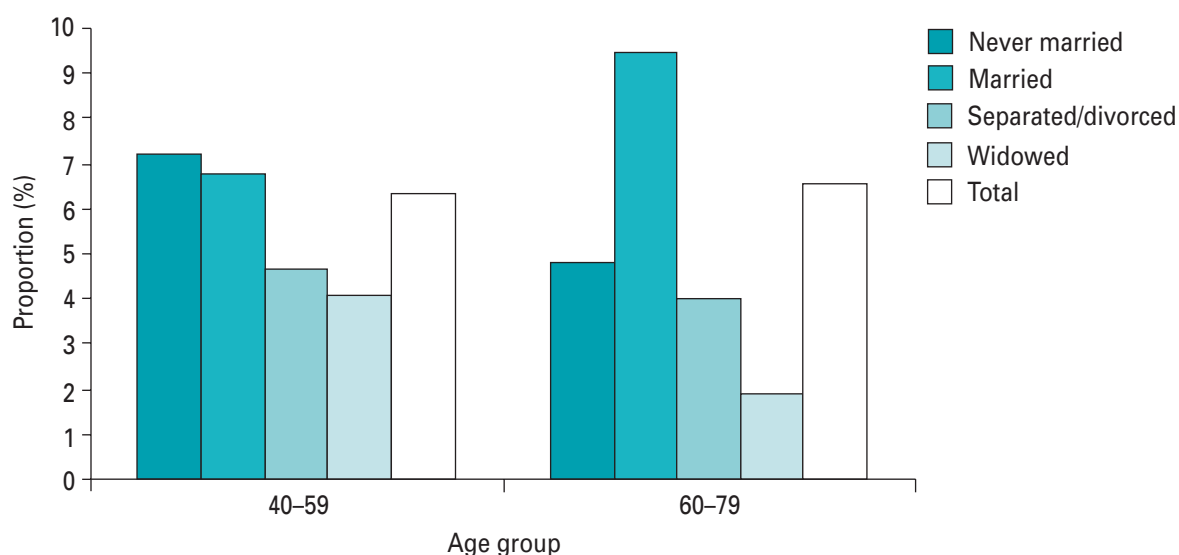
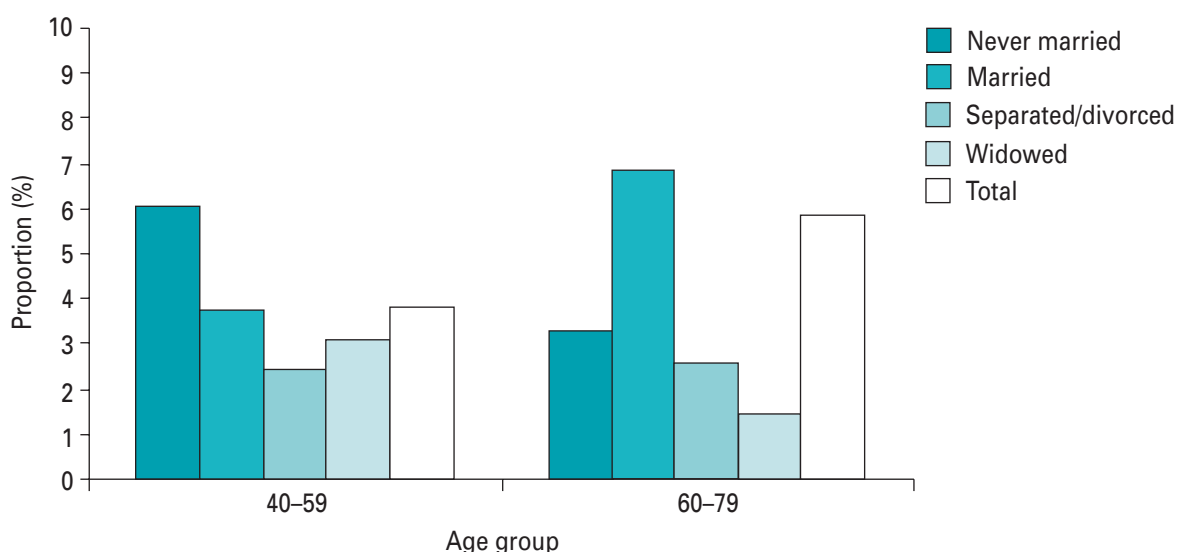


Figure 20 Proportion of men providing unpaid care for 20+ hours per week by age and marital status, England and Wales, 2001



In the younger 40–59 age group, women who were never married and married included a similar proportion of caregivers, at approximately 7 per cent. For younger men, the married group had a lower prevalence of care provision than never-married men. However, for both men and women aged 60–79, those who were married were much more likely to provide care than those in any other marital status group. For example, the married were over twice as likely to provide care as the never married.

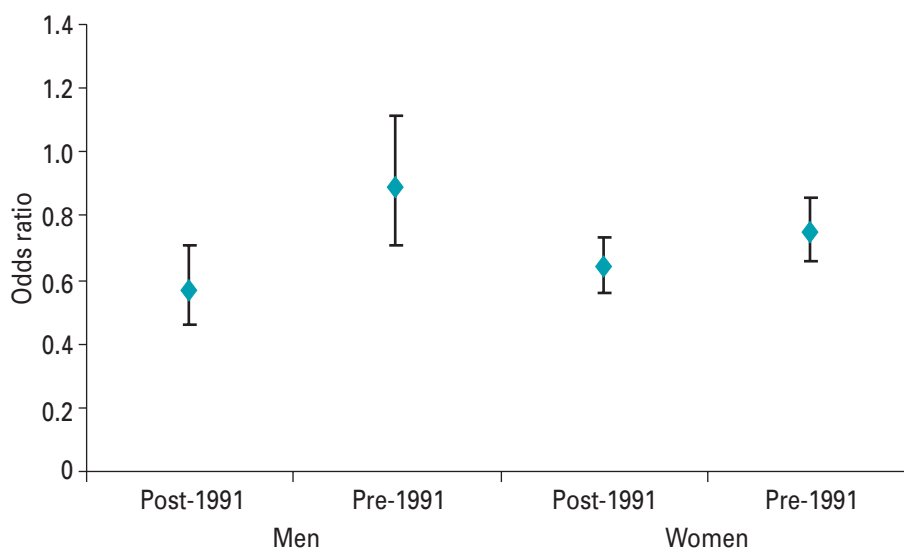
For both sexes and age groups, those who were separated or divorced and those who were widowed, were least likely to provide unpaid extensive care. The widowed group aged 60–79 included the lowest proportion providing care for 20 hours or more per week.

Research has shown that there is a complex relationship between marital status and caregiving, mediated by a number of factors including age, gender and the presence of co-residents, and availability of close-kin relationships (Brody and Litvin *et al.*, 1994; Hirst, 1999). Differences in the presence of co-residents and kin by marital status are likely to explain the major differences in Figures 19 and 20. The higher prevalence of care provision among married women and men in the age group 60–79 may reflect care provision for a spouse. The very low proportion of older widowed men and women providing care supports this suggestion. In the younger age group, care provision is likely to be for a member of the parental generation, and never-married children may be more likely to provide this type of care perhaps because they have fewer other commitments. As we saw in Chapter 5, never-married adults are more likely to live with an elderly parent than married or formerly married people.

In some cases, long-term caregiving commitments may be associated with the reasons for never marrying. The lower likelihood of care provision by younger widowed and divorced people may reflect the fact that they not only lack a spouse, but also are less likely to undertake caregiving for parents-in-law than their married counterparts. Stresses associated with becoming widowed or divorced may also influence propensity to become a caregiver, and the divorced group especially may have less of a family focus.

We also examined the influence of timing of divorce and widowhood on propensity to provide unpaid care for 20 hours or more per week in 2001. Figure 21 shows the odds ratios of care provision by timing of divorce (pre- and post-1991) for men and women, compared with those who remained married between 1991 and 2001. Note that an odds ratio of below 1 signifies a lower propensity to provide care than in the reference group of those who remained married. The key finding here, however, is the difference in the odds ratios between those divorcing pre- and post-1991. Figure 21 shows that, for both men and women, the likelihood of caregiving was lower for those who experienced widowhood or divorce post-1991 than those who experienced the event before 1991, although these differences were not statistically significant (as indicated by the fact that the lines showing the confidence intervals around the odds ratios overlap). In other words, there is some indication (though not unequivocal) that propensity to provide care is lower if an individual divorced more recently than if it happened at an earlier time. This finding may lend support to the hypothesis that disruption of lifestyle may be a causal factor in lower propensity to provide care. Further research would be needed to clarify these findings.

Figure 21 Odds ratio of proportion of the population aged 40–59 providing care for 20+ hours per week, by timing of event for those divorced compared with those remaining married 1991–2001 and by gender



Caregiving, education and employment

The socio-economic status of caregivers is of interest for several reasons. First, previous studies suggest that factors such as education may be associated with differentials in likelihood of becoming a carer. More highly educated people, for example, generally have higher-paid jobs than the less well educated and so may be less likely to want to take on a caregiving role if it involves giving up paid employment. A range of studies have also shown that more highly educated people have less frequent face-to-face contact with close relatives and are less likely to live near to them (Grundy and Shelton, 2001; Tomassini and Glaser *et al.*, 2004; Grundy, 2005). This supports other research showing that more highly educated groups tend to have networks and interests that are less family orientated than those of less well educated groups (Willmott, 1986). Conversely, because health is associated with socio-economic status, those in disadvantaged groups may be more likely to have a spouse in poor health and in need of care. Glaser and Grundy (2002), for example, found this effect in their analysis of spouse caregivers included in the 1988–94 Retirement Surveys. Apart from aiding understanding of the factors leading people to become caregivers, the socio-economic characteristics of caregivers are of interest because they may reveal needs for support relevant to policy and service providers.

As we showed in Chapter 2, the proportion of caregivers in local authority areas is highest in the most deprived areas. Here, we use the LS to extend this analysis by examining individual-level characteristics and their association with caregiving. We used highest educational qualification as an individual-level indicator of socio-economic status and examined its association with care provision. We then examined the associations of caregiving with employment status, both past and present. We limited analysis of employment to those aged 20–39 in 1981, who were therefore still of employment age in 2001.

Caregiving and education

The education variable comes from the 2001 census questions on educational and professional qualifications. These questions were asked only of those under age 75, so those aged 75–79 are excluded from this analysis. For this analysis we grouped education into four categories: first, those with no academic or professional qualifications; second, those with only GSCEs, up to one A level or NVQ level 2; third, those with two or more A levels, a degree or other qualification, such as a teacher, doctor, nurse, dentist. The final group consisted of those with other qualifications, for example City and Guilds, or those with unknown qualifications. Figure 22 shows highest educational qualifications by age group and gender. It

shows that approximately 60 per cent of men and women aged 60–74 had no formal qualifications, while 30–40 per cent of those aged 40–59 had none. Those with no qualifications comprised approximately 40 per cent of the whole population and those with A levels comprised approximately 20 per cent.

Figure 23 shows the prevalence of extensive care provision by educational level for women aged 40–59 and 60–74. This figure shows that, in the younger age group, there were clear differentials in care provision by highest educational level in 2001

Figure 22 Highest educational qualification by age and gender for the population aged 40–74 in England and Wales, 2001

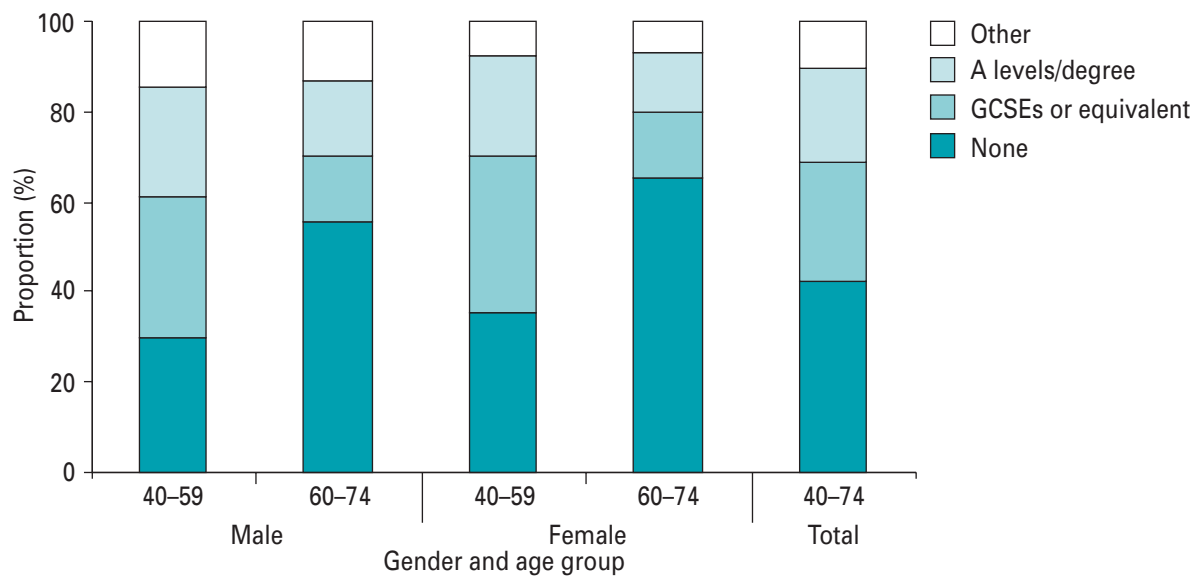
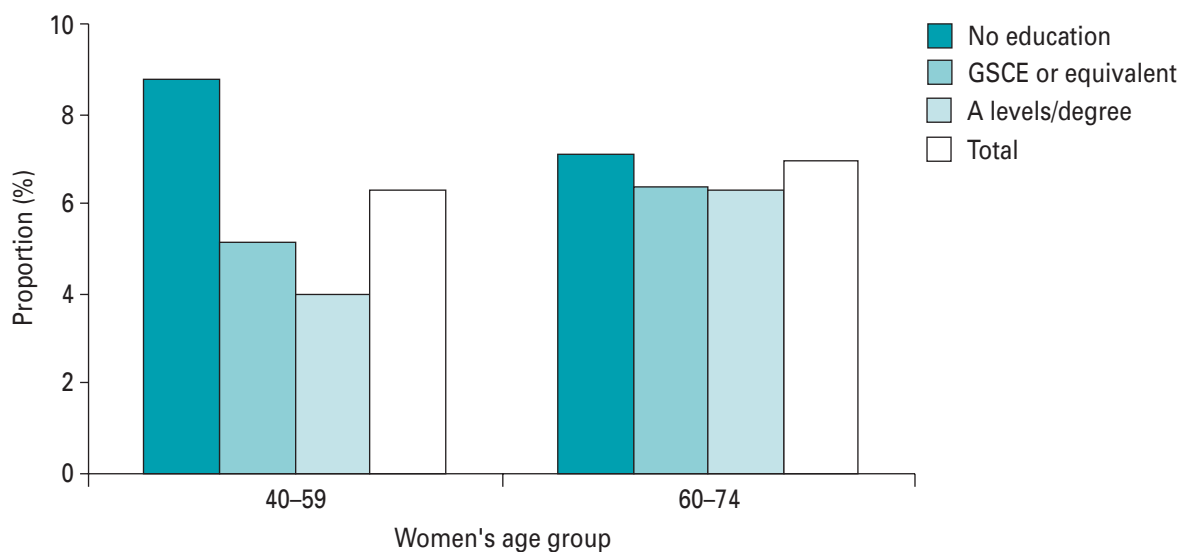


Figure 23 Proportion of women providing unpaid care for 20+ hours per week by age group and educational level in England and Wales, 2001



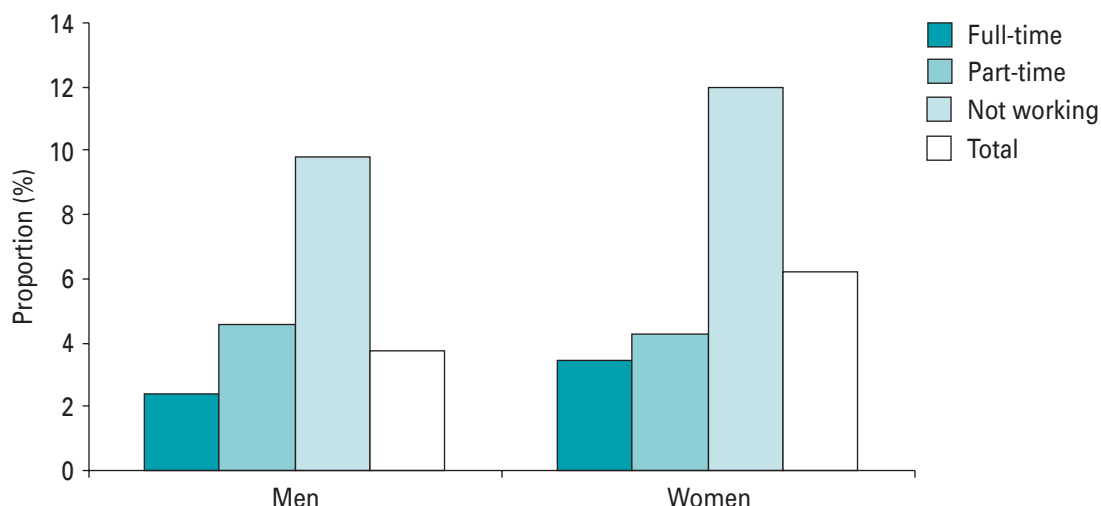
(results for the ‘other’ educational category are not shown). The proportion of women providing care of 20 or more hours a week decreased with increasing level of education. In the older age group, however, these differentials were very small. Similar associations were found for men (figure not shown).

These findings are likely to reflect differing caregiver profiles by age and, in particular, differences between those above and below usual retirement ages. For more highly educated women below the age of 60, there may be more of a conflict between paid work and unpaid caregiving, as hypothesised above, and additionally they may have more resources to pay for care for a relative if needed. For those aged over 60, conflicts with employment are less of an issue and moreover, in this age group, most carers are likely to provide care to a spouse, rather than a parent or other relative. There may be less of a tendency to make other care arrangements when this is the case.

Caregiving and past and present employment

Certainly, as shown in Figure 24, there is an association between current employment status and caregiving. Those in full-time work were less likely to provide care than those who were retired or otherwise not working.

Figure 24 Prevalence of unpaid care provision for 20+ hours per week by employment status in 2001 and gender for those aged 40–59, England and Wales, 2001



However, this association may reflect withdrawal from the labour market as a result of caregiving, rather than differences in labour market involvement influencing likelihood of assuming a caregiver role. In order to investigate this further, in the following section we examine caregiving by history of labour market involvement in 1981 and 1991.

In this analysis, we used a measure of employment score described in the introduction to this chapter to distinguish those with the most, least and intermediate levels of labour market activity in 1981 and 1991. Table 8 shows the proportions of men and women aged 40–59 with these different levels of employment history. This shows that the majority of men had a history of most employment while only approximately 20 per cent of women did so. However, 36 per cent of women had a history of least work and, for men, the equivalent figure was only 4 per cent. This small group may include men who have cared for a parent for a long period, with consequences for their ability to obtain work.

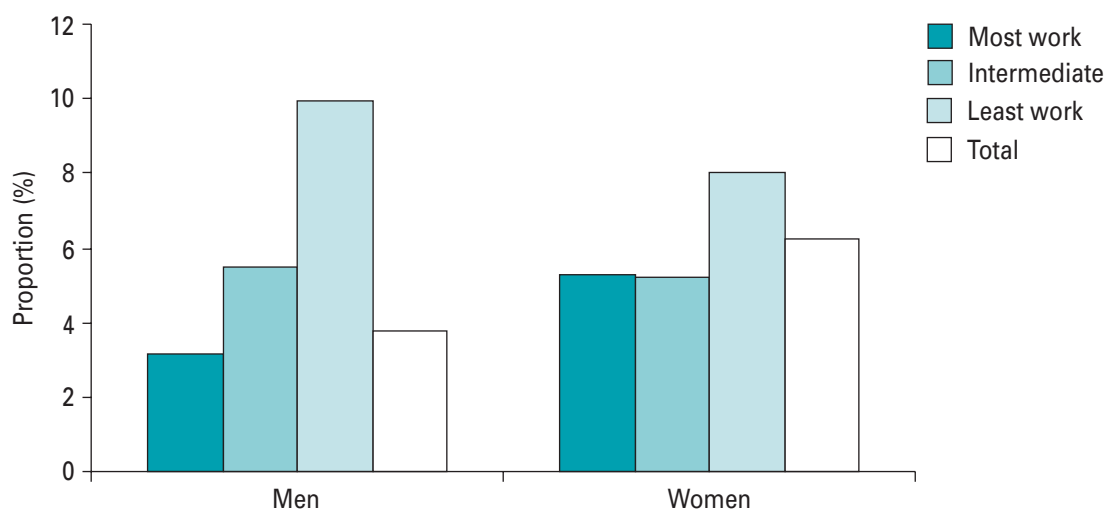
The association between employment history and extensive caregiving for those aged 40–59 in 2001 is shown in Figure 25. The figure shows that, for men, caregiving propensity was associated strongly with history of employment. Men with a history of most formal employment were the least likely to provide care, while those with a history of least work were most likely to provide care. However this latter group is very small.

For women, the differences in caregiving by employment history were less striking. Women with a history of most and intermediate work had an approximately equal caregiving prevalence of 5.3 per cent for those with history of most work and 5.4 per cent for a history of intermediate work. Only women with a history of least work had a higher propensity to provide care. Within the group in full-time employment in both 1981 and 1991, women were more likely than men to be caregivers in 2001. However, gender differences were negligible in the intermediate employment group and the small group of men in the lowest employment category included a higher proportion of caregivers than the equivalent female group. Caregiving and employment for women is explored in more detail below.

Table 8 Proportion of men and women aged 40–59 with different levels of employment history in 1981 and 1991, England and Wales, 2001

	Men		Women	
	%	<i>n</i>	%	<i>n</i>
Most work	81.7	40,899	19.3	10,346
Intermediate	14.5	7,252	44.6	23,857
Least work	3.8	1,886	36.1	19,338

Figure 25 Prevalence of unpaid care provision for 20+ hours per week by employment history and gender for those aged 40–59, England and Wales, 2001



Combined association of marital status, education and employment history with caregiving

In order to ascertain the association of each of the factors explored above with caregiving controlled for other factors that may affect the associations, we carried out logistic regression. This allowed us to see the independent association of each factor with caregiving net of the contribution of the other variables considered in the same model. This is important because, for example, the association between education and caregiving may actually be explained in whole or part by the association between employment history and care provision, because education and employment are closely associated. Table 9 shows the results of this regression for women aged 40–59 in 2001, and for men of the same age. In this analysis, we controlled for age, employment history 1981–1991, educational status in 2001, marital status in 2001, health (as measured by cumulated presence of LLTIs in 1991 and 2001), age and, for women, an indicator of presence of children in the household. This latter variable was derived from the age of household members of the LS member.

Table 9 Logistic regression model of proportion of men and women aged 40–59 providing unpaid care, by selected characteristics, England and Wales, 2001

Variable	Value	Women		Men	
		Odds ratio	<i>p</i> value	Odds ratio	<i>p</i> value
Educational qualifications	A level and degree	1.00	–	1.00	–
	GCSE or equivalent	1.34	***	1.46	***
	None	2.09	***	1.95	***
Employment history 1981–91	Most work	1.00	–	1.00	–
	Intermediate	0.91		1.54	***
	Least work	1.30	***	2.16	***
Marital status 2001	Never married	1.10		1.35	**
	Married	1.00	–	1.00	–
	Divorced or separated	0.64	***	0.57	***
	Widowed	0.44	***	0.81	

Also controlled for age, health score, indicator of children in household for women. 'A level and degree' includes equivalent and higher-level qualifications.

* *p* < 0.05.

** *p* < 0.01.

*** *p* < 0.001.

These results indicate that, for both men and women, all three factors of interest had independent associations with caregiving in 2001. For education, the reference group was those with A levels or a degree, as indicated by the odds ratio (OR) of 1.00. Women with GCSEs or their equivalent were 34 per cent more likely to provide care than the reference group, and men with GCSEs or equivalent were 46 per cent more likely to provide care than the reference group. The statistical significance of this per cent difference is shown in the *p* value column. The smaller the *p* value, the stronger the certainty of a difference (note that there is never a *p* value for the reference group).

Thus, the results indicate a similar association between caregiving and education for men and women. They also indicate that employment history was more strongly associated with caregiving for men than for women, as indicated by larger odds ratios and that ORs are greater than 1.00. Women with a history of least work were 30 per cent more likely to provide care than those with a history of most employment outside the home. Men with a history of least work were 116 per cent more likely to provide extensive care. For marital status, those with a history of divorce, separation or widowhood were less likely to provide care than other marital status groups, as shown by smaller odds ratios. The odds ratio for widowed men was non-significant (*p* value bigger than 0.05). This finding may be due to the fact that there were very small numbers of widowed male caregivers in this age group.

These results confirm the findings in previous sections of this chapter. They indicate that, for those aged 40–59, employment history, educational qualifications and marital history were all associated with propensity to provide care, with employment history being a more important factor for men than for women. For the age group 60–79 (results not shown), prior employment history and socio-economic status were more weakly associated with caregiving propensity, and marital status was more strongly associated with caregiving propensity than in the younger age group.

In the following section, we examine caregiving and employment history in more detail for women who, as we have seen, were more likely to be care providers than men and to provide care while employed.

Caregiving and employment for women

As we have seen above, both current employment status and employment status at earlier points in time were associated with differences in the proportions of caregivers. The variations may reflect several influences, including differences in likelihood of having a close relative in need of care and the fact that those without a current paid job may find it easier to assume a caregiving role. Additionally, there may be variations in willingness to reduce or give up paid work in order to provide unpaid care. In order to investigate this further, we looked at whether women who had given up or reduced paid work when they had a small child were more likely to later become caregivers than women with a stronger labour market attachment who continued work after childbearing. Our supposition was that women who had a history of strong attachment to the labour market after childbirth would be less likely to provide unpaid extensive care at a later date than women who modified their work patterns in response to changed family circumstances. We therefore looked at women who were employed full-time in 1981 (at that time aged 20–29) and who had a child between 1981 and 1991. We examined their employment status at 1991 and categorised those who by then were not in paid work as having a weak labour market attachment, those in part-time work in 1991 as having an intermediate level of labour market attachment and those in full-time work as having a greater attachment to the labour market.

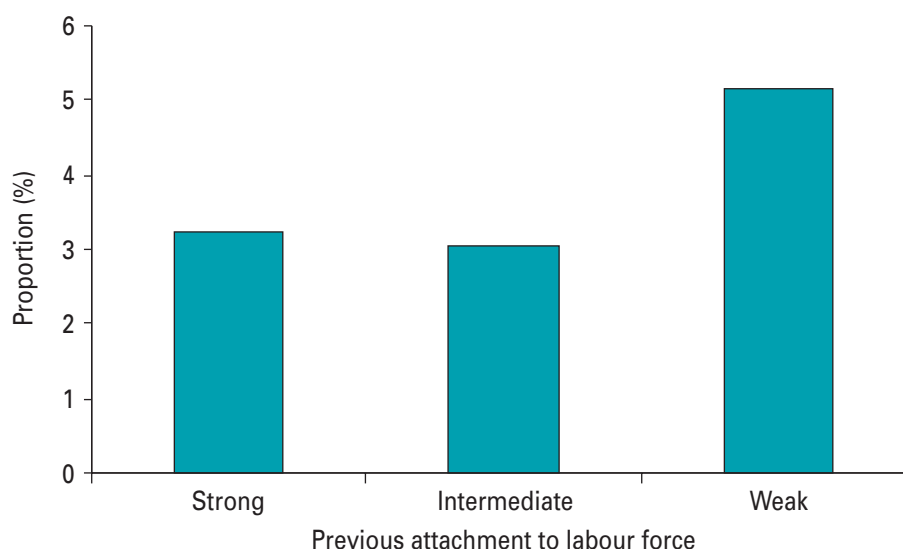
Figure 26 shows the prevalence of caregiving in 2001 by this labour market attachment indicator. Results show that higher proportions of the weak labour market attachment group provided unpaid extensive care in 2001. There was a minimal difference between the strong and the intermediate groups. We carried out logistic regression analysis and controlled for other relevant factors including age, highest

educational qualification, housing tenure, region, limiting long-term illness and household and family type (couple, lone-parent or two-plus families). This analysis showed that those characterised as having a weak labour market attachment were 51 per cent more likely to provide unpaid care than those with a history of strong labour market attachment (CI 1.08–2.11).

Finally, in order to ascertain whether women who worked in certain types of profession were more likely to provide care in 2001, we examined association of unpaid extensive caregiving in 2001 with work in the public sector in 2001 and history of employment in a caregiving capacity. We hypothesised that conditions of work in the public sector might make it easier for women to combine work and caregiving, and so lead to a higher prevalence of caregiving in this group. We also thought that women who had occupations that involved an element of caregiving might be more likely to later become unpaid caregivers.

We defined public sector industries as those in which the majority of employers were likely to be public sector, for example hospitals, nursery or primary education and local or national government. After control for other factors using logistic regression, the results indicated that women who were employed full-time in 2001 were 22 per cent more likely to provide care if they worked in the public sector rather than in the private sector (CI 1.09–1.38).

Figure 26 Proportion of women aged 40–49 providing care for 20+ hours per week by history of labour market attachment with respect to family commitments, England and Wales, 2001



Caregiving occupations selected included matrons and house-parents, nurses, physiotherapists, chiropodists, other therapists (including occupational therapists and psychotherapists), nursery nurses, hospital ward assistants, care assistants and midwives. Those who had worked in a caregiving capacity in either 1981 or 1991 were 33 per cent more likely to provide unpaid extensive care in 2001 after control for other factors than those who had not done so (CI 1.17–1.53).

These results therefore indicate that, for women, employment in the public sector and a history of work in a caregiving profession were associated with increased propensity to provide care. Women who have worked in a caregiving capacity may be more likely to volunteer for caregiving because they may have the requisite skills, or are perceived to have them by other family members and professionals. Possibly, too, certain personal characteristics and values may lead women to choose to work in a caring profession and also to be more likely to take on an unpaid caregiver role.

Conclusions

In this chapter, we analysed current and previous characteristics of caregivers aged 40–79, including marital status, educational qualifications and employment history. Results showed a lower propensity to provide care if divorced. This may be because of characteristics associated with both risk of becoming divorced and likelihood of becoming a caregiver, and also because divorced people are probably less likely to become involved in caring for in-laws than those who are currently married.

Those of lower socio-economic status were more likely to provide care. This association is stronger for extensive carers aged 40–59 than for older carers. For those with a history of full-time employment, women were more likely to provide care than men. Women who had a history of strong or intermediate labour market attachment after having children were less likely to provide care than women who had stopped working after childbearing. This also may have implications for the future availability of care providers, with rising employment rates for women. However, we should be cautious about assuming the associations we find will remain unaltered in the future. Among the women we examined here, for example, the proportion going back to full-time work after having a baby was quite small, whereas now this pattern is fairly usual. It would be useful to undertake more research on this topic, perhaps including some qualitative element, as current policies are aimed at encouraging all adults to work and it is not clear how these policies may affect the supply of carers.

In the next chapter, we examine in more detail one particular type of caregiver, those living with a spouse with a limiting long-term illness.

7 Caregiving among older couples

Key findings

- Seventy-three per cent of couple-only households with a Longitudinal Study (LS) member over age 65 had no caregiver. The second most common type of household was where the LS member or their spouse provided 20+ hours of care per week and the other partner provided none. Only 1.6 per cent of older-couple households had two extensive care providers and, in 85 per cent of these, both household members had a limiting long-term illness.
- Women were marginally more likely to provide extensive care for 20+ hours per week to a spouse than men and propensity to care for both genders increased with age. Extensive carers were more likely to have lower levels of education, a limiting long-term illness and poor self-rated health than those providing less or no care.
- Those who provided extensive unpaid care and who had a spouse with a limiting long-term illness were more likely to be of lower socio-economic status, with the following household characteristics:
 - renting accommodation from a social landlord
 - no car access, especially for women
 - no central heating.
- Presumed spouse recipients of care for 20+ hours per week were more likely than presumed spouse recipients of one to 19 hours' care to be male, to be older, to provide extensive care themselves, to have poor self-rated health and, for carers aged 65–74, to have lower levels of education.

Introduction

In this chapter, we examine the characteristics of married older carers aged 65 and over, focusing particularly on those who live just with a spouse and whose spouse has a limiting long-term illness. We make the assumption that, in these circumstances, the caregiver is providing care for their spouse. We examine the characteristics of the LS member carer, the presumed recipient of care and household characteristics.

As discussed in Chapter 6, older people are important providers of care, often to a spouse. Reductions in death rates at older ages, including a slight narrowing in mortality differentials between men and women, have resulted in widowhood occurring later in life than in the past. Additionally, past changes in marriage patterns mean that the proportion of never-married women in the older population is lower now than in previous decades (Grundy, 1995) and projections show that the proportion of older people who are married will continue to increase over the next quarter century (Murphy and Grundy, 2003). These changes are generally regarded as positive developments, as they mean that more older people have the support of a spouse available to them. However, they also mean that more older people are likely to be involved in providing care for a spouse, possibly with implications for their own health in cases where the care needs of the spouse are extensive. Other research has shown that older carers are likely to offer higher levels of personal and physical care than other carers, and over half of them report a long-standing illness or disability (Milne and Hatzidimitriadou, 2002). How to support these carers, and the growing number of mutually supporting but perhaps frail older couples, is an important policy issue (Allen and Perkins, 1995).

The specific objectives for this chapter are as follows:

- 1 examine proportions of the population aged 65+ who provide unpaid extensive care and who have a spouse with a limiting long-term illness by:
 - housing and household characteristics,
 - characteristics of the LS member caregiver, including health status.
- 2 explore the characteristics of the presumed care recipient (spouse of caregiver).

In this chapter, the sample consists of the population aged 65 and over, living with a spouse, in couple-only households. The LS data set includes census information on those living in the same household as the LS member. We used individual data from the 2001 Census on both the LS member and their spouse. Variables used include caregiving (for both the LS member and their spouse), marital status (first marriage or remarried), education, presence of limiting long-term illness and self-rated health status. We also used LS member census data to ascertain household characteristics including housing tenure (owner, private rental or 'other', social rental), car access (no car or one+ cars), central heating (yes, no) and, finally, region of residence (South and East; Central; North East, North West and Wales).

Household characteristics

As shown in Table 10, the proportion of older people in couple-only households varied considerably by age group and gender. Most men aged 65–74 but relatively few women aged 85 and over lived just with a spouse. In the remainder of the chapter, we focus on these couple-only households. It is important to remember that, for men under age 85, this is the most usual living arrangement but that, for women aged 85 and over, it is an uncommon one.

Table 11 shows the distribution of older LS members living in couple households by their own carer status and that of their spouse. Table 11 shows that, in 73 per cent of cases, neither the LS member nor their spouse reported providing care.

Table 10 Proportion of the LS sample aged 65+ living in different household types, by gender and age group

Gender and age group	Couple-only household		Other type of private household		All (excluding those in non-private households) = 100 per cent <i>n</i>
	%	<i>n</i>	%	<i>n</i>	
<i>Men</i>					
65–74	64.32	12,236	35.68	6,788	19,024
75–84	58.62	5,955	41.38	4,203	10,158
85+	40.75	846	59.25	1,230	2,076
65+	60.90	19,037	39.10	12,221	31,258
<i>Women</i>					
65–74	49.46	10,352	50.54	10,580	20,932
75–84	28.44	4,414	71.56	11,107	15,521
85+	8.89	448	91.11	4,592	5,040
65+	36.67	15,214	63.33	26,279	41,493

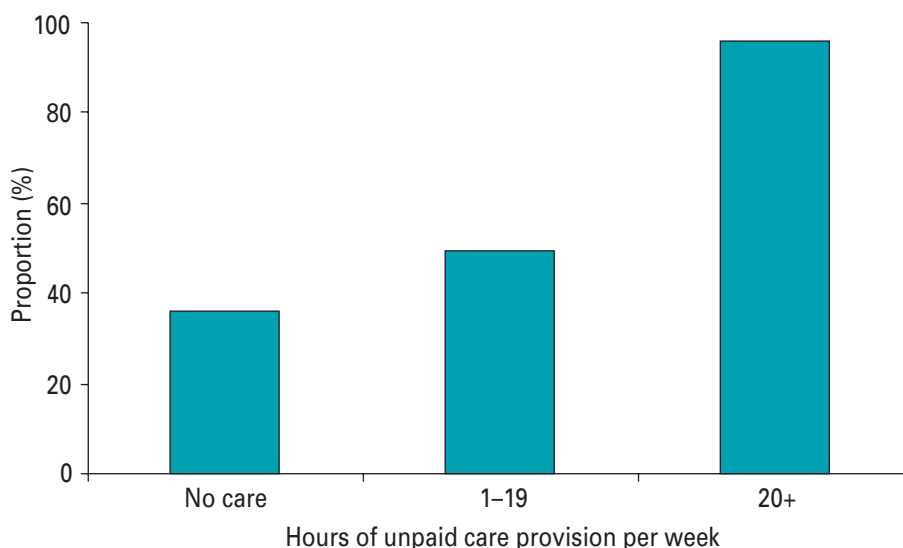
Table 11 Proportion of two-person households with each combination of care provision, by LS members aged 65+ and their spouse, England and Wales, 2001

Care by spouse (%)	Care by LS member (%)			Total
	No care	1–19 hours	20+ hours	
No care	72.89	3.02	6.46	82.37
1–19 hours	3.59	5.13	0.26	8.98
20+ hours	6.69	0.33	1.64	8.66
Total	83.17	8.48	8.36	100
Number	28,485	2,903	2,863	34,251

In 20 per cent of cases, either the LS member or their spouse was a caregiver and in the remaining 7 per cent of cases both spouses reported caregiving. However, cases where both spouses provided 20 or more hours of care a week accounted for less than 2 per cent of the total. In 85 per cent of these households where both members provided 20+ hours of care, both individuals also had a limiting long-term illness, indicating that they were likely to provide care for each other.

Figure 27 shows the proportion of spouses who had a limiting long-term illness (LLTI) by amount of care provided by the LS member. Nearly all (96 per cent) of the spouses of LS members who provided 20+ hours of care per week had an LLTI, as did half of the spouses of LS members providing one to 19 hours of care. Obviously, not all of those with an LLTI need care but it seems a reasonable assumption that, where the spouse has an LLTI and the LS member is providing care, in most cases at least some of this care is being provided to the spouse. Unless otherwise stated, in the rest of this chapter, we focus on carers in couple households whose spouse had an LLTI and the term ‘spouse carers’ is used to refer to this group.

Figure 27 Proportion of spouses of LS members aged 65+ with a limiting long-term illness, by LS member care provision, England and Wales, 2001

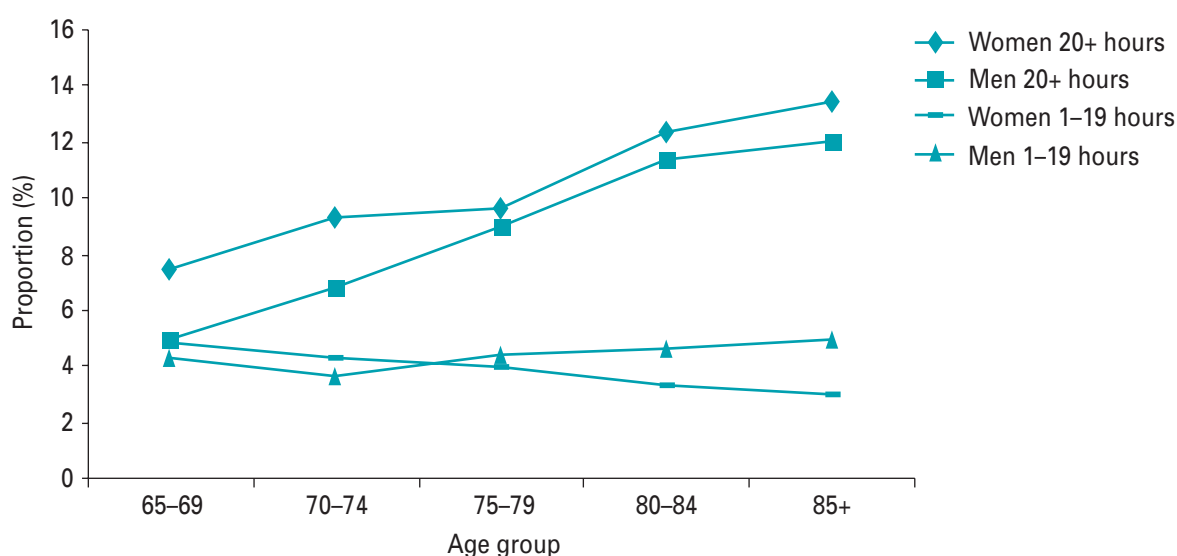


Prevalence of caregiving by individual characteristics of LS members

In this section, we investigate the characteristics of older spouse carers and examine differences in the prevalence of care by individual characteristics of the LS member. Differences by age and gender are illustrated in Figure 28. This shows that the proportion of spouse carers providing one to 19 hours of care per week varied little by age for men, and gradually decreased with age for women. The proportions providing 20+ hours of care per week (and having a spouse with an LLTI) were larger and, for both women and men, increased with age.

Table 12 shows the proportions of spouse carers (i.e. they reported caring and their spouse had an LLTI) by various socio-demographic characteristics, including their own health status. This shows that the proportion of spouse carers was slightly lower among remarried sample members than among those in their first marriage. This may reflect differences in the age distribution of the two groups. It is also possible that there are variations in propensity of spouses to undertake extensive care by marriage order, but we lack sufficient information to investigate this in detail. The proportion of spouses providing extensive care was highest among those with lower levels of education (although we have information on educational qualifications only for those aged under 75). However, the gradient of 'lighter' (one to 19 hours) care provision ran in the opposite direction, with higher prevalences among those with higher-level qualifications. The proportion of spouse carers, among both extensive and 'lighter' providers, was higher among those who themselves had poor health or

Figure 28 Prevalence of care provision for the population aged 65+ with a spouse with an LLTI, by gender, age and amount of care provided per week, England and Wales, 2001



limiting long-term illness. This may reflect concordance of health risks within couples (i.e. the health of both spouses may reflect their shared environment and shared health-related behaviours); age differences; or possibly, as discussed in Chapter 4, the effects of caregiving itself. Whatever the cause, the result suggests a need for support for older spouse caregivers.

Table 12 Proportion of the population aged 65+ with a spouse with an LLTI who were providing unpaid care, by characteristics of the LS member and hours of care provided, England and Wales, 2001

Variable	Value	Carers 1–19 hours per week and spouse has LLTI		Carers 20+ hours per week and spouse has LLTI	
		n	%	n	%
Gender	Male	788	4.14	1,384	7.27
	Female	645	4.24	1,366	8.98
Age group	65–69	564	4.50	765	6.10
	70–74	387	3.85	787	7.84
	75–79	294	4.16	650	9.20
	80–84	134	4.05	387	11.71
	85+	54	4.17	161	12.44
Marital status	First marriage	1,234	4.21	2,400	8.19
	Remarried	199	4.03	350	7.08
Highest educational qualification*,***	None	443	3.62	948	7.75
	Other**	104	5.00	130	6.26
	GCSEs or equivalent	156	5.31	124	4.22
	A levels/degree	169	5.18	157	4.82
Limiting long-term illness***	No	534	2.87	1,164	6.25
	Yes	873	5.89	1,516	10.23
Self-rated health***	Good/fair	1,138	4.16	1,998	7.30
	Poor	294	4.29	748	10.91
Total		1,433		2,750	

* This variable applies only to those aged 65–74. The census question on education was asked only of those aged 16–74.

** 'Other' educational qualifications include City and Guilds and other professional qualifications, and 'level unknown'.

*** Individuals with imputed records were excluded for this variable, hence numbers do not add up to the number in the total row.

Variations in the proportions of spouse carers by household tenure, amenities and grouped region

Table 13 shows the proportion of the population who had a spouse with a limiting long-term illness and provided care, by household-level characteristics and region of residence.

Housing tenure, car access and central heating are all indicators of socio-economic status, but may also have direct practical implications for caregiving. For example, access to a car may make shopping or taking a care recipient to appointments easier. Table 13 shows that the proportion of carers providing more extensive care of 20 or more hours per week was higher among tenants of social housing than among owner-occupiers; higher among those without access to a car or lacking central heating than among those with these facilities; and also higher in Wales and Northern England than in Southern or Central regions. Among those providing smaller amounts of care, however, differentials were less marked and, except in the case of grouped region, in the opposite direction.

Table 13 Proportion of the population aged 65+ who had a spouse with an LLTI providing care, by household characteristics and hours of care provided, England and Wales, 2001

Variable	Value	Carers 1–19 hours per week and spouse has LLTI		Carers 20+ hours per week and spouse has LLTI	
		<i>n</i>	%	<i>n</i>	%
Housing tenure**	Owner	1,231	4.43	1,945	7.00
	Private rental and other*	38	3.27	112	9.62
	Social rental	136	3.07	610	13.79
Car access**	1+ car	1,221	4.53	1,749	6.49
	No car	193	2.87	951	14.15
Central heating**	Yes	1,329	4.25	2,434	7.79
	No	89	3.55	272	10.85
Grouped region	South and East	685	4.10	1,127	6.74
	Central	394	4.07	816	8.43
	NE, NW and Wales	354	4.50	807	10.27
Total		1,433		2,750	

* 'Other' for housing tenure includes those living rent free and, where landlord is an employer of household member, a relative, friend or 'other'.

** Individuals with imputed records were excluded for this variable, hence numbers do not add up to the number in the total row.

We carried out the analysis reported in Table 13 separately by gender, but results showed little difference by gender (results not shown). The only major gender variation in care provision was for car access. For men, 28 per cent of extensive carers who had a spouse with an LLTI had no car access. The equivalent figure for women was 42 per cent. Higher proportions of women who cared for 20+ hours per week than men were therefore disadvantaged in their caregiving by not having access to a car. Women looking after a disabled husband may be less likely to have car access than men caring for a disabled wife because of gender differences in ability to drive in older cohorts.

Characteristics of presumed care recipients

Table 14 shows the characteristics of spouses of LS members who have an LLTI, comparing spouses of carers providing one to 19 hours and 20+ hours of care per week. These assumed recipients of care were slightly more likely to be male if the carer spouse was providing care for 20 or more hours per week than if the carer

Table 14 Characteristics of spouses (who had an LLTI) of LS members aged 65+, by amount of unpaid care provided by LS member, England and Wales, 2001

Variable	Value	Proportion of recipients of spousal care with particular characteristics	
		Spouse of carer providing 1–19 hours of care per week	Spouse of carer providing 20+ hours of care per week
Gender	Male	45.08	49.71
	Female	54.92	50.29
Age group	<64	14.38	7.6
	65–74	50.52	41.09
	75–84	31.54	41.75
	85+	3.56	9.56
Care provision	No/1–19 hours per week	94.84	81.64
	20+ hrs per week	5.16	18.36
Educational level	None	53.37	73.57
	GSCE or equivalent	19.02	8.25
	A levels/degree	17.99	9.73
	Other	9.63	8.44
Self-rated health	Good/fairly good	57.57	21.96
	Poor	42.36	78.04
Total	Number in sample	1,433	2,750
	Per cent	100	100

spouse provided one to 19 hours of care per week. Consistent with previous findings and the large literature on socio-economic differences in health, those with no educational qualifications constituted three-quarters of recipients of 20+ hours of care per week but only half of the recipients of lower levels of care. Finally, as expected, most recipients of spousal care of 20 or more hours per week rated their health as poor.

Conclusions

In this analysis, we focused on married LS members aged 65 and over in 2001 who lived only with their spouse. The outcome of interest was having a spouse with a limiting long-term illness *and* reporting providing care (being a spouse carer). Being a spouse carer and providing one to 19 hours of care per week was, if anything, associated with socio-economic advantage. However, for extensive care providers of 20 hours or more per week, those from less-advantaged groups, including those with poor health themselves, were the most likely to be spouse carers (see 'Key findings' at beginning of chapter). These results support the findings of other research on older carers, which also show that caregiving propensity increases with age for those providing 20+ hours of care per week and that these carers are more likely to be deprived (Milne and Hatzidimitriadou, 2002). These results also point to the need for support to help spouse carers providing large amounts of care and perhaps more provision for couples in supported settings such as very sheltered housing, especially as projected increases in the proportion of older people who are married imply that the number of spouse carers will also increase.

In the next chapter, we turn from a focus on care provision by family members to examine moves to residential or nursing homes and other institutions.

8 Moves to institutional care in later life

Key findings

- The probability of moving from a private household in 1991 to a communal establishment in 2001 was higher for those living in rented accommodation (both private and social) in 1991, and for those with a limiting long-term illness in either 1991 or 2001. The probability was also higher for those unmarried at 2001, for women and for those aged 80 plus. Those living in the North of England in 1991 were more likely to be living in a communal establishment in 2001 than those living in the South East in 1991.
- Childless women were more likely than those with children to make the transition from a private household in 1991 to a communal establishment ten years later.
- The comparison of periods showed that older people were less likely to make the transition to a communal establishment in the period 1991–2001 compared to the previous ten years, but that both these periods had a higher transition proportion compared with 1971–81.
- Among those who lived in ‘independent’ households in 1991 (mainly people living alone or with a spouse), the proportion who were living with other relatives by 2001 was much lower than the proportion who were living in a communal establishment by 2001.

Introduction

In the previous chapters of this report, we examined unpaid care provision at home. In this chapter, we examine households and care from a different perspective, and look at variations in the proportions of older people who were in a private household (in the community) in 1991 but by 2001 lived in a communal establishment such as a residential or a nursing home. We focus on people aged 65 and over in 1991 who were then living in a private household. We also use data on earlier periods available in the LS to compare proportions moving from a private to an institutional household for 1991–2001 with equivalent proportions in 1981–91 and 1971–81. Finally, we look at variations in the proportions that moved to join relatives and try to identify factors associated with making one or other of these types of transition.

The great majority of older people prefer to live in their own homes with support, if needed, from family, friends and community services. However, for those with more serious disabilities, moving to institutional care or to live with relatives may sometimes be the only option, especially if resources at home are lacking. Earlier studies based on LS data from Censuses prior to 2001 showed that, in the 1971–81 and 1981–91 decades, transition rates from private households to communal households were strongly related to age; higher among women than men; higher among the unmarried, especially the never married, than the married; and higher among tenants, especially tenants of privately rented accommodation, than owner-occupiers (Grundy, 1992; Grundy and Glaser, 1997; Glaser and Grundy *et al.*, 2003). This research also showed that rates of transition to communal establishments were considerably higher during the 1981–91 decade than in the previous ten years, even after allowance for factors associated with this kind of transition. It was thought likely that this increase was an unintended consequence of changes in the administration of social security benefits, which meant that more people received financial support to pay for residential and nursing home care (Laing, 1993). Improvements in standards may also have meant that institutional care became a more acceptable alternative to family care for those with heavy support needs (Laing and Saper, 1999; Laing and Buisson, 2005). It is also possible that the availability of family care diminished.

Since 1991, there have been a number of important changes in policy, which were designed partly to halt the increase in institutional admissions seen during the 1980s. These included requirements for an assessment of all older people moving into residential or nursing home care (apart from those paying themselves), targeting of home care resources on those most at risk of such a move, and shifting funding decisions and resources back from the social security system to local authorities. Analysis of admissions undertaken using other sources has shown that these policies appear to have had some success in that admission rates levelled off during the 1990s (Laing, 1993), but less is known about possible changes in the characteristics associated with increased risk of institutional admission.

Our specific objectives here are to examine:

- 1 the key factors that are associated with a transition to a communal establishment, including gender, age, marital status, housing tenure and limiting long-term illness
- 2 the association between parity (live children ever born) and the transition to a communal establishment, for women only
- 3 extent of 1991–2001 transitions to a communal establishment in comparison to previous ten-year periods covered by the Census: 1971–81 and 1981–91

- 4 transitions to live with relatives and characteristics associated with moving to live with relatives rather than moving to institutional care.

In this chapter, the sample consisted of older people aged 65+ years and then resident at a private (non-institutional) household who were still alive and in the study in 2001. For the 1991–2001 transitions from a private household to a communal establishment, some comparisons were made with transitions in the equivalent populations in the periods 1971–81 and 1981–91 using similar data sets for these periods. On the basis of previous research, we included in the analysis age, gender, limiting long-term illness in 1991 and 2001, housing tenure in 1991 and marital status in 2001. We used marital status in 2001, rather than 1991, because this probably gives a better indicator of marital status at the time of the move to the communal establishment. Grouped region at 1991 was also included in some models, as previous work showed regional differences in residence in intergenerational households, which we would expect to be associated negatively with moves to institutions. As we have seen in earlier chapters of this report, there are regional variations in proportions of caregivers in the population. For women, we were also able to examine transition rates by parity (number of live children ever born) using information collected in the 1971 Census on fertility histories and subsequent linkages of births. As fertility history data in 1971 were not collected from women aged 60 and over, this analysis is restricted to women aged 65–89 in 2001 and excludes those who joined the sample after 1971. We also undertook some work restricted to those we defined as living in ‘independent’ households in 1991. We included in this group those living alone; those living just with a spouse; and those living in other types of family (e.g. with a spouse and child), provided that they or their spouse were identified as ‘head of household’. Our estimates of transitions between different types of household are based on comparing circumstances in two successive Censuses for people alive and present in both. This means that we miss transitions made by people who died before the second Census considered. We also cannot identify people who made short-term moves to an institution after 1991 but then returned to a private household before 2001.

Transitions to communal establishments

There were 36,791 people (13,586 men and 23,205 women) aged 65+ living in a private household at 1991 who were still alive and in the LS in 2001. Of these, 7.5 per cent were resident in a communal establishment (CE) at 2001. Figure 29 shows the proportion of older people who had made this type of transition, by age group and gender. As would be expected, the proportions in institutions by 2001 increased with age and were higher among women than men. A third of women living in a private household in 1991 and then aged 80 and over were resident in a communal establishment by 2001 (when aged

90 or over). Overall, slightly more than twice the proportion of women had moved to a CE by 2001 than men (9.3 per cent and 4.3 per cent, respectively).

Figure 30 shows differences in the proportions making a transition to a CE by whether or not they reported a limiting long-term illness in 1991 and in 2001. As would be expected, those who had a limiting long-term illness at 2001 were more likely to be in a communal establishment at 2001 than their counterparts without a limiting long-term illness. Overall, 10.4 per cent of those with a limiting long-term illness at 2001 and 0.8 per cent of their healthier counterparts lived in a CE at 2001. However, the effect of having a long-standing illness in 1991 is relatively small in comparison with health status in 2001. We later control for this in logistic regression models.

Figure 29 Proportion of older people who lived in a private household in 1991 and a communal establishment in 2001, by gender and age group

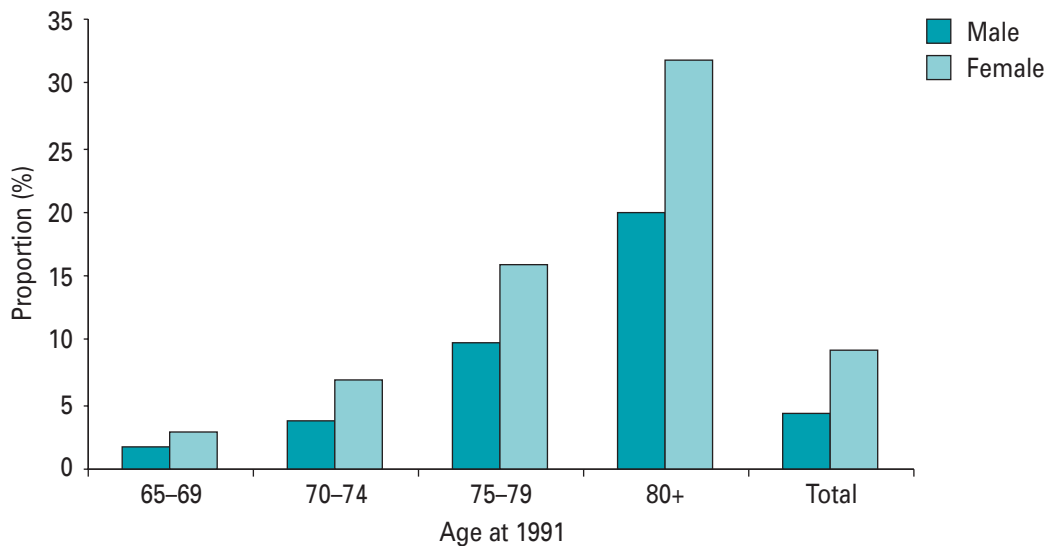
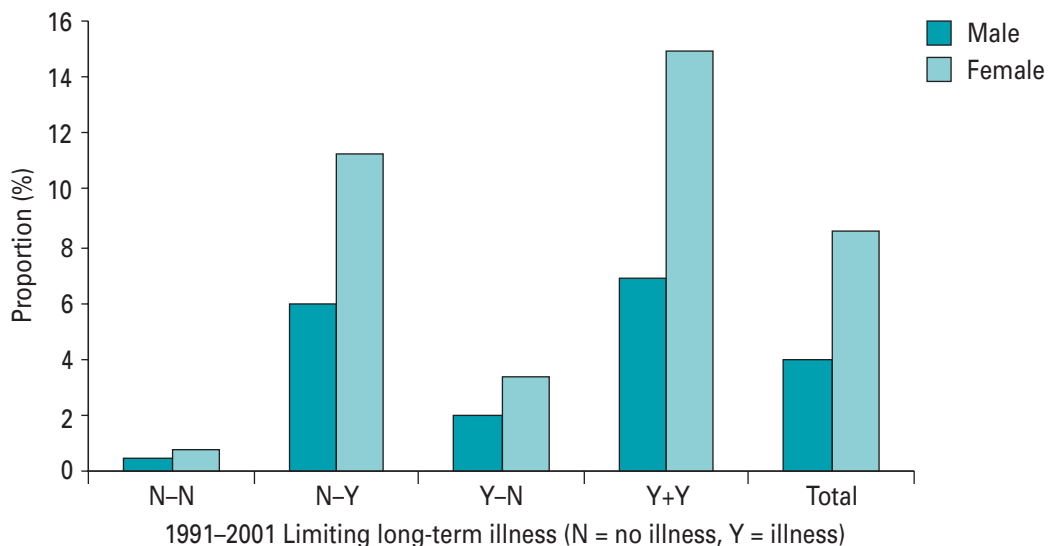


Figure 30 Proportion of older people making the 1991–2001 transition from a private household to a communal establishment, by gender and 1991–2001 health status



Earlier work based on the LS showed that transitions to live in institutions for 1971–81 and 1981–91 were associated with marital status and housing tenure, as well as age and gender. As shown in Tables 15 and 16, this was the case in 1991–2001 as well. Overall, 10.2 per cent of those who had been tenants in social housing in 1991 lived in a CE in 2001 compared with 6.2 per cent of owner-occupiers. The difference in proportions making the transition to a CE by housing tenure appeared more pronounced for men than women. Those who were married in 2001 had a much lower chance of then living in a CE than people of other marital statuses and, except for men aged 75 and over, transition rates were higher for never-married people than for the widowed and divorced.

Overall, 1.5 per cent of married men lived in a CE at 2001, compared with 9.5 per cent of never-married and 9.1 per cent of widowed, divorced or separated men. Equivalent proportions for women were 2.2 per cent, 15.0 per cent and 11.4 per cent.

Table 15 Proportion (per cent) of men who lived in private households in 1991 and in communal establishments in 2001, by age, housing tenure and marital status

Age and housing tenure at 1991	Marital status at 2001			Total
	Never married	Married	Widowed/divorced/separated	
<i>65–69 years old</i>				
Owner-occupier	4.7	0.6	2.2	1.1
Private rental	6.1	1.0	5.0	3.0
Social rental	11.3	1.4	6.4	4.1
All	7.0	0.7	3.6	1.8
<i>70–74 years old</i>				
Owner-occupier	5.2	1.1	6.5	2.8
Private rental	20.0	4.0	2.4	5.2
Social rental	14.0	3.0	8.0	5.6
All	9.6	1.6	6.6	3.6
<i>75+ years old</i>				
Owner-occupier	18.3	4.4	17.5	11.0
Private rental	20.0	4.9	20.6	15.0
Social rental	18.4	6.9	22.0	16.4
All	18.5	4.9	19.0	12.5
Total	9.5	1.5	9.1	4.3

n = 13,543.

Table 16 Proportion (per cent) of women who lived in private households in 1991 and in communal establishments in 2001, by age, housing tenure and marital status

Age and housing tenure at 1991	Marital status at 2001			Total
	Never married	Married	Widowed/divorced/separated	
<i>65–69 years old</i>				
Owner-occupier	5.3	0.9	3.3	2.4
Private rental	3.9	1.7	3.9	3.3
Social rental	8.6	1.5	5.2	4.4
All	6.0	1.0	3.9	2.9
<i>70–74 years old</i>				
Owner-occupier	9.2	2.8	6.6	5.7
Private rental	11.1	2.0	8.5	7.3
Social rental	12.7	2.5	11.1	9.8
All	10.5	2.7	8.1	7.0
<i>75–79 years old</i>				
Owner-occupier	25.2	4.0	16.1	15.2
Private rental	23.1	7.0	16.4	16.0
Social rental	16.3	12.2	17.5	17.0
All	22.3	6.1	16.6	15.8
<i>80+ years old</i>				
Owner-occupier	41.9	11.7	31.2	31.0
Private rental	43.5	25.0	30.2	31.3
Social rental	27.9	23.8	34.7	33.7
All	37.7	15.5	32.2	31.9
Total	15.0	2.2	11.4	9.3

n = 23,104.

Multivariate analysis

We used logistic regression to further investigate the associations between the proportion of older people moving to a communal establishment, with age (measured in single years), gender, marital status, long-term illness, housing tenure, and region of residence in 1991. This analysis confirmed the results of the bivariate analysis above, and indicated that age, gender, marital status, housing tenure and long-term illness were all associated with transition to a CE even when all were taken account of together. Results showed that women were 13 per cent more likely to be resident in a CE than men (95 per cent confidence interval [CI]: 1.01-1.27). Every increase of one year in age was associated with a 14 per cent increase in chance of being a resident in a CE at 2001 (CI 1.13–1.15). The never married were six times more likely to reside in a CE at 2001 than the married (CI 4.99–7.46) and the widowed,

divorced and separated more than three times more likely than the married (CI 3.17–4.33). Those who were tenants in 1991 were 26 per cent more likely to have made the transition to a CE at 2001 than owner-occupiers (CI 1.15–1.39). Those who did not have a limiting long-term illness at 1991 but had one by 2001 were nearly 12 times as likely to be resident in a CE at 2001 than their counterparts who remained without an LLTI (CI 9.33–15.15). There was not a strong geographical effect, but those living in Wales and the Northern regions of England (the North East, North West and Yorkshire and Humberside) had a raised odds of making a transition to an institution compared with those living in the South (London, the South East and the South West) (odds ratio 1.14; CI 1.03–1.27).

Parity and moves to communal establishments

For women who were present at the 1971 Census and were then aged under 60, we were also able to examine the effect of parity (live children ever born) on transitions to communal establishments 1991–2001. Parity is a measure of children that women have given birth to; unfortunately we do not have information on whether these children were still alive or not. However, there is likely to be a strong association between children ever born and children still alive.

Children are the main source of family care for older people who do not have a spouse alive, so we wanted to see if women with no children or only one child had higher risks of entering a CE than those who had had more children. Of the 19,254 women included in this analysis, 6.9 per cent were resident in a CE at 2001. Figure 31 shows the distribution of women making the transition to a CE at 2001 by parity. This suggests that women who had not given birth to any live children were more likely to be resident in a CE by 2001 than those who had borne children. Those who had had four or more children were the least likely to be living in a CE in 2001.

To investigate this further we used logistic regression. Results showed that, even allowing for other factors (age, marital status, household type, long-term illness and housing tenure), parity was associated with being in a CE in 2001. Odds ratios from this analysis are shown in Figure 32; for women who had had two children the odds ratio was 0.64 (95 per cent CI 0.52–0.78), which implies a 36 per cent decreased chance of residing in a CE compared with nulliparous women.

Figure 31 Proportion (per cent) of women who lived in private households in 1991 and in communal establishments in 2001, by parity

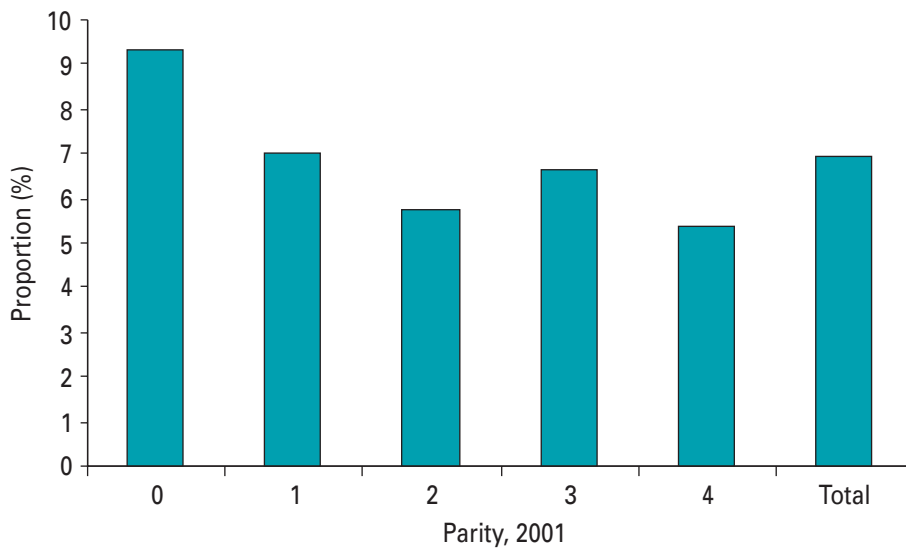
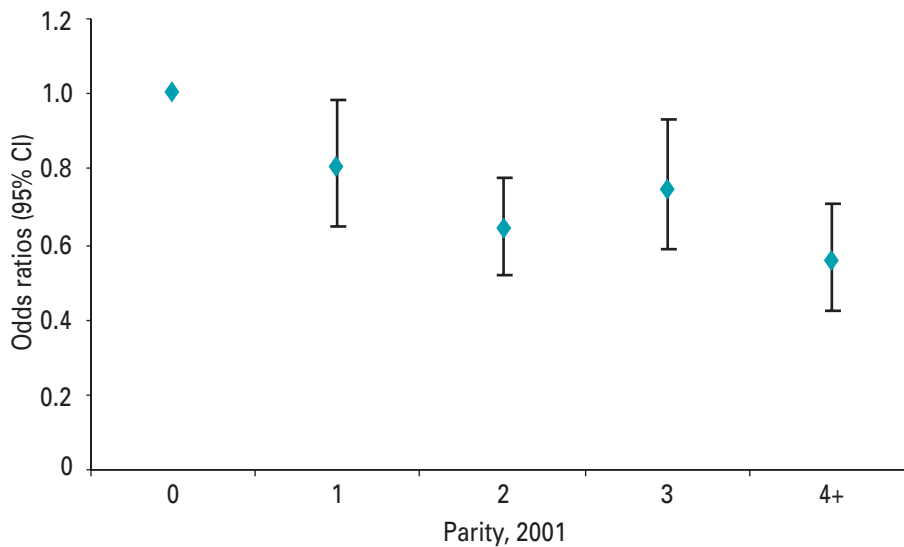


Figure 32 Odds ratios (with 95 per cent confidence intervals) for making the 1991–2001 transition from a private household to a communal establishment, by parity at 2001, after control for other factors

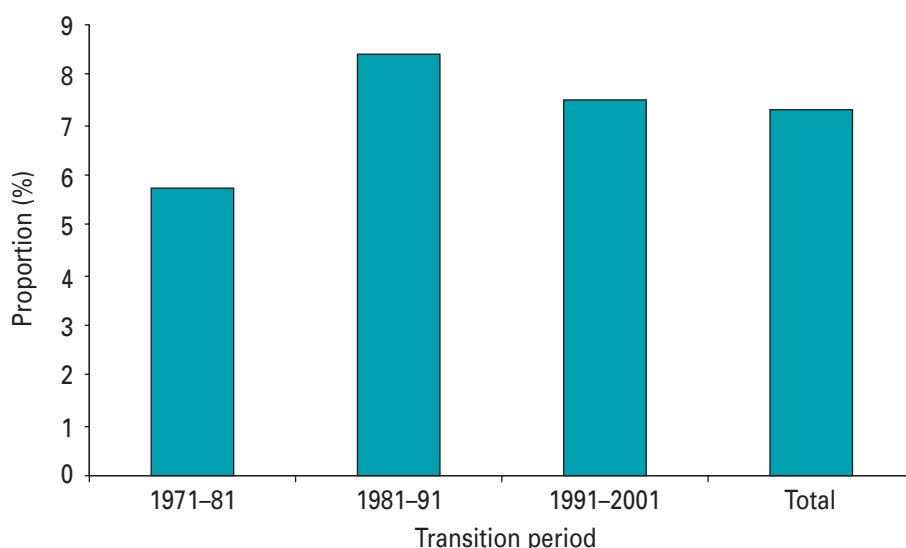


Time trends

As discussed in the introduction to this chapter, a number of important changes in policy on long-term care were implemented in the 1990s and, because the LS spans three decades, we can see whether these, or other changes, were reflected in differences in transition rates to CEs when the 1971–81, 1981–91 and 1991–2001 decades are compared.

Figure 33 provides a visual guide to how transitions from private households to communal establishments ten years later have changed over the three time periods. The peak of 8.4 per cent is in the middle decade, 1981–91, whereas 1971–81 has a transition proportion of 5.8 per cent and 1991–2001 a transition proportion of 7.5 per cent. Of course, differences in the age, gender and marital status composition of the population might influence these results. To take this into account we ran logistic regression models including age, gender, marital status and housing tenure (information on limiting long-term illness is not available for 1971 or 1981). Results showed that there were significant differences between periods even when these factors were taken into account. A smaller proportion of older people made the transition to a CE in 1971–81 than in 1981–91 or in 1991–2001, and the transition rate for 1991–2001 was significantly lower than that for 1981–91.

Figure 33 Proportion of older residents in a communal establishment of those in a private household and then aged 65 and over ten years previously



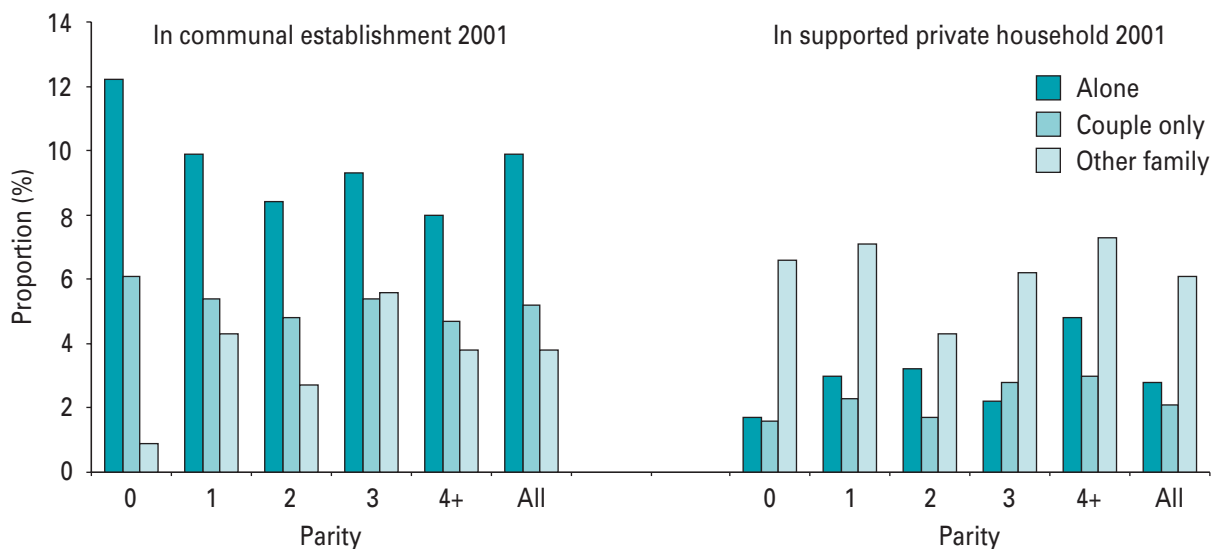
Moves to supported private households

In some cases, older people with disabilities who do not have enough support and care available at home may move to join relatives (or have relatives move in with them) rather than moving to a residential or nursing home. In order to investigate this, we wanted to exclude older people who were already living in relatives' households in 1991, so we restricted our analysis to people who in 1991 lived alone; lived just with a spouse; or lived in some other family type (for example, with a child, or a spouse and child) but where either they or their spouse was identified as 'head of the household'. (This term is no longer used in the Census, but a 'household reference person' – generally the first adult completing the form – is identified.) We

looked to see what proportion of these people were by 2001 living in ‘supported’ private households. These we defined as living with relatives or friends and not being the head of the household (for example, living with a married daughter and her husband). The proportion who made a transition from an ‘independent’ to a ‘supported’ household was very low (less than 3 per cent of men and 7 per cent of women), and was lower than the proportion who moved to a communal establishment. In Figure 34 we look at the proportion of women who lived in independent households in 1991 who were in communal establishments or supported private households ten years later, according to their initial family/ household type and parity. Those who lived alone in 1991 were most likely to be in a CE ten years later, while those who lived in the ‘other family’ category in 1991 were the most likely to be in a supported household in 2001. For women who lived alone or in a couple in 1991, those with higher parities included slightly lower proportions in communal establishments in 2001 (as already discussed) but higher proportions in supported private households.

We examined these associations further (for both women and men) by using a form of logistic regression analysis that allows more than one binary outcome to be compared (multinomial logistic regression). For those living in independent households in 1991, we contrasted three outcomes in 2001: still being in an independent household; being in a communal establishment; and being in a supported private household. This analysis showed that being a tenant increased risks of moving to a communal establishment, but had no effect on chance of moving

Figure 34 Proportion of women who lived in an independent household in 1991 and who lived in a communal establishment or supported private households by 2001, by parity and living arrangement in 1991



to a supported private household. Additionally, although having a limiting long-term illness in 2001 was associated with an increased chance of being in a supported private household, the effect on the chance of being in a communal establishment was much greater. The analysis also showed that, whereas single people had the highest chance of moving to a communal establishment (compared with those of other marital statuses), moving to a supported private household was associated with being widowed.

Conclusions

In this chapter, we focused on older people aged 65 and over who were living in a private household in 1991, and who were still alive and present in the 2001 Census. We examined what proportions of this group were living in communal establishments, such as residential or nursing homes, by 2001. We found that the following characteristics all increased the probability of moving from a private household in 1991 to a communal establishment ten years later: living in rented accommodation in 1991; having a limiting long-term illness in 1991 and, even more particularly, a long-term illness in 2001; being unmarried at 2001; increased age; and being female. Women who had never had children were more likely to be resident in a communal establishment in 2001 than women who had given birth to any children. The overall transition rate for 1991–2001 was lower than for 1981–91 but still higher than for 1971–81. We also looked at people living in ‘independent’ private households in 1991 and ‘supported’ private households ten years later. This kind of change was also associated with age, marital status and health (although not with housing tenure), but in rather different ways. The proportion making this kind of change was much lower than the proportion moving to a communal establishment.

9 Conclusions and implications

Key messages

- Caregivers are a heterogeneous group but are disadvantaged compared with the general population. In general, they are more likely to have health problems themselves and to live in poorer areas and households with fewer resources, and they are less likely to have educational qualifications or to be in employment. Supporting caregivers may not only help them with their role but also provide a way of addressing social inequalities.
- For women, there are associations between types of employment and employment history and caregiving. Women working in the public sector are more likely than other full-time workers to be carers, as are women with a history of working in a caring profession. Women who went back to work soon after childbirth were less likely to later become caregivers. These findings suggest that changes in the employment patterns of women may have implications for the future supply of caregivers and that it is important to find ways of helping people to combine work and caring roles if they wish to.
- Fewer people moved from homes in the community to live in institutions in 1991–2001 than in the previous decade (although the proportion was higher than in 1971–81). However, the proportion of people making this kind of move was much higher than the proportion moving to live with relatives.

Caregiving groups

This research has provided a detailed distribution of the population providing extensive care by local authority in England and Wales, not previously possible with other smaller data sets. It has also shown geographical distribution of caregivers by ethnic group. This analysis reiterates that caregivers are by no means a homogeneous group, and so have differing support needs.

We found that Bangladeshis and Pakistanis were much more likely to provide care than other ethnic groups throughout England and Wales after control for the age structure of the population. Some research has indicated that this increased propensity to provide care by members of ethnic minorities may be a result of socio-economic and demographic factors rather than culture. For example, Evandrou

(2000) showed that minority ethnic older people are more likely to be of low socio-economic status. Additionally, among Bangladeshis for example, it is common for women to marry spouses older than them. Women may therefore begin providing care to a spouse at an early age. Intergenerational households may also increase the likelihood of care provision within families. It is important that support services for caregiving are culturally appropriate and sensitive for these groups.

This analysis also showed that higher proportions of the population provided extensive care in the North of England and in Wales, and the lowest in the South East of England. Areas with high proportions of caregivers were more likely to be deprived, with higher proportions of caregivers in poor health. This implies that, in different areas of England and Wales, caregivers are likely to have different needs in terms of formal support. Those providing care in more deprived areas may need more support, especially as it has been shown elsewhere that caregiving may lead to increasing deprivation, as discussed in more detail below.

Socio-economic status, health and employment

Socio-economic status and health

Our analyses showed that caregivers providing 20 or more hours of care per week were likely to be of lower socio-economic status than those not providing care. We showed this for different age groups, using both individual- and household-level indicators of socio-economic status. Additionally, as mentioned above, we found that carers were more likely to live in deprived areas.

In Chapter 3, we showed that younger carers aged 20–29 were more likely to have lower educational qualifications and less likely to be employed than non-carers. Analyses indicated that women in this group may have provided care for disabled or sick children. However, this would require further verification. Even after controlling for having young children, we still found associations between extensive care provision and lower educational and employment levels. These circumstances are likely to bring consequences for the quality of life and future opportunities of young extensive carers.

We found that extensive caregivers aged 40–74 were also more likely to have lower educational levels than non-caregivers (Chapter 6). This association was stronger for those aged 40–59 than for those over retirement age. This difference may be because, for those under age 60, there are more likely to be conflicts between

caregiving and employment, whereas older people are likely to have retired and to have no such conflict. Additionally, older carers were more likely to provide care for a spouse, with a lower tendency to make other arrangements for care provision. For midlife carers, we also found that those who were employed while caregiving were more likely to have a limiting long-term illness than those who did not provide care. This association could reflect the well-documented association between low socio-economic status and poor health. Another possibility is that risks for ill health are shared with care recipients, especially if care is provided within the household, and so these carers may be likely to develop poor health anyway. However, the association could also reflect the impact of caregiving on health, which has been documented in other research (Schulz and Beach, 1999; Lee and Colditz et al., 2003).

Analyses in Chapter 7 of older carers providing care for a spouse showed that those in less advantaged groups were more likely to provide care. Older spouse carers providing care for 20 or more hours per week were more likely to have no central heating, to live in socially rented accommodation and to have no car access, the latter especially for women. These circumstances may have direct ramifications for caregiving in addition to being indicators of general disadvantage. Our analyses also showed that 57 per cent of older spouse extensive carers were in poor health themselves. Other research has shown that older spouse caregivers tend to provide higher levels of personal and physical care than other carers, and that their care recipients tend to have physical disabilities (Milne and Hatzidimitriadou, 2002). This suggests that the strains of caregiving may be particularly great for this group, and potentially health damaging. Propensity to provide care for 20+ hours per week for a spouse increased with age for both men and women aged 65 and over, and so these stresses are likely to increase with age.

Employment

Our analyses showed that both young and midlife carers providing 20 hours or more care per week were less likely to be employed than non-caregivers or those providing less care (Chapter 3). Midlife carers in 2001 were also more likely to have a history of lower levels of employment (Chapter 6) and to have given up employment since 1991 (Chapter 4). This does not necessarily imply that giving up employment is a consequence of care provision; it may equally be likely that those who have given up employment are more likely to take on a caregiving role. However, other research has indicated that some carers do end employment as a result of care provision (Evandrou and Glaser, 2003; Henz, 2004). We also found gender differences in propensity to provide care by both present and previous

employment. Women were more likely than men to combine caregiving and work. We discuss caregiving and employment among women in more detail below.

Higher levels of deprivation, poorer health and lower levels of employment are likely to have multiple implications for care providers. Caregiving incurs both direct and indirect costs, and may further exacerbate deprivation. Care providers are likely to spend their household income on caregiving, and may even have to take out loans to facilitate caregiving (Glendinning, 1992; Emanuel and Fairclough *et al.*, 2000). Indirect costs include likelihood of smaller labour market incomes for carers (Hutton, 1999). If carers reduce labour market participation as a result of care provision, this will result in reduced opportunities for pension contributions. Additionally, when care provision ceases, individuals may find it more difficult to get work and incomes tend to be slow to catch up (Hutton, 1999). Caregiving at young ages may have lifelong implications for employment. The new Carers (Equal Opportunities) Act 2004 stipulates that, when assessing carers' needs, local authorities must consider whether the carer works, or undertakes education, training or leisure activities, or wishes to do any of these. This provides a framework for helping carers to continue employment and to gain skills while providing care. The latter may be especially important for young care providers.

Women and employment

Women aged 40–59 were more likely to provide care despite a history of employment and to be employed while caregiving than men, as shown in Chapter 3. There were variations in the association between caregiving and employment for working-age women, by employment and family characteristics.

Women who had previously given up work after having children were more likely to provide care later on than women who carried on working after childbearing, either part-time or full-time. This suggests that women with a strong labour market attachment may be less likely to later assume the role of caregiver. Women who had previously had a caring job were more likely to provide care later, and those working in the public sector were more likely to provide care while working than those in other sectors (mainly private sector). This may be because public sector employment allows more flexible work practices or provides more support for caregivers; it is worth investigating this further.

Increasing proportions of women in the labour market, including increasing proportions working when their children are young, may mean that the future supply

of women caregivers decreases. Employed carers, especially those providing care for 20 hours per week or more, find it difficult to continue both roles (Arksey and Kemp *et al.*, 2005). This is supported by our finding that carers are more likely to have given up employment than non-carers (Chapter 4). However, other research suggests that women do continue employment while providing care (Moen and Robison *et al.*, 1994; Rowlands and Parker, 1998). Importantly, it has been shown that most carers wish to remain in work, and are reluctant to give up, and also that employment may be a buffer for the strain of care giving (Martire and Stephens *et al.*, 1997). This points to the importance of policies allowing flexibility for those wanting to combine work and care. Research has shown that most carers have little access to carer-friendly workplace schemes and most employers do not have carer-friendly work practices, especially in the private sector (Arksey and Kemp *et al.*, 2005).

Conclusion

Unpaid carers are an essential and vitally important component in the system of support for people with assistance needs. Many of those with such needs are older people and much of the help they need is provided by other older people or by those in late middle age. However, there are caregivers of all ages and caregivers are a heterogeneous group. Certain common features can be identified though, and these include an association between caregiving and disadvantage. In general, people providing care for 20 or more hours per week are more likely to have health problems themselves and to live in poorer areas and in households with fewer resources, and are less likely to have educational qualifications or to be in employment. Supporting caregivers may not only help them with their role but also provide a way of addressing social inequalities.

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Appendix 1: Acronyms

CE: communal establishment. This is defined as an establishment providing managed (full-time or part-time supervision) residential accommodation. Examples include nursing homes and care homes.

CI: 95 per cent confidence interval. This is provided together with a statistical measure of relationship and, in the case of this report, usually with the odds ratio. The level of confidence (often 95 per cent) states the certainty to which the true value lies within the confidence interval. For example, in Chapter 8, we investigated the effect of parity on the 1991–2001 transitions from private households to communal establishments. In the case of women with one child compared to nulliparous women, the odds ratio is 0.80, with a confidence interval of 0.65–0.98. Whereas the odds ratio indicates that women with one child have a 20 per cent decreased probability of residing in a CE compared to their nulliparous counterparts, the 95 per cent confidence interval implies that we can state with 95 per cent certainty that the true decrease lies between 2 and 35 per cent.

GOR: Government Office Region.

IMD: Index of Multiple Deprivation. This is a geographical index of deprivation, which enables comparison of deprivation between geographical units. The ward-level index is made up from 33 indices in six domains including income, employment, health, education, housing and service access.

LA: local authority.

LLTI: limiting long-term illness. This was recorded at the 1991 and 2001 Censuses. At both these census points a question was asked whether individuals have a limiting long-term illness, health problem or disability that limits their daily activities or work they can do, including problems due to old age.

LS: ONS Longitudinal Study. This Study consists of individual-level census records linked between successive Censuses. The sample consists of people born on one of four selected dates of birth. The Study represents just over 1 per cent of the total population in England and Wales.

LSHTM: London School of Hygiene and Tropical Medicine.

LSM: Longitudinal Study member. This is somebody who qualifies for inclusion in the LS. By the 2001 Census there were just fewer than one million LSMs.

ONS: Office for National Statistics.

OR: odds ratio. This is a measure of association between two factors and compares whether the probability of a certain event is similar for two or more groups. For example, in an examination of gender differences in care provision, an odds ratio of 1.00 for a comparison of caregiving by females compared to males would imply that caregiving is equally likely for both sexes. An odds ratio of 1.40 would imply that women in the sample are 40 per cent more likely to provide care than men, while an odds ratio of less than 1.00 would mean that caregiving would be less likely among females than among males.

Appendix 2: Definitions of main variables used in analysis

Caregiving: the definition is based on the 2001 census question. Care providers are considered as those who look after, or give any help or support to, family members, friends, neighbours or others because of long-term physical or mental ill health or disability, or problems related to old age. Individuals are asked to not count anything they do as part of paid employment. In this research we distinguish between extensive care providers who give 20 or more hours of care per week and those who provide no care or one to 19 hours of care per week. In some analyses we also distinguish between no care and one to 19 hours of care per week (Chapter 7).

Communal establishment (CE): is defined as an establishment providing managed (full-time or part-time supervision) residential accommodation. Most residents in a CE reside in a nursing home or a care home.

Employment status: in this analysis, employment status refers to whether an individual is employed full-time, part-time or not working. Those not working include those who are searching for employment, students, permanently sick, retired, and looking after the home and family. The 1981 census employment-status question did not distinguish between employed and self-employed work. For 1991 employment status, those who were self-employed were all placed in the full-time employed category. For 2001 employment status, self-employment is distinguished between full-time and part-time, and so these individuals were placed in the categories full- and part-time employment, respectively.

Ethnicity: we define ethnicity using the self-reported ethnicity question in the 2001 Census. We distinguish between the following ethnic groups: white, Indian, Bangladeshi, Pakistani, black Caribbean, black African and 'other'.

Highest educational qualification: this question was asked in the 2001 Census and enquires about the highest educational and professional qualifications achieved. The four categories we used in this analysis were: no educational or professional qualifications; GSEs or equivalents; A levels, or degree, or equivalents; and 'other'. This latter category includes 'other' professional qualifications, City and Guilds and unknown educational level.

Household and family composition: this describes the position of each individual in the context of their household and their family within the household. Categories

include the following: living alone; couple only; couple and children; couple and others; couple and children and others; lone parent; lone parent and others; two or more families; no family but living with others; child in family; and living in a communal establishment. We used aggregations of these categories in different parts of this research.

Housing tenure: in this analysis, housing tenure at 2001 is classified into the following groups: owner-occupier (including owning outright and with a mortgage), private rental, social rental and 'other'. 'Other' includes living rent free and, where landlord is an employer of a household member, a relative, friend or 'other'. At 1991, housing tenure is classified into three groups – owner-occupier, private rental and social rental – although in some analyses the two rental categories were combined.

Index of Multiple Deprivation (IMD): this is a geographical index of deprivation, which enables comparison of deprivation between geographical units. The ward-level index is made up from 33 indices in six domains including income, employment, health, education, housing and service access. These domains are combined to form a ward-level index of multiple deprivation. We used a further aggregation for the analysis in Chapter 2, a population-weighted average of ward score at the local authority level. For more information on the IMD, see <http://www.odpm.gov.uk/index.asp?id=1128626>.

Limiting long-term illness (LLTI): at both the 1991 and 2001 Censuses, the question on LLTI asks whether an individual perceives that they have a limiting long-term illness, health problem or disability that limits their daily activities or the work they can do, including problems that are due to old age.

Marital status: this identifies the legal marital status of the individual at the time of the respective Census. The four categories of marital status that we used included never married (single), married, separated or divorced, and widowed. In some analyses we used only three categories and those who were separated, divorced or widowed were placed in one category.

Parity: is an indicator of how many live births a woman has had. It was only possible to collect this data for women under age 90 at the 2001 Census.

Self-rated health: in the 2001 Census, there was a self-reported question on whether the respondent felt that their health had been good, fairly good or not good over the previous 12 months. We grouped this variable into two categories: good and fairly good, or not good.

Appendix 3: Definition of standardisation

The aim of standardisation is to adjust results for the effects of confounding variables, in this case the age and gender structure of the relevant populations. It involves the calculation of the number of expected events, which are compared to the number of observed events to produce a standardised ratio. The number of expected events may be calculated in two ways. One involves the multiplication of age – gender stratified population numbers of the separate comparison groups by a common set of suitably chosen ‘standard’ rates. This is indirect standardisation, which we use in this study.

We use age-specific rates for the whole of England and Wales as our standard. We use six age-group stratifications: 16–34, 35–49, 50–59, 60–64, 65–84, 85+. Expected events calculated are summed to produce a total number of expected events for a given population group. The corrected estimate is in the form of a standardised ratio, which is obtained by dividing the number of observed cases by expected cases for the study population. It is then possible to compare the standardised ratios of different population groups – for example, different ethnic groups – controlled for age. In standardisation by ethnicity in this study, for example, a ratio of over 1 implies a higher rate of caregiving for a particular ethnic group than the standard; a ratio of under 1 implies a lower rate of caregiving.