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# **The Changing Face of Caring: secondary analysis of the 1985 General Household Survey and the 2009/10 Survey of Carers in Households**

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## Chapter 1: Introduction

It is difficult now to recall that, prior to the mid-1980s, information about the prevalence and characteristics of informal (unpaid) carers and caring activity had to be estimated from a range of non-representative sources (see Parker, 1985 for the first attempt to do this). It was not until 1985 that the first national survey of carers in the UK took place, via a module included in that year's General Household Survey (GHS). This provided the first conclusive evidence on the prevalence of informal caring activity in the population and the distribution of caring across different socio-economic groups in Great Britain. The survey also allowed researchers to identify different types of caring activity, and to explore how these related to different types of carers (Parker and Lawton, 1994).

The carers module was subsequently repeated (with some changes) in the 1990, 1995 and 2000 GHSs, which allowed some (albeit cross-sectional) exploration of change over time (Rowlands and Parker, 1998; Maher and Green, 2002). The GHS no longer exists and its replacement, the General Lifestyle Survey (to 2012), never included a module about carers. In 2009/10, however, GfK NOP, on behalf of the Health and Social Care Information Centre, carried out a separate survey – the Survey of Carers in Households (SCH). Although it was a representative sample survey, the SCH was confined to England and had other differences from the GHS that limit, to some extent, the comparisons that can be made between the two time points. The most significant of these differences is the lack of household composition data for the SCH; only adults aged 16 years or over were identified in the screening part of the survey (which was used to calculate prevalence). As a result, there is no information about whether or not carers have dependent children, and no standard household composition data were collected.

The British Household Panel Survey (BHPS) and its successor, the UK Longitudinal Household Study (known as Understanding Society), have also offered opportunities for understanding change over time. This is less in terms of population change (although population estimates are possible because successive waves can be amalgamated) but more in terms of understanding movement in and out of caring responsibility and the impact of caring over time (Hirst, 2012).

The English Longitudinal Study of Ageing (ELSA) has also opened up potential opportunities for examining change over time, but only in those over the age of 50 (Vlachantoni, 2010). In 2001, a simple question on caring responsibilities was included for the first time in the UK Census and this was repeated in 2011, again opening opportunities for exploration of change (White, 2013). If repeated at the next Census, the existence of three data points, combined with the other data collected via the Census, will offer opportunities for powerful analysis of change in caring over time.

Data from all these sources have allowed a rich stream of secondary analysis about caring and carers to develop. However, recent policy (HMG 2010; HMG/Carers UK/Employment for Carers, 2013) and academic preoccupations (Carmichael et al., 2010; Heitmueller, 2007; Pickard, 2002, Pickard et al., 2015) have tended to focus on carers' paid employment and/or on *intergenerational* care for people over the age of 65. This leaves a large part of the current population of carers, including those caring for a child or older people caring for someone of a similar age as themselves, rather in the shade.

The research reported here was designed specifically to take a wider view of the whole population of carers and, by comparing types of carers and of caring activity at two time points, change over time.

The analyses described here were part of a larger study, funded by the ESRC as part of its Secondary Data Analysis Initiative, which explored the links between disability, care and participation, using secondary analysis of data from the two surveys reported here, alongside a separate stream of analysis using the Life Opportunities Survey (ONS, 2012). The latter is reported in another working paper (Kampanellou et al., 2017).

### **Summary of the working paper**

In this working paper we initially describe some of the technical detail about the analyses we carried out. We then report the findings of two distinct streams of analysis. The first of these compares the characteristics of people reporting themselves as carers, receipt of services by the person being supported by the carer, and getting a break from caring, as evidenced by the two surveys. The second stream focuses on two groups that seemed to have changed most over time – those caring for a disabled or ill child and those caring for a spouse or partner. The discussion and concluding sections explore the limitations and strengths of our work and then examine the findings in the context of a period, between 1985 and 2009/10 that saw increased emphasis on, policy discussion of, and legislative change intended to provide, support for carers.

## **Chapter 2: Data sources and methods**

### **General Household Survey 1985 and Survey of Carers in Households 2009/10**

The General Household Survey was a survey of all adults living in a representative sample of households in England, Wales and Scotland. It was cross-sectional and repeated, usually each year, between 1971 and 2007, when the General Lifestyle Survey, which then ran until 2012, superseded it.

The SCH is the latest in a line of surveys/survey modules that have broadly followed the format of the 1985 GHS module about carers and caring. It was also a representative, sample survey but one that focused only on carers and did not collect data from other members of the household. It has not, to date, been repeated. While the SCH used a different sampling technique from the GHS, it is said to be comparable in relation to the predicted prevalence of heavily involved carers, although it is thought to have underestimated lower levels of caring activity (NHSIC, 2010). It is almost wholly comparable in the detailed questions that were asked about carers and care giving, but less so in relation to questions asked about service receipt.

The existence of the two surveys and the ability to compare detailed data about carers and caring, offers the opportunity to take a long view, albeit cross-sectional, about changes in the pattern, nature and impact of caring over more than 25 years. The comparison thus adopts a quasi-cohort approach in order to examine change in the nature of the caring population over time. We are not, of course, comparing the same individuals over time.

### **Methods**

We have reanalysed the 1985 GHS and the SCH to compare the prevalence and patterns of carers and caring and impact over time. In this section we summarise the technical work done to achieve this, which is reported in detail in Kampenellou, 2017a and b.

### **Ensuring comparability of the GHS and SCH**

The main difference between the work done originally on the GHS and the current analysis is the restriction of the latter to England. While the GHS included Wales and Scotland, the SCH was carried out only in England. The first stage of the analysis was thus to create a GHS data set that included only households in England.

Other differences between the GHS and SCH have also limited, to some extent, the work that we could do on either. For example, the GHS defined the main cared for person using the following criteria, in this order of priority (Green, 1988, p.16):

1. The person to whom the carers devoted the longest time on caring activities or supervision;
2. The person being supported who lived inside the carers' household;
3. The person being supported for whom the carer took the main responsibility.

These criteria were fitted to the data post-hoc and 'where there was no difference between [the people being supported] the main dependent was chosen randomly' (ibid).

All questions in the GHS carers' module were asked of all carers, and for each person that the carer said that they supported.

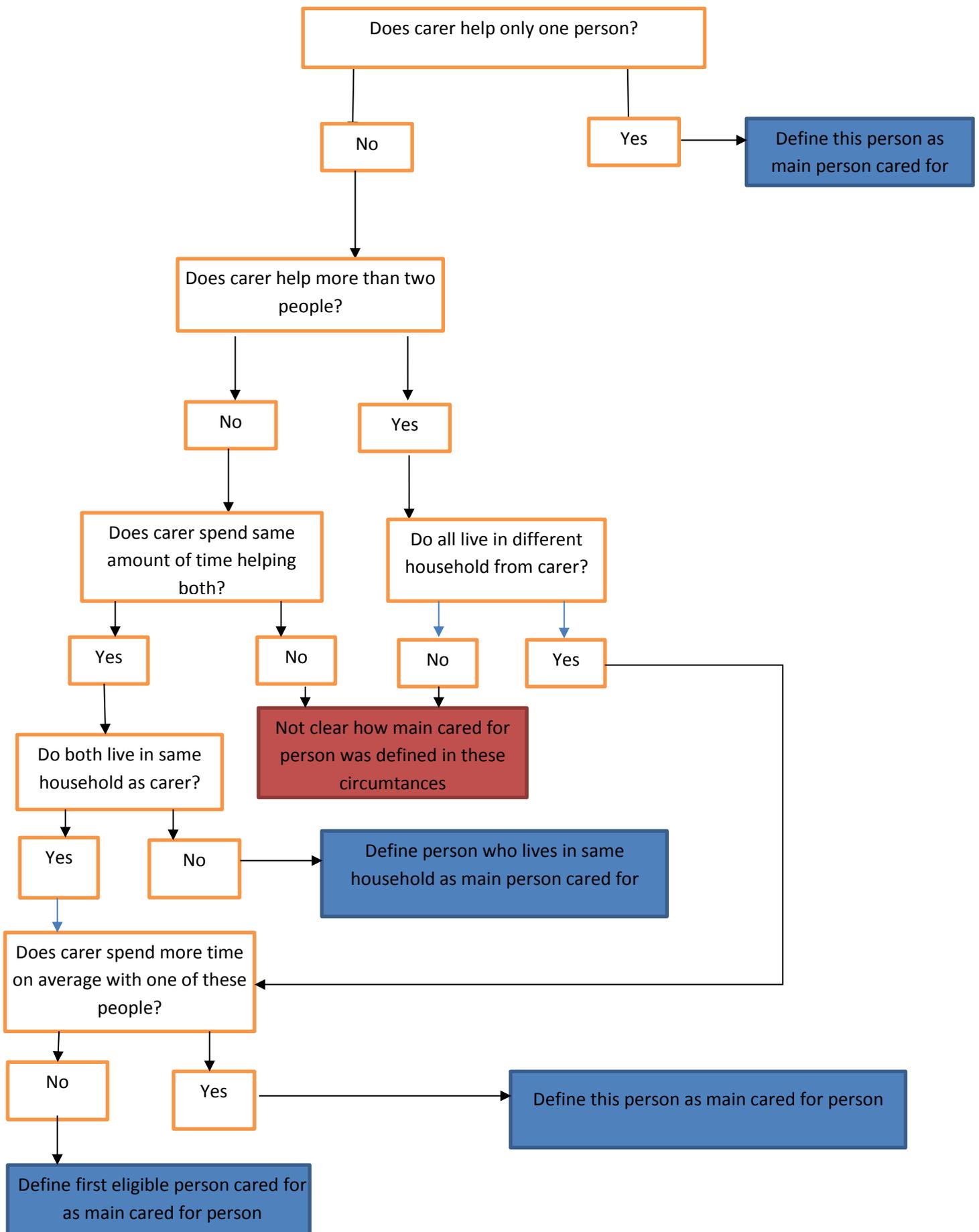
By contrast, the SCH defined a 'main person cared for' using an algorithm (see Figure 1). As the algorithm shows, in some cases it seems that a main person cared for was not defined at all.

Having defined the main cared for person, some SCH questions – on service receipt and support for the carer – were then asked only if the main cared for person was **also** a relative or living in the same household as the carer. This is a more restricted range of questioning than that used in the GHS and is disappointing, not least, because any analysis of substitutability of services for carer input is more difficult. In our work we replicated the SCH restrictions in the GHS analysis, to ensure comparability.

A proportion of other elements of the analysis presented in the SCH main report (NHS Information Centre, 2010) also relates only to the main cared for person.

Because of these differences between the GHS and the SCH, we decided to restrict all analysis of both datasets to carers and the person being supported the most. As a result, we do not present any data that related to the carers in either survey who reported supporting more than one person.

**Figure 1: Algorithm used in SCH to define main cared for person**



## Analysis

After ensuring comparability of the two data sets, we carried out simple comparisons of the GHS and SCH, examining, for example, the patterning of caring in different age groups or by different relationships to the person being supported.

We then used the SCH data to replicate and compare the typology of carers and caring developed from the 1985 GHS data (Parker and Lawton, 1994). This typology was originally developed using cluster analysis, and showed that the type(s) of care provided fell into clearly differentiated patterns and that these discriminated between heavily and less heavily involved carers. Six types of caring were identified and analysis demonstrated how types of caring distinguished between types of carers. Logistic regression analysis then explored whether and how service receipt varied between the different types of carers.

The typology was found still to stand with the SCH data (though with some changes in patterns – see below). Replicating this work on the SCH allowed us to explore in detail whether and how caring activity in households had changed between 1985 and 2009/10, and then to repeat our exploration of the relationship between types of carers and types of caring, service receipt and impact, using both bivariate and multivariate (logistic regression) statistical techniques.

Our results are in three main sections.

The first section examines the characteristics of people reporting themselves as main carers: their age and sex, relationship to the person they supported, and the type of care they provided. This includes some analysis of Census data, to set information about change among carers into overall population change. We then move on, within this section, to explore the characteristics of the most heavily involved carers (defined as those providing both physical and personal care).

An exploration of service receipt comes next. This uses both bivariate and multivariate analysis to show how service receipt varied by the characteristics of the carer and the person being supported, their relationship and the economic activity of the carer, and at how this may have changed between 1985 and 2009/10. This section concludes with bivariate analysis of change in carers' opportunities to take a break from caring.

The final main results section focuses on two groups that the earlier analysis suggested had changed the most over time – those caring for a disabled child (whether dependent or adult) and those caring for a spouse or partner. We report change in the age and sex of those caring for a child and explore their employment status. With those caring for a spouse/partner, we examine their age and the age of the person they supported, and a

range of other characteristics, including the condition of the person they supported. We also present a separate multivariate analysis of patterns of service receipt in this group.

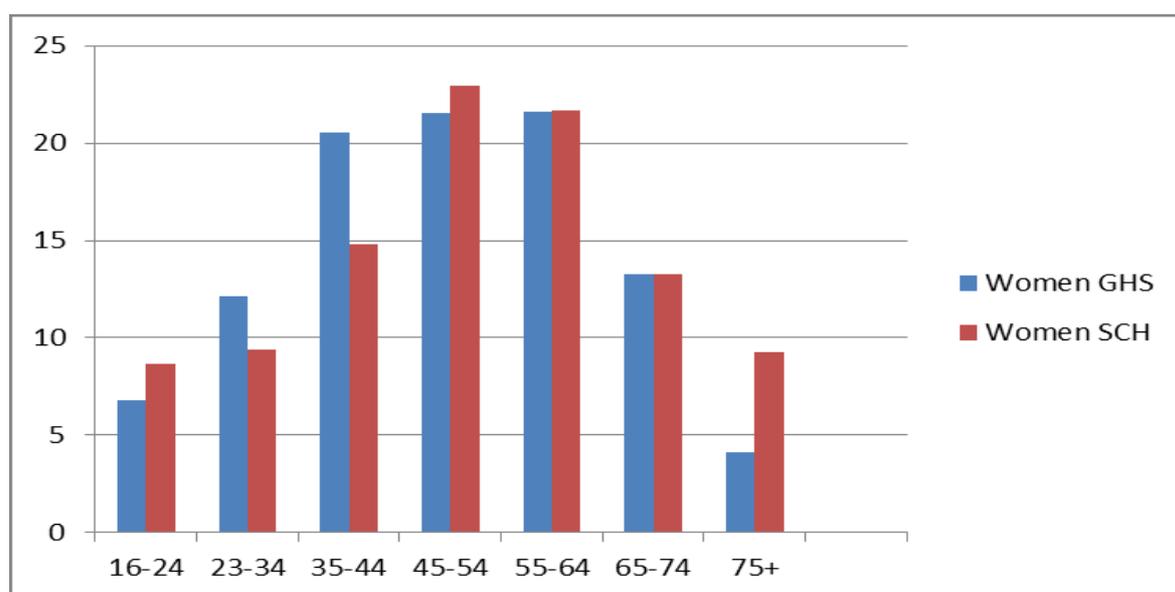
## Chapter 3: Change in patterns of caring: 1985 and 2009/10

### Age and sex

Overall, the population of people identifying themselves as carers was older in 2009/10, on average, than it was in 1985. The proportion of carers in all age groups up to 45 years fell between 1985 and 2009/10 and increased in all age groups of 45 years and over, and particularly in the 75 years and over group. This change varied slightly by sex (Figures 2 and 3). Figure 2 shows that, among women identifying themselves as carers, there was a slight increase in the proportion aged between 16 and 24, reductions in age groups between 25 and 44, and increases or stability in age groups over 45 and under 75. There was a very large increase in the proportions of all female carers who were aged 75 and over. Figure 3 shows that change in age patterns among male carers was slightly different, with reductions in all age groups up to 54, increases or stability in age groups between 55 and 74, and, as with women, a very striking increase between the two surveys in the proportion of all male carers who were aged 75 and over.

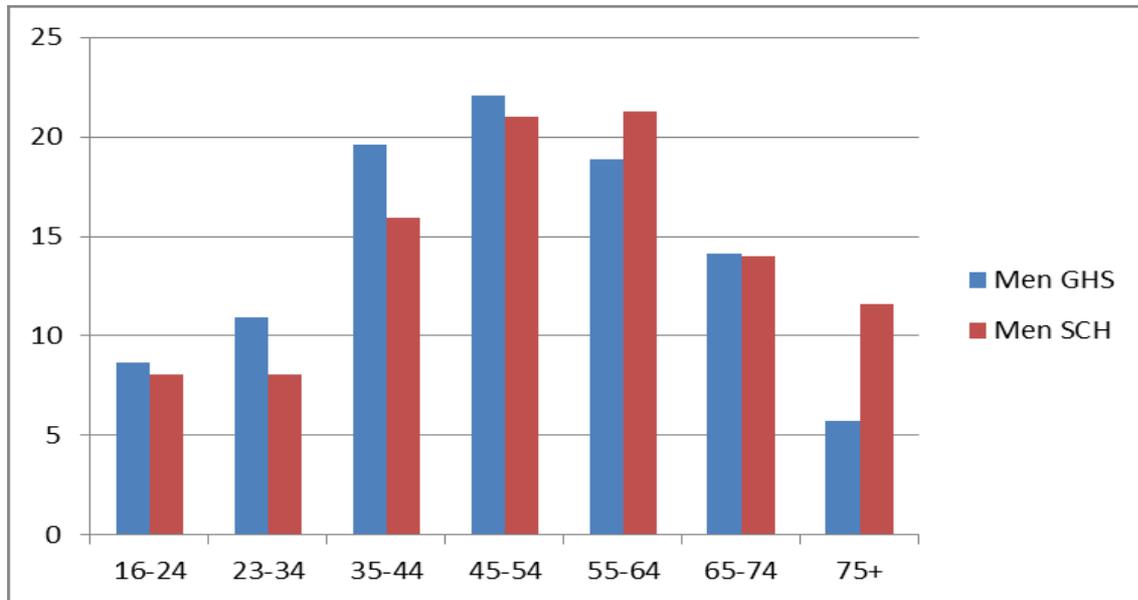
One possible explanation for the ageing of the carer population is simply the overall ageing of the total population since 1985. However, if we compare the age distribution of carers in the SCH with the overall age distribution in England in the 2011 Census, we can see that carers are currently, as a group, older than the total adult population (Figures 4a and b). This is the case regardless of sex although the pattern is more pronounced among men aged 65 and over.

**Figure 2: Change in the age of female carers: % in each age group 1985 and 2009/10**



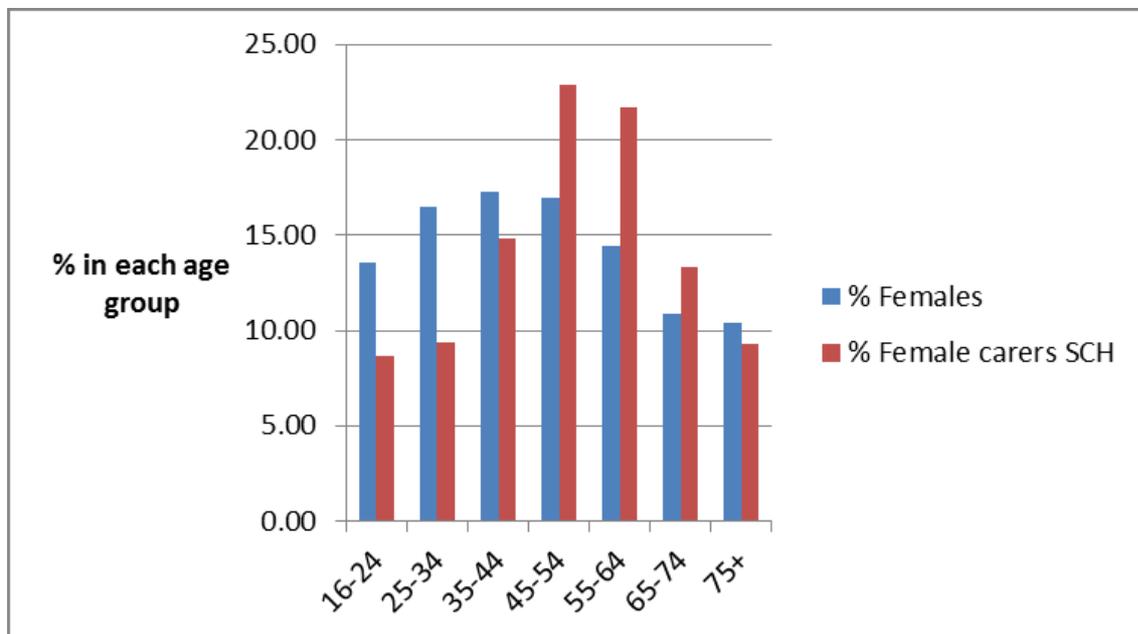
Sources: 1985 GHS, 2009/10 SCH

**Figure 3: Change in the age of male carers: % in each age group 1985 and 2009/10**



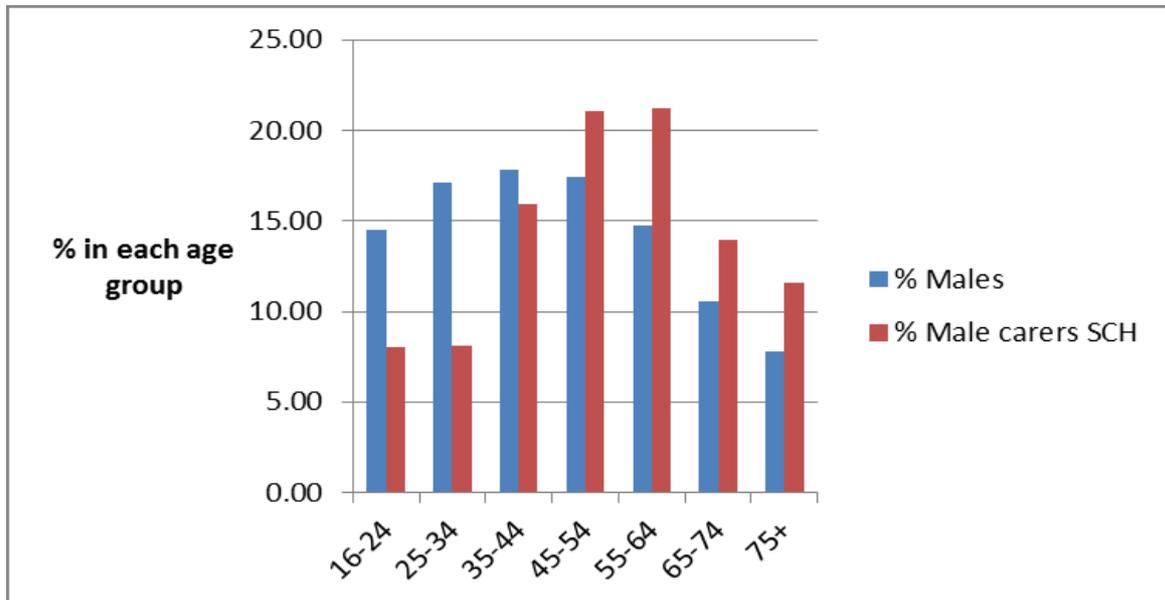
Sources: 1985 GHS, 2009/10 SCH

**Figure 4a: Age distribution of female adult population (England, 2011) and population of female carers in SCH: % in each age group**



Sources: 2011 Census; 2009/10 SCH

**Figure 4b: Age distribution of male adult population (England, 2011) and population of male carers in SCH**



Sources: 2011 Census; 2009/10 SCH

We can confirm this picture of caring as a feature of middle and later life by comparing people in the 2001 and 2011 Census who reported that they had caring responsibilities with those who did not and calculating the relative risk of being a carer in each age group (Table 1).

This shows that, in both Censuses, people aged 50 to 64 years were at twice the risk of being carers compared to adults of any other age, but that this risk decreased a little between the two Censuses. By contrast, while people aged 65 and over in 2001 were very slightly less at risk of being a carer in 2001, compared to all other adults, this risk had increased by 2011. This clearly underlines both that late middle/early old age is a 'risk factor' for having caring responsibilities, and that the risk has increased in the oldest age groups.

**Table 1: Relative risk of being a carer by age group (2001 and 2011 Censuses, all adults 16 and over, England)**

Age group	Relative risk of being a carer if in this age group (2001)	Relative risk of being a carer if in this age group (2011)
16-24	0.339353	0.352027
25-34	0.517497	0.489478
35-49	1.151327	1.019946
50-64	2.005710	1.988198
65+	0.942313	1.145745

Base: all people 16 and over usually resident in households, England.

Sources: 2001 Census; 2011 Census

## Employment

In line with the ageing of the carer population, lower proportions of carers reported themselves as in paid work in the SCH (51% in 1985 and 46% in 2009/10) and higher proportions as retired (19% and 25% respectively). However, this varied between men and women, with a greater drop in reporting of paid work among men and a slight *increase* overall among women. This latter result is likely an artefact caused by the increase in all women's labour market participation since 1985.

## Relationship to the person being supported

One possible interpretation of the ageing of the population of carers is that the 2009/10 survey identified a similar population to that identified in the 1985 survey, but one that was, simply, drawn from older groups because the population as a whole had aged. If this were the case, then we might expect to see similar patterns of relationships between carers and the person being supported. However, this is not the case; our analysis shows that there has been substantial change over time in the type of people carers report supporting.

In 1985, the largest group being supported was parents; 33 per cent<sup>1</sup> of carers reported that this was the only or main person they supported. While this was still the largest group overall in 2009/10 (32% of carers), the proportions reporting supporting a spouse had doubled (from 11% to 23%). This is an important finding as, all other things being equal, one might have expected the proportions supporting parents to have increased in line with the overall ageing of the population since 1985. Other researchers have suggested that this

<sup>1</sup> All percentages are rounded, so may sometimes sum to more or less than 100.

would be the case. For example, in their examination of changing economic and social roles for people in mid-life between 1985 and 2000, based on analysis of the GHS, Evandrou and Glaser (2002, p.110) suggested a link between the increased likelihood of ‘having a surviving parent in need of care’ and the increased likelihood of being a carer in mid-life for later cohorts.

There are several possible explanations for the lack of change in the proportions caring for parents that *our* work identifies. First, while the population is ageing, the age at which care is required may increase if frailty is ‘postponed’ through a compression of morbidity (Fries et al., 2011)<sup>2</sup> thus offsetting the increased numbers of older people against a delayed need for support from adult children. Secondly, and as argued by others (Pickard, 2002) there may be an increasing gap between the need for care in older age groups and the ability or willingness of children to provide it. Thirdly, and as seems to be supported by the analysis presented here, spousal relationships have become more prevalent in current older age, as a consequence both of the ‘very married’ generations who were born between the two world wars (Wilson and Smallwood, 2007) and of men surviving longer into older age (Dunnell, 2008). As a result spouses/partners may have become a more important source of care in older age, perhaps replacing or supplementing care provided by daughters and daughters-in-law for parents in earlier generations. This increase in *spousal* caring might also help to explain Evandrou and Glaser’s (2002) argument that we are seeing increased levels of caring in mid-life.

The proportions reporting supporting a child has also doubled, from six per cent of carers in 1985 to 13 per cent in 2009/10; this includes both young and adult children. Possible explanations here include higher numbers of babies and infants surviving with impairments, technological change that allows children with severe impairments to survive longer and to live at home, and increased emphasis in policy on reducing reliance on long-term care settings for disabled children and young adults.

### **Type of care being provided**

When the 1985 GHS data were originally analysed, we created a typology of caring activity that reflected the types of tasks carers were helping with. We found that this was closely related to other caring characteristics, such as whether care was provided in the same household, the hours of care provided, and impact on other roles (Parker and Lawton, 1994). Carers providing both personal and physical care for the person they were supporting were the most heavily involved in terms of hours of care, reduced paid employment and

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<sup>2</sup> We acknowledge that this remains a contested issue; see, for example, Crimmins and Beltrán-Sánchez (2010; Parker and Thorslund (2007) for alternative views.

other impacts. These were followed, in terms of involvement and impact, by carers providing personal but not physical care and those providing physical but not personal care. Again, comparison of the 1985 and 2009/10 data shows change. In 1985, 13 per cent of carers reported providing both personal and physical care; by 2009/10 this had increased to 20 per cent. The proportions reporting providing personal but not physical and physical but not personal care had also increased somewhat. At the same time, the proportions reporting providing practical help, but not personal or physical help, the category of least heavily involved carers, had reduced from 54 per cent to 38 per cent.

We are thus seeing not only an ageing of the population of carers, but also an increase in levels of responsibility. The substantial increase in reported hours of care provided per week also underlines this change. In 1985, 77 per cent of carers reported caring for fewer than 20 hours a week and 23 per cent for 20 hours or more. By 2009/10, the comparable proportions were 58 per cent and 40 per cent.

As with the increase in spousal caring, there are several possible explanations for these changes. These include increased dependency in the population of people requiring care, reduced dependency in the population of older people as a whole (which means less need for 'low level' help), fewer women at home to provide low level help because of changes in female labour market participation, reduced support from formal services that might act to increase carers' hours of activity, and different expectations about caring and being cared for in different caring relationships. Some of these can be explored with the GHS and SCH data (and we do so below) others cannot. We also need to bear in mind the suggestion, referred to earlier, that the SCH may have underestimated lower levels of caring activity.

### **Heavily involved carers**

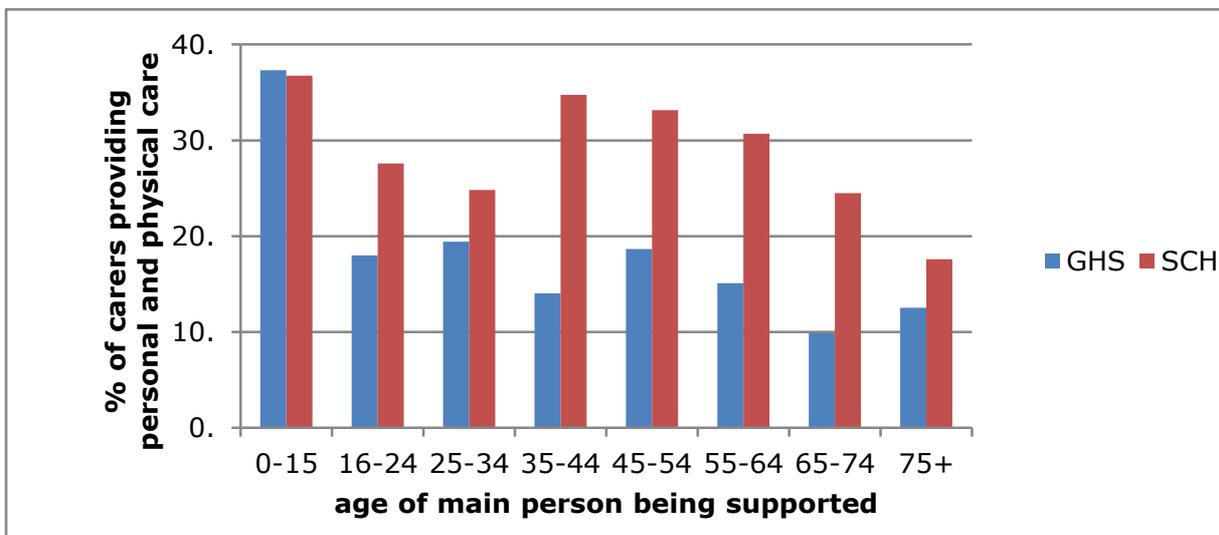
As described above, carers who provide both personal and physical care are likely to be the most heavily involved. In this section, we focus on this group of carers in the two surveys to explore what, if anything has changed in relation to those with the most substantial caring responsibilities between 1985 and 2009/10.

In both surveys, carers most likely to be involved in this most arduous form of caring were those aged 75 and over, but with little change between the two surveys (26% and 27% of carers in this age group reported providing both personal and physical care in 1985 and 2009/10, respectively). By contrast, all other age groups of carers showed substantial increases in the proportions reporting this type of caring activity. Overall, differences between different age groups have evened out since 1985, with between 22 per cent and 27 per cent of all age groups falling into this category of caring activity.

As Figure 5 shows, the age distribution of the person being supported has also evened out somewhat between the two surveys. In 1985, providing personal and physical care moved above 20 per cent of cases only when the carer was supporting someone under the age of 16 years. By 2009/10, over 20 per cent of *all* age groups (apart from those aged 75 and over) were receiving this type of care from the carer. The greatest proportionate increases in this type of care provision were when the person being supported was aged between 35 and 44 or between 65 and 74.

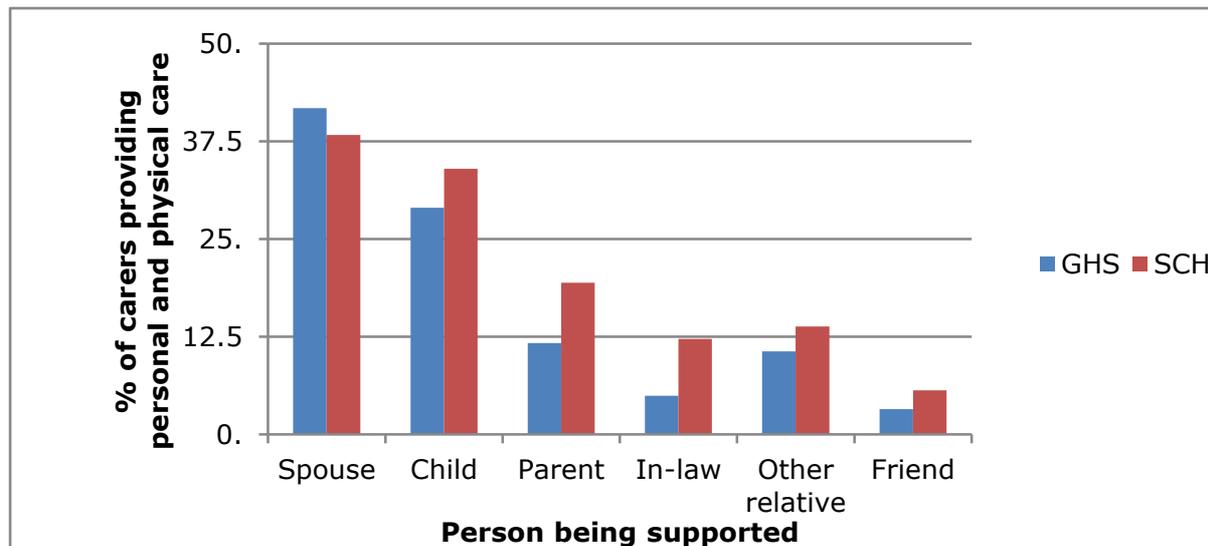
Figure 6 shows that, except for spouses, there were increases in all other types of relationships in the proportions of carers who reported providing personal and physical care. These increases were proportionately greatest among those caring for parents or parents-in-law. In other words, those caring for parents or parents in law were more likely to be involved in ‘heavy end’ caring in 2009/10 than they were in 1985. This does not immediately suggest a ‘hollowing out’ of intergenerational caring activity that other analysts have suggested is occurring (Pickard, 2002), at least at the most demanding end of caring.

**Figure 5: Age of main person being supported: % of carers providing personal and physical care, 1985 and 2009/10**



Sources: 1985 GHS, 2009/10 SCH

**Figure 6: Relationship between cared for person and carer: % of carers who were providing personal and physical care, 1985 and 2009/10**



Sources: 1985 GHS, 2009/10 SCH

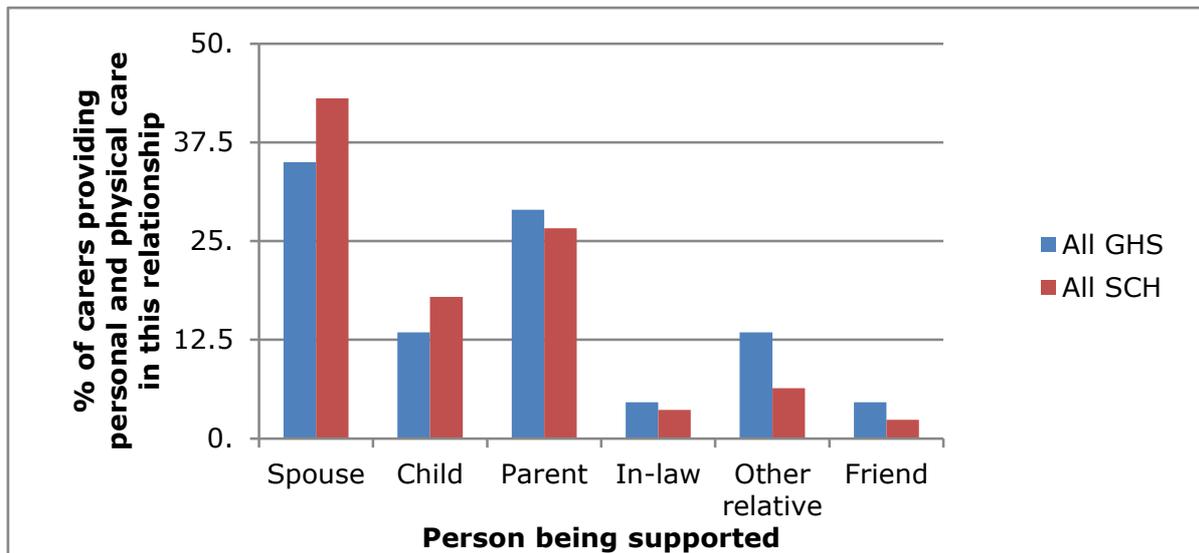
However, there are other ways of exploring this relationship. If we examine what proportion of carers providing personal and physical care were supporting a parent or parent-in-law, a slightly different pattern emerges (Figure 7). Here we see that while 35 per cent of heavily involved carers were supporting a spouse in 1985, by 2009/10 this had increased to 43 per cent. Similarly, the proportions of heavily involved carers supporting a child increased from 13 per cent to 18 per cent. By contrast, the proportion of heavily involved carers providing support to parents or parents-in-law decreased somewhat (from 29% to 27%). In other words, those caring for spouses or children made up a greater proportion of the most heavily involved carers in 2009/10 than they did in 1985.

These subtle differences in patterns of change, depending on which way one analyses the relationship, show the importance of careful disentanglement of overall population change (i.e. the proportions of carers in different sort of relationships to the person being cared for) from change in the experience of caring within those different relationships.

Although personal and physical care provision remained associated with longer hours of care, this association had weakened a little, with 10 per cent of carers in this category reporting providing fewer than 20 hours of care a week in 2009/10, compared with only five per cent in 1985. Similarly, there was an increase in the proportion of carers reporting that they provided personal and physical care to someone outside their own household (from 6% to 12%). Further analysis is needed here, but this may suggest that more carers were providing this type of care in a slightly less intense form in 2009/10 than was the case in 1985. One possible explanation for this is that services for the person being supported focus

on situations where carers are heavily involved and have, thereby, 'substituted' in some way for hours of care otherwise provided by carers. The analyses of service receipt in the following chapter allow some light to be thrown on this possibility.

**Figure 7: Proportion of carers who provided personal and physical care by relationship**



Sources: 1985 GHS, 2009/10 SCH

## Chapter 4: Change in receipt of services: 1985 and 2009/10

For reasons explored in some detail in Parker and Lawton (1994), using carer survey data to understand the relationship between need for formal services and whether or not carers and the people they support get appropriate help from those services is difficult. Where and with whom people live, the sex and age of both the carer and the person being supported and their relationship to each other, the ‘substitutability’ of carers’ help for different types of services, the lack of detailed information about the impairments of the person being supported and other factors all make such judgements difficult. The solution adopted in our earlier work, and which we repeat here, was to:

*... change the nature of the question asked of the data. Instead of asking whether services appear to discriminate against people with comparable levels of need when they have an informal carer, we can ask whether services appear to discriminate between carers providing similar levels of care and, if so, on what basis.*

(Parker and Lawton, 1994, p.53).

In doing this again here, we first look at services received by the main person carers were supporting, regardless of their level of involvement, and comparing patterns in 1985 with 2009/10.

After presenting the straight comparison of service receipt in 1985 and 2009/10, and examining how this may be related to carer characteristics, we then go on to examine if and how service receipt varied dependent on the level of involvement of the carer, as reflected in our caring typology.

As we outlined earlier, there were differences between the GHS and SCH definitions of ‘main cared for person’ and subsequent limiting (in the SCH) of questions about service receipt and support for the carer to those who lived in the same household as the carer or who were relatives. This means that there are differences in the results from the GHS analysis presented here from those in the Parker and Lawton (1994) report.

### Service receipt in the whole group of carers

The first striking difference between 1985 and 2009/10 is the fall in receipt of almost all types of services for the main person being cared for (Table 2). Large proportionate reductions<sup>3</sup> in receipt are evident in relation to some health service input – doctors and

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<sup>3</sup> Calculated by dividing the reduction/increase in percentage receiving by the original percentage receiving and multiplying by 100.

health visitors – with smaller proportionate reductions in home care, nurse visits and social work. These reductions are underlined in Table 3 where we can see the substantial increase in the proportion of carers reporting that the main person they supported received none of the services asked about (from 58% to 69%).

**Table 2: Services received by the main person<sup>1</sup> being supported (1985 and 2009/10)**

Type of service	% receiving service (1985)	% receiving service (2009/10)	% reduction/increase from 1985
Home care	19	12	37
Doctor	18	7	61
Nurse	14	9	36
Meals on wheels	5	3	40
Health visitor	5	2	60
Social worker	4	5	20
Voluntary worker	4	2	50
Warden (sheltered accommodation)	2	Not asked	-
Chiropodist	1	Not asked	-
Other	4	5	25
Base (100%)	1699	1991	

1. As previously defined.

**Table 3: Number of services received by main<sup>1</sup> person being supported (1985 and 2009/10)**

Number of services	% receiving <sup>2</sup> (1985)	% receiving <sup>2</sup> (2009/10)
None	58	69
1	22	18
2	11	8
3	5	3
4	3	2
5 or more	1	1
Base (100%)	1699	1991

1. As previously defined.

2. May sum to more than 100% because of rounding

Our original reanalysis of the 1985 GHS data showed that service receipt for the person being supported and carer characteristics were sometimes related. This is evident again, with the more restricted reanalysis possible here (Tables 4 to 6). Here we have recoded the services into types - medical, personal care (which included nursing input), home care (which included home help and meals), advice (health visitors and social workers) and other. We have then explored how receipt of these services by the main person being supported varied by sex and age of the carer and the relationship of the person being supported to the carer.

Domestic services such as home help and meals on wheels have changed dramatically between the two surveys. Services that are only about cleaning or maintaining a house are now rarely provided via the public sector; instead home care services have usually become personal social care services. However, individuals may purchase purely domestic services themselves, and do so in considerable numbers (Forder, 2007). Further, things that might have been done by nurses or nursing assistants in 1985 – such as helping people to wash or bathe – are now done almost exclusively by social care services. The questions asked in the GHS and SCH were slightly different<sup>4</sup>, so it is possible that the ‘home care’ category in 2009/10 included some services that in 1985 would have been categorised under personal (nursing) care.

### Sex of the carer

First, we can see that in 1985, home care support (home care and meals) was significantly more likely when the carer was a man (Table 4). By 2009/10, in contrast, such straightforward discrimination appeared to have disappeared.

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<sup>4</sup> In the GHS ‘community or district nurse’ and ‘home help’ were separate response categories for the relevant questions. In the SCH the related categories were ‘community/district nurse/Community Matron’ and ‘home help/care worker’. The SCH also included a category ‘specialist/nursing care/palliative care’.

**Table 4 Service received by main<sup>1</sup> person being supported by sex of carer (1985 and 2009/10)**

Type of service	% receiving service <sup>2</sup> (1985)		Statistical significance <sup>3</sup>	% receiving service <sup>2</sup> (2009/10)		Statistical significance <sup>3</sup>
	Men	Women		Men	Women	
Medical	17	18	NS	7	8	NS
Personal	16	14	NS	10	12	NS
Home care	23	19	.023	12	13	NS
Advice	9	8	NS	7	6	NS
Other	9	10	NS	7	7	NS
Minimum base	822	1234		767	1224	

1. As previously defined.

2. May sum to more than 100% because of rounding

3. Tested with chi-squared statistic; any p value larger than .05 defined as non-significant (NS)

### Age of the carer

In 1985, the age of the carer was significantly related to whether the main person being supported had regular visits from a doctor; those with younger carers were more likely to get such visits (table 5a). In 2009/10, people with carers aged 25-34 were again more likely to receive visits from a doctor and those aged 65-74 less likely, but these differences were not large enough to reach statistical significance. This table also shows that greater reductions over time were evident when the carers were in the youngest and oldest age groups.

There were no significant differences in either survey in relation to personal care services for the main person being supported (Table 5b), but, again, reductions were not evenly spread across the carer age groups, with the youngest and oldest most affected .

In both surveys, receipt of advice support (from a health visitor or social worker) was most likely when the carer was younger, and in 1985 also when the carer was in the oldest age group. However, while these differences achieved statistical significance in 1985, they did not do so in 2009/10. Again, we see the oldest carer groups with the greatest proportionate reductions in support, but exceptionally here we also see some *increases* in support over time, particularly when carers were in the youngest age group. There are two possible explanations that spring to mind for this change over time. First, younger carers will include those caring for young disabled or ill children; the role of health visitors and social workers in early assessment and support for disabled children is perhaps more common now than it was in 1985. Secondly, we may be seeing here the effect of increased support to younger

adults defined as ‘young carers’ (although no one under the age of 16 was included in either survey).

In 1985, home care support (home care and meals) was most likely when carers were in the oldest age groups, but the differences did not reach statistical significance. By contrast, in 2009/10, home care support was significantly more likely to be received by the main person being supported when carers were aged between 45 and 54. This pattern is also reflected when we look at proportionate reductions; while all groups were less likely in 2009/10 to report that the person they supported received home care support, the largest decreases were in the youngest and oldest age groups and the smallest in the middle age groups.

Given the change in the nature of home care service that we referred to earlier, it is difficult to be sure about the cause of these differences. It is possible that it shows the effect of concentrating such support on carers who are in paid employment or those supporting someone who lives in a different household. It may also, of course, reflect carers or the people they support choosing to pay for such services. Unfortunately, neither survey asked about *how* services were provided or paid for, so it is difficult to throw much additional light on this.

Finally in this section, we see that ‘other’ types of support varied little between different carer age groups in 1985; By 2009/10, however, the main person being supported was significantly more likely to be receiving other types of support when carers were aged between 25 and 44. To some extent, this may reflect the different range of other services included in the two surveys. In the GHS, other visits were from voluntary workers, housing wardens and ‘other’ unspecified services. In the SCH, specific questions were asked about voluntary workers, occupational therapists, educational professionals, and community mental health services, all of which we classed as ‘other’, in order to maintain consistency with the larger service categories in the GHS. It is possible that the inclusion of educational professionals could explain the apparent increase in support for the carers aged 25 to 44 who were more likely to be caring for a disabled child.

In the following tables the figures in red indicate where the adjusted standardised residual for that cell was above 1.96, and thus was making a large contribution (whether positive or negative) to the overall chi-squared value. The figures in green indicate the largest proportionate reductions between the two surveys.

**Table 5a: Services received by main person being supported by age of carer (1985 and 2009/10): Visits from doctor**

Age of carer	% in age group receiving type of service (1985)	% receiving type of service (2009/10)	% reduction/increase in receipt
16-24	24	7	71
25-34	24	13	46
35-44	13	7	46
45-54	18	8	56
55-64	15	7	53
65-74	17	4	77
75+	24	8	67
All	18	7	61
$\chi^2=$	18.22, df=6, p=.006	12.38, df=6, p=.054	

**Table 5b: Services received by main person being supported by age of carer (1985 and 2009/10): Personal care support**

Age of carer	% in age group receiving type of service (1985)	% receiving type of service (2009/10)	% reduction/increase in receipt
16-24	19	7	63
25-34	13	9	31
35-44	15	9	40
45-54	14	12	14
55-64	14	13	7
65-74	15	10	33
75+	21	12	43
All	15	11	27
$\chi^2=$	5.291, df=6, p=.507	6.82, df=6, p=.338	

**Table 5c: Services received by main person being supported by age of carer (1985 and 2009/10): Advice support**

Age of carer	% in age group receiving type of service (1985)	% receiving type of service (2009/10)	% reduction/increase in receipt
16-24	9	13	44
25-34	15	6	60
35-44	7	8	14
45-54	7	6	14
55-64	5	5	0
65-74	9	6	33
75+	11	5	55
All	8	6	25
$\chi^2=$	19.20, df=6, p=.004	10.29, df=6, p=.113	

**Table 5d: Services received by main person being supported by age of carer (1985 and 2009/10): Home care support**

Age of carer	% in age group receiving type of service (1985)	% receiving type of service (2009/10)	% reduction/increase in receipt
16-24	17	7	59
25-34	18	4	78
35-44	16	9	44
45-54	21	15	29
55-64	24	18	25
65-74	22	11	50
75+	28	13	54
All	20	13	35
$\chi^2=$	11.35, df=6, p=.078	34.22, df=6, p<.001	

**Table 5e: Services received by main person being supported by age of carer (1985 and 2009/10): Other support**

Age of carer	% in age group receiving type of service (1985)	% receiving type of service (2009/10)	% reduction/increase in receipt
16-24	9	6	33
25-34	11	14	27
35-44	10	12	20
45-54	9	6	33
55-64	9	4	56
65-74	12	6	50
75+	8	4	50
All	10	7	30
$\chi^2=$	2.70, df=6, p=.845	36.40, df=6, p<.001	

### Relationship of the main person being supported to the carer

Early research on carers and service receipt showed clear links between whether or not people received formal support and their relationship to their carers (Arber et al., 1988). This was certainly evident in our original secondary analysis of the 1985 GHS (Parker and Lawton, 1994) and remains so in the more restricted analysis possible here. Further, it seems that the apparent discrimination in relation to some relationships has sharpened in some areas.

One caveat with the analysis presented relates to the very small numbers in the ‘friend/neighbour’ category, because of the additional restriction that the SCH imposed on this question. Only nine cases of a friend who also lived in the same household as the carer were identified in the GHS and 20 in the SCH. Despite this, the cell counts in the rest of the tables were adequate for use of the chi-squared statistic so we have retained this category in the following analyses.

We saw above that medical support (visits from a doctor) to the main person being supported had reduced considerably between the two surveys. In 1985, those supporting a child were least likely and those supporting an ‘other’ relative most likely to report that the main person they cared for received such visits (Table 6a). This difference was statistically significant. By 2009/10, significant differences were also evident, with those supporting a child still very unlikely to report this type of support. However, those supporting a

spouse/partner or a child were also less likely, while those supporting a parent were more likely than other carers to report such visits in the SCH. The greatest proportionate reductions were seen for those supporting a spouse/partner or a friend.

In 1985, those supporting their child were significantly less likely, and those supporting an 'other' relative more likely, to report that the person being supported received personal care services (Table 6b). By 2009/10, those helping a spouse/partner or child were significantly less likely and those helping a parent or other relative significantly more likely to report this type of support. Indeed, the level of support to parents was the same in both surveys, despite the reduction in receipt of personal care services across the board.

In both surveys, those caring for their children were most likely to report that advice support was received, although the differences did not reach statistical significance (Table 6c). This is perhaps understandable given the role of both health visiting and social work in early years support for disabled children and those with long-term or life-limiting conditions, and adds weight to the suggestion we made above when examining the age of the carer. In 2009/10, those helping a spouse or partner were less likely than others to report this type of support; this meant that the differences in support reached statistical significance in the SCH. Although those caring for a child were the most likely to report this type of support in both surveys, nonetheless this group of carers saw the greatest proportionate reduction over time.

In both surveys, receipt of home care services by the main person being supported varied significantly, depending on the relationship to their carer, with those helping a spouse/partner or their child being less likely to report such services (Table 6d). By 2009/10, this difference had increased, as those helping parents or parents-in-law were significantly more likely than other carers to report that these types of services were in place. This difference is underlined by the large proportionate reduction in this type of service reported by carers of spouses/partners. Again, we have no way of knowing whether these services were provided via help from local authorities or were purchased privately.

Finally in this section, Table 6e shows that there were few systematic differences in receipt of other types of services in 1985. By contrast, in 2009/10, those supporting a spouse/partner were significantly less likely and those supporting children more likely to report that other services were received; indeed those supporting a child saw proportionate *increase* in support from other types of services (see the earlier discussion about the nature of such services).

**Table 6a: Receipt of services by relationship of supported person to carer (1985 and 2009/10): Medical support**

Relationship to carer	% in group receiving type of service (1985)	% in group receiving type of service (2009/10)	% reduction/ <i>increase</i> in receipt
Spouse/partner	14	5	64
Child	6	3	50
Parent	19	10	47
Parent in law	18	9	50
Other relative	23	11	52
Friend/neighbor	11	0	100
All	18	7	61
$\chi^2=$	20.72, df=5, p<.001	22.03, df=5, p=.001	

**Table 6b: Receipt of services by relationship of supported person to carer (1985 and 2009/10): Personal care support**

Relationship to carer	% in this group receiving type of service (1985)	% in this group receiving type of service (2009/10)	% reduction/ <i>increase</i> in receipt
Spouse/partner	11	8	27
Child	7	5	29
Parent	14	14	0
Parent in law	15	12	20
Other relative	21	17	19
Friend/neighbor	22	5	77
All	15	11	27
$\chi^2=$	20.32, df=5, p<.001	36.10, df=5, p<.001	

**Table 6c: Receipt of services by relationship of supported person to carer (1985 and 2009/10): Advice support**

Relationship to carer	% in this group receiving type of service (1985)	% in this group receiving type of service (2009/10)	% reduction/ <i>increase</i> in receipt
Spouse/partner	5	4	20
Child	17	10	41
Parent	8	6	25
Parent in law	6	6	0
Other relative	10	9	10
Friend/neighbour	0	10	*
All	8	6	25
$\chi^2=$	10.75, df=5, p=.057	15.20, df=5, p=.01	

\*not calculable

**Table 6d: Receipt of services by relationship of supported person to carer (1985 and 2009/10): Home care support**

Relationship to carer	% in this group receiving type of service (1985)	% in this group receiving type of service (2009/10)	% reduction/ <i>increase</i> in receipt
Spouse/partner	13	6	54
Child	6	5	17
Parent	21	17	19
Parent in law	27	27	0
Other relative	25	16	36
Friend/neighbour	0	10	*
All	20	13	35
$\chi^2=$	39.48, df=5, p<.001	80.19, df=5, p<.001	

\*not calculable

**Table 6e: Receipt of services by relationship of supported person to carer (1985 and 2009/10): Other support**

Relationship to carer	% in this group receiving type of service (1985)	% in this group receiving type of service (2009/10)	% reduction/increase in receipt
Spouse/partner	7	4	43
Child	10	16	60
Parent	9	6	33
Parent in law	10	8	20
Other relative	12	6	50
Friend/neighbour	0	5	*
All	10	7	30
$\chi^2=$	5.02, df=5, p=.413	47.96, df=5, p<.001	

\*not calculable

### Economic activity of carer

Support for carers to remain in or obtain paid employment has been a key policy objective of the last four governments (Department of Health, 1999; HMG, 2010; HMG/Carers UK/Employment for Carers, 2013). We have also seen above some suggestion that carers in mid-life and/or supporting parents/in-law may have been ‘protected’ from overall reductions in service receipt, either through state support or private expenditure. Does exploration of the GHS and SCH data allow us to throw light on whether this change reflects these policy ambitions? Exploring how, if at all, support services for the person being helped have changed in relation to carers’ economic activity may help here.

First in this section, then, we look at all carers who were supporting someone who lived in the same household or who was a relative (as per the SCH), regardless of their age. We then go on to examine patterns of service receipt only among carers under 65<sup>5</sup>.

In neither survey were there any obvious relationships between receipt of medical support and the economic activity of the carer (Table 7a). The greatest proportionate reductions in medical support for the person being helped were when carers were seeking work or were themselves ill on a long-term basis.

<sup>5</sup> We chose this age recognising that there have been changes between 1985 and 2009/10 in the length of working lives, in the age at which people become entitled to a state pension, between men and women in relation to both of these, and between different age cohorts; the choice of 65 was thus a compromise in an attempt to encompass all these changes and ensure some degree of comparability between the two surveys.

By contrast, personal care support did seem potentially to have become slightly more targeted towards supporting carers in paid work (Table 7b). In 1985, there was no obvious relationship between personal care support and the carers' economic activity. By 2009/10, however, there was a significant difference, with carers in paid work and carers seeking paid work more likely to report that the person they supported received personal care services. Indeed, those seeking work were the only group of carers where a proportionate *increase* in support was seen between the two surveys. By contrast, large proportionate decreases were seen for carers who were long-term sick, keeping house and otherwise economically inactive.

There was no obvious relationship between carers' economic activity and advice support in 1985 but in 2009/10 carers who were categorised as keeping house were significantly more likely than other carers to report that the person they helped received this type of support (Table 7c). This may well reflect the presence of parents of younger children in this group, as we saw earlier.

In neither survey was there any significant relationship between home care support and the carers' economic status (Table 7d). However, the proportionate reductions, that were large overall as we have already seen, were not shared equally between all groups. Carers who were in paid work showed the smallest proportionate decrease, while those seeking work, who were ill themselves, who were retired or keeping house all showed large proportionate decreases.

There was a substantial difference between the two surveys in relation to other support services and carers' economic activity (Table 7e). In 1985 there was no obvious pattern, but in 2009/10 those in paid work and those keeping house were significantly more likely and those who were retired less likely to report that the person they supported received other types of services. As we noted above, there were differences in what the two surveys asked about, so this may explain the difference to some degree. However, the proportionate decreases across the board were, as before, not evenly shared; those keeping house and those otherwise economically inactive saw proportionate *increases*, those in paid work a lower than average proportionate reduction, and those seeking work, long-term ill and retired higher than average proportionate reductions.

**Table 7a: Receipt of services by main supported person by economic activity of carer (1985 and 2009/10): Medical support**

<b>Economic activity</b>	<b>% in group receiving type of service (1985)</b>	<b>% in group receiving type of service (2009/10)</b>	<b>% reduction/increase in receipt</b>
Employed	18	8	55
Seeking work	14	5	64
Long-term ill	24	4	83
Retired	14	7	50
Keeping house	19	10	47
Other	24	5	79
All	18	7	61
$\chi^2=$	5.87, df=5, p=.320	6.79, df=5, p=.237	

**Table 7b: Receipt of services by main supported person by economic activity of carer (1985 and 2009/10): Personal care support**

<b>Economic activity</b>	<b>% in group receiving type of service (1985)</b>	<b>% in group receiving type of service (2009/10)</b>	<b>% reduction/increase in receipt</b>
Employed	14	12	14
Seeking work	11	14	27
Long-term ill	12	4	67
Retired	16	12	25
Keeping house	17	7	59
Other	24	5	79
All	15	11	36
$\chi^2=$	4.63, df=5, p=.463	15.14, df=5, p=.01	

**Table 7c: Receipt of services by main supported person by economic activity of carer (1985 and 2009/10): Advice support**

<b>Economic activity</b>	<b>% in group receiving type of service (1985)</b>	<b>% in group receiving type of service (2009/10)</b>	<b>% reduction/increase in receipt</b>
Employed	7	6	14
Seeking work	9	2	78
Long-term ill	5	2	60
Retired	8	6	25
Keeping house	10	10	0
Other	7	6	14
All	8	6	25
$\chi^2=$	3.46, df=5, p=.629	12.12, df=5, p=.03	

**Table 7d: Receipt of services by main supported person by economic activity of carer (1985 and 2009/10): Home care support**

<b>Economic activity</b>	<b>% in group receiving type of service (1985)</b>	<b>% in group receiving type of service (2009/10)</b>	<b>% reduction/increase in receipt</b>
Employed	21	14	33
Seeking work	15	6	60
Long-term ill	19	6	68
Retired	25	14	44
Keeping house	17	9	47
Other	17	11	35
All	20	13	35
$\chi^2=$	8.04, df=5, p=.154	10.65, df=5, p=.06	

**Table 7e: Receipt of services by main supported person by economic activity of carer (1985 and 2009/10): Other support**

Economic activity	% in group receiving type of service (1985)	% in group receiving type of service (2009/10)	% reduction/increase in receipt
Employed	11	8	27
Seeking work	10	6	40
Long-term ill	2	4	50
Retired	10	4	60
Keeping house	8	11	38
Other	3	5	67
All	10	7	30
$\chi^2=$	5.71, df=5, p=.336	16.52, df=5, p=.006	

When we confined analysis to those under the age of 65 we found virtually no differences from the patterns revealed across all age groups, in either survey, with one exception - home care support in the 2009/10 survey. Here, those classed as retired (even though under the age of 65) were significantly more likely than all other carers to report home care support (22% compared to 13% of all carers,  $\chi^2= 20.49$ , df=5, p=.001). Possible explanations here include the ability of people who are able to retire early also to be able to pay for such services themselves and/or services that have continued to support the carer from a time when they were able to maintain paid work.

### **Type of care provided by the carer**

As explained above, our typology of care largely discriminated between more and less heavily involved carers, with those providing both personal and physical care (with or without other types of care) being the most heavily involved. When we examined patterns of service receipt by type of care in our original work (Parker and Lawton, 1994) we suggested that two different sorts of effect were evident. First, some types of service seemed to supplement the type of care in which carers were already involved. Secondly, there seemed to be a substitution effect, where service input meant that carers were not involved in particular types of care. This work also suggested both that services might be more targeted than had been obvious in exploring other carer characteristics, and that the typology might be a better proxy for the level of 'need' for care of the person being supported than we had originally thought it might.

The more restricted analysis that we were able to carry out this time, still suggests that these effects were evident in 1985. Here we can see (Table 8a) that when physical care was being provided (whether or not in combination with personal care) the person being supported was more likely to receive medical visits. These differences were large enough to reach statistical significance. Similarly, when the carer was providing both personal and physical care, personal support services were significantly more likely to be in place for the person being helped (Table 8b). By contrast, when the carer was involved in less demanding types of care, personal care services were less likely to be in place. None of the other types of service support in the GHS showed any significant differences related to the type of care in which the carer was involved.

In 2009/10, the only significant difference with any type of support was in the provision of advice (Table 8c). Here, those providing both personal and physical care were somewhat more likely and those providing other practical help somewhat less likely to report that they person they helped had such services.

The proportionate changes also show some unexpected patterns, suggesting that the people supported by the most heavily involved carers have experienced the *greatest* reductions in both personal care and home care support. Which is cause and which effect is, of course, difficult to judge: are carers providing personal and physical care because the person they support does not get services that provide this sort of help, or are services not provided because carers provide this sort of help? Whatever the direction of causation, the analysis suggests that in 2009/10 heavily involved carers were less well supported, via services for the person they cared for, than such carers were in 1985.

**Table 8a: Receipt of services by main cared for person and type of care provided by carer (1985 and 2009/10): Medical support**

Type of care provided	% in this group receiving type of service (1985)	% in this group receiving type of service (2009/10)	% reduction/ increase in receipt
Personal and physical	23	10	57
Personal only	16	6	63
Physical only	28	8	71
Other practical help	16	7	56
Practical help only	13	5	62
Other	13	5	62
All	18	7	61
$\chi^2=$	23.53, df=5, p<.001	7.68, df=5, p=.175	

**Table 8b: Receipt of services by main cared for person and type of care provided by carer (1985 and 2009/10): Personal care support**

Type of care provided	% in this group receiving type of service (1985)	% in this group receiving type of service (2009/10)	% reduction/ <i>increase</i> in receipt
Personal and physical	26	12	54
Personal only	16	9	44
Physical only	20	11	45
Other practical help	11	11	0
Practical help only	11	5	55
Other	11	9	18
All	15	11	27
$\chi^2=$	41.10, df=5, p<.001	3.91, df=5, p=.562	

**Table 8c: Receipt of services by main cared for person and type of care provided by carer (1985 and 2009/10): Advice support**

Type of care provided	% in this group receiving type of service (1985)	% in this group receiving type of service (2009/10)	% reduction/ <i>increase</i> in receipt
Personal and physical	9	8	11
Personal only	9	8	11
Physical only	13	6	54
Other practical help	6	4	33
Practical help only	6	0	100
Other	9	6	33
All	8	6	25
$\chi^2=$	8.53, df=5, p=.129	14.40, df=5, p=.013	

**Table 8d: Receipt of services by main cared for person and type of care provided by carer (1985 and 2009/10): Home care support**

Type of care provided	% in this group receiving type of service (1985)	% in this group receiving type of service (2009/10)	% reduction/ <i>increase</i> in receipt
Personal and physical	22	13	41
Personal only	17	9	47
Physical only	24	10	58
Other practical help	22	15	32
Practical help only	15	13	13
Other	16	11	31
All	20	13	35
$\chi^2=$	7.21, df=5, p=.206	7.61, df=5, p=.179	

**Table 8e: Receipt of services by main cared for person and type of care provided by carer (1985 and 2009/10): Other support**

Type of care provided	% in this group receiving type of service (1985)	% in this group receiving type of service (2009/10)	% reduction/ <i>increase</i> in receipt
Personal and physical	9	7	22
Personal only	14	9	36
Physical only	10	7	30
Other practical help	10	6	40
Practical help only	6	0	100
Other	8	9	13
All	10	7	30
$\chi^2=$	5.872, df=5, p=.319	7.34, df=5, p=.196	

## Accounting for patterns in service receipt

Having explored service receipt in bivariate analysis we now move on to examine it using multivariate methods.

In our original analysis of the 1985 survey (Parker and Lawton, 1994), we created a composite variable that combined the age of the person being supported, his or her relationship to the carer and whether s/he lived in the same household as the carer. Given the restricted questioning about service receipt in the SCH that we outlined earlier, the composite 'caring relationship' variable created for the analysis here was more restricted. Table 9 shows the categories and numbers in each in the two surveys (for main carers only). We excluded here the very small numbers (seven in the GHS and 13 in the SCH) of people caring for a non-relative in the same household as themselves.

The change in patterns of main caring relationships between the two surveys echoes, to some degree, the overall change in caring relationships reported at the beginning of this working paper. Table 9 shows an increase in the proportion of main carers supporting a child or adolescent or a non-elderly adult in the same household as themselves. The proportion supporting an older relative in the same household has remained stable, while the proportions supporting both non-elderly and older adults in a different household fell between the two surveys.

**Table 9: Different caring relationships (main caring relationship only) in GHS and SCH**

Caring relationship	N (%) of main carers <sup>1</sup> in 1985	N (%) of main carers <sup>1</sup> in 2009/10
1. Relative, under 16, in same household	62 (4%)	146 (10%)
2. Relative, 16-74, in same household	248 (17%)	437 (30%)
3. Relative, 75+, in same household	129 (9%)	123 (9%)
4. Relative, 16-74, in different household	399 (28%)	206 (14%)
5. Relative, 75+, in different household	591 (41%)	522 (36%)
Total (100%)	1429	1434

1. Main carer for person who is a relative or lives in the same household

As well as creating this composite caring relationship variable, the following analysis also compresses the typology of caring activity into three categories: personal care (any personal care provided); physical care (any physical care provided not alongside personal care); and other (any other type of help not including physical or personal care). Doing this allows us to explore whether the people that carers help have different support from a range of services and the extent to which this is related to the types and levels of care carers provide and to different types of relationships.

Given that the outcome that we are exploring here is dichotomous (whether or not a service is received by the person being supported) we used binary logistic regression to explore the relationship between this outcome and our two independent (predictor) variables – caring relationship and type of care provided. There was a strong, separate, relationship between caring relationship and type of care provided (see Appendix 1). However, including this interaction effect in the analysis did not strengthen the model; once both variables had been considered separately, few of the interaction terms contributed significantly to understanding of service receipt.

The statistics presented in the tables that follow are odds ratios, each of which is calculated in relation to a 'contrast' or comparison category, which always has the value of 1.00. In the case of caring relationships, the comparison category was relatives aged 75+ living in a different household from the carer. For the type of care variable, the comparison category was 'other' type of care.

Odds ratios can be interpreted as likelihoods. So, if the odds ratio is less than 1.00, then the likelihood of receipt of the service in question is less than in the comparison category; for example, an odds ratio of .80 means that carers in that category are a fifth (20%) less likely to report the service in question than the comparison category. If the odds ratio is greater than one, then the likelihood of service receipt is greater than in the comparison category; for example, an odds ratio of 2.50 means that the carer is two and a half times (250%) more likely to report the service in question than the comparison category.

In all tables, the odds ratios represent the likelihood (relative to the comparison category) of services being received by the main person being supported, all other things being equal. Thus the relationship between caring relationship and service receipt is that which is present after the type of care provided has been controlled for. Similarly, the relationship between type of care provided and service receipt is that present after the type of caring relationship has been taken into account or controlled for.

**Table 10: Relative probability (odds ratio) of medical support to the main person being cared for (GHS and SCH)**

Type of care:	GHS		SCH	
	Odds ratio	95% CI	Odds ratio	95% CI
Personal	2.281***	1.597 to 3.257	1.897***	1.285 to 2.800
Physical	2.886***	1.876 to 4.439	1.508	.880 to 2.585
Other	1.00	-	1.00	-
<b>Caring relationship:</b>				
Relative, under 16, in same household	0.090***	.021 to .381	.216**	.076 to .613
Relative, 16-74, in same household	0.360***	.223 to .581	.506**	.322 to .794
Relative, 75+, in same household	0.434**	.243 to .776	.574*	.341 to .966
Relative, 16-74, in different household	1.351	.984 to 1.855	1.287	.790 to 2.097
Relative, 75+, in different household.	1.00	-	1.00	-

\* significantly different from comparison category at .05 level

\*\* significantly different from comparison category at .01 level

\*\*\* significantly different from comparison category at .001 level or beyond

Table 10 shows that in 1985, medical support to the main person being cared for was over twice as likely when the carer was providing personal care and almost three times as likely when providing physical care, compared to when other types of care were being provided, regardless of the type of caring relationship. However, it was clear that when the person being supported lived in the same household as the carer, medical support was significantly less likely, regardless of the type of care provided.

Broadly similar, though not so stark, differences were evident in 2009/10. First, medical support was almost twice as likely when the carer was providing personal care as when providing 'other' types of care. In this later survey, however, there was no evidence that medical support was significantly more likely when the carer provided physical care. If we take type of care as a proxy for level of need, then this suggests some increased focusing of medical support on those with the highest levels of need. We also see in the later survey that when a child or a younger adult in the same household was being supported, medical support was significantly less likely, regardless of type of care.

**Table 11: Relative probability (odds ratio) of personal care support to the main person being cared for (GHS and SCH)**

Type of care:	GHS		SCH	
	Odds ratio	95% CI	Odds ratio	95% CI
Personal	3.291***	2.292 to 4.725	1.676**	1.203 to 2.334
Physical	2.498***	1.553 to 4.020	1.411	.895 to 2.224
Other	1.00	-	1.00	-
<b>Caring relationship:</b>				
Relative, under 16, in same household	.216**	.082 to .568	.111***	.040 to .310
Relative, 16-74, in same household	.418***	.263 to .666	.264***	.176 to .398
Relative, 75+, in same household	.640	.337 to 1.088	.522**	.347 to .787
Relative, 16-74, in different household	.660*	.451 to .965	.657	.419 to .1030
Relative, 75+, in different household.	1.00	-	1.00	-

\* significantly different from comparison category at .05 level

\*\* significantly different from comparison category at .01 level

\*\*\* significantly different from comparison category at .001 level or beyond

As with medical support, personal care support (which included nursing care) has also apparently become more focused on those with the very highest levels of need between 1985 and 2009/10 (Table 11). In the earlier survey, when the carer provided personal care, the person being supported was over three times as likely to receive personal care support as when the carer provided other types of care. When providing physical care, personal care services were almost two and a half times as likely. By 2009/10, only when personal care was being provided was service receipt significantly higher than in the comparison category, and by a smaller proportion.

Similar apparent biases in provision of personal care support to those who lived in the same household as the carer or who were younger adults are evident in both surveys and, in some cases, seem to have sharpened. So, even when controlling for the type of care provided, carers supporting a child were almost 80 per cent less likely than comparison group carers to report personal care service receipt; by 2009/10 they were almost 90 per cent less likely to do so.

**Table 12: Relative probability (odds ratio) of advice support to the main person being cared for (GHS and SCH)**

Type of care:	GHS		SCH	
	<i>Odds ratio</i>	<i>95% CI</i>	<i>Odds ratio</i>	<i>95% CI</i>
Personal	1.392	.822 to 2.358	2.189***	1.410 to 3.398
Physical	2.615***	1.484 to 4.610	1.551	.822 to 2.928
Other	1.00	-	1.00	-
<b>Caring relationship:</b>				
Relative, under 16, in same household	2.161	.990 to 4.720	1.302	.676 to 2.507
Relative, 16-74, in same household	.658	.351 to 1.231	.694	.421 to 1.146
Relative, 75+, in same household	.157*	.037 to .663	.434*	.220 to .858
Relative, 16-74, in different household	1.132	.710 to 1.806	1.551	.822 to 2.928
Relative, 75+, in different household.	1.00	-	1.00	-

\* significantly different from comparison category at .05 level

\*\* significantly different from comparison category at .01 level

\*\*\* significantly different from comparison category at .001 level or beyond

In 1985, those providing physical care were much more likely to report input from advice services, while those supporting an older relative in the same household were less likely to do so (Table 12). In 2009/10, carers were more than twice as likely as comparison group carers to report such services if they were providing the most intense type of care (personal care). Differences related to the category of person being supported remained the same, with only those caring for an older relative living in the same household being significantly less likely than the comparison groups to report advice services. Again, these changes suggest a sharper focus of services on those whose carers are providing the most intense forms of care.

**Table 13: Relative probability (odds ratio) of home care support to the main person being cared for (GHS and SCH)**

Type of care:	GHS		SCH	
	Odds ratio	95% CI	Odds ratio	95% CI
Personal	1.904***	1.328 to 2.732	1.471*	1.075 to 2.012
Physical	1.900**	1.197 to 3.016	.938	.590 to 1.494
Other	1.00	-	1.00	-
<b>Caring relationship:</b>				
Relative, under 16, in same household	0.00 <sup>1</sup>	-	.076***	.027 to .211
Relative, 16-74, in same household	.135***	.081 to .226	.117***	.073 to .185
Relative, 75+, in same household	.037***	.011 to .118	.410***	.279 to .603
Relative, 16-74, in different household	.356***	.257 to .494	.530**	.350 to .802
Relative, 75+, in different household	1.00	-	1.00	-

1. No carers in this group reported receipt of domestic care support, so an odds ratio cannot be calculated

\* significantly different from comparison category at .05 level

\*\* significantly different from comparison category at .01 level

\*\*\* significantly different from comparison category at .001 level or beyond

In 1985, both carers providing personal and those providing physical care were almost twice as likely as those providing other types of care to report that the person they supported received home care visits (Table 13). There was evidence of substantial variation with the caring relationship; all categories were significantly less likely to report such services compared to the comparison category. Those caring for an older relative in the same household were particularly unlikely to report home care support, regardless of the type of care they provided.

In 2009/10, only those providing personal care were significantly more likely to report home care support, again suggesting some increased focus on those with the highest level of need. However, in this case, this could also reflect the change in the nature of home care services that we discussed earlier. If home care services are now more likely to be providing personal rather than domestic care, then one might expect them also to be concentrating on those with personal care needs. The SCH also showed similar discrimination in service receipt in terms of the caring relationship, with those caring for a young child or for a younger adult being particularly unlikely to receive home care support relative to the comparison category. Overall, however, both surveys show that home care input of any kind

is much less likely to be in place when the person being supported is a relative living in the same household as the carer.

**Table 14: Relative probability (odds ratio) of other support to the main person being cared for (GHS and SCH)**

	GHS		SCH	
	<i>Odds ratio</i>	<i>95% CI</i>	<i>Odds ratio</i>	<i>95% CI</i>
<b>Type of care:</b>				
Personal	2.266***	1.449 to 3.543	1.209	.764 to 1.914
Physical	1.328	.693 to 2.542	1.267	.645 to 2.488
Other	1.00		1.00	-
<b>Caring relationship:</b>				
Relative, under 16, in same household	.779	.361 to 1.680	4.819***	2.625 to 8.845
Relative, 16-74, in same household	.171***	.079 to .368	1.238	.689 to 2.224
Relative, 75+, in same household	.080**	.019 to .333	.487	.143 to 1.657
Relative, 16-74, in different household	.737	.484 to 1.121	2.724***	1.508 to 4.919
Relative, 75+, in different household.	1.00	-	1.00	-

\* significantly different from comparison category at .05 level

\*\* significantly different from comparison category at .01 level

\*\*\* significantly different from comparison category at .001 level or beyond

Finally, we turn to ‘other’ types of support (Table 14). For reasons explained earlier, a straight comparison between the two surveys is difficult here. In 1985, other types of service support were most likely when the carer was providing personal care; in 2009/10 there was no obvious patterning of service receipt related to type of care. In 1985, none of the other categories was more likely than the comparison category to report receipt of other services. By contrast, in 2009/10 those caring for a young child and those caring for a younger adult in a different household were both substantially more likely to report other service receipt than the comparison category. These differences, when considered alongside the general similarities observed with the services we have already covered, underline again the influence of the wider range of other services included in the SCH questions.

### Getting a break from caring

Good quality services for the person being supported by carers have been shown, over many years, to be what usually best supports carers themselves. Nonetheless, respite or

‘getting a break from caring’ is seen as a key way of supporting carers in policy documents. This is despite the fact that research has yet to prove that respite care is an effective intervention for improving outcomes for carers (Thomas et al., 2017) and that it sometimes makes outcomes for the person being supported worse (Maayan et al., 2014).

Both the GHS and the SCH asked carers who were providing 20 or more hours of assistance a week if they had had a break of two or more days since starting to care for the person they supported. In the SCH, this was asked only about the main person the carer supported; this is different from other SCH questions about service support which were asked only if the main person cared for was also a relative or lived in the same household. There were other differences between the two surveys that have complicated the comparison we offer here. First, the SCH question about experience of a break was restricted to carers who had said, in an earlier question, that they would *need* someone else to look after the main cared for person if they wanted to take a break for a couple of days. Those who responded ‘yes’ were then also asked if there was anyone that they could rely on to do this. The GHS, by contrast, asked carers providing twenty hours or more of help whether there was anyone they could rely on to look after the main cared for person if they wanted such a break. Secondly, the GHS question about experience of having a break was asked of all carers involved for 20 hours or more, regardless of their answer to the previous question.

As with the service receipt analysis presented above, we have restricted the GHS analysis in this section in the same ways as the SCH, to ensure comparability between the two surveys, but accept that the additional filter question in the SCH may have affected the direct comparison to some degree.

**Table 15: Having a break from caring (1985 and 2009/10) and time since last break (carers providing 20 or more hours of care and who said that they had someone they could rely on to provide a break)**

	<b>% in this group who have had a break of two days or more since starting to care for main cared for person (1985)</b>	<b>% in this group who have had a break of two days or more since starting to care for main cared for person (2009/10)</b>	<b>% reduction/increase</b>
Has had a break	60	54	10
Has had a break in past year	49	41	16
Last had a break more than a year ago	7	14	100
Missing (n)	9	0	
All <sup>2</sup> (100%)	255	431	

1. As previously defined

Table 15 shows that the proportion of carers involved for 20 or more hours a week who reported having had a break of at least two days since starting to support the main cared for person had fallen between the two surveys. This reduction is in some contrast to the size of the other service reductions (i.e. smaller) that we saw in the previous section.

If carers reported that they had managed to get a break since starting to care, they were then asked how long it was since they last had done so. Table 15 shows that the proportion of carers having had a break in the past year was 49 per cent in 1985 and 41 per cent in 2009/10; this is a proportionate reduction of 16 per cent. As a corollary, the overall proportion of carers who reported having a break, but more than 12 months ago, doubled from seven per cent in 1985 to 14 per cent in 2009/10.

Overall, then, these figures may suggest that respite services could have been protected to some degree, compared to services directly intended for disabled children and adults. However, the frequency of breaks appears to have reduced over the same period.

Respite care perhaps fits better with some sorts of relationships than it does with others. For example, good quality respite care for a disabled child or young adult might be seen as an opportunity for them to develop new relationships and skills, and thus be something that parents seek not only as a break for themselves but also as a positive thing for their child. By contrast, respite fits less well with spousal relationships, where an opportunity to take a break together, but with additional support so that the carer can also relax, may be more valued. Different sorts of carers might thus be more likely to take up the opportunity for a break and, therefore, changes in the population of carers might influence the prevalence of breaks.

Further, it is possible that breaks from caring are provided by others in the carer's family or informal networks rather than by formal services. For example, adult children may enable a parent to take a break from caring from their spouse, grandparents may care for young grandchildren for a few days to give the children's parents a break, or adult siblings may care for a parent to give the main carer a break. However, while the SCH asked main carers who reported having a break how it had been provided, the GHS did not.

Tables 16 and 17 explore some of these issues about the nature of breaks from caring. First, Table 16 examines whether carers reported having had a break of two or more days since starting caring by the relationship to the main person being supported and how this changed between the two surveys.

**Table 16: Having a break from caring (1985 and 2009/10) by relationship of main person supported to carer (carers providing 20 or more hours of care and who said that they had someone they could rely on to provide a break)**

Relationship of main person supported to carer	% in this group who have had a break of two days or more since starting to care for main cared for person (1985)	% in this group who have had a break of two days or more since starting to care for main cared for person (2009/10)	% decrease/increase in proportion reporting a break
Spouse	39	28	28
Child	62	53	15
Parent	69	67	3
Parent-in-law	81	89	10
Grandparent <sup>2</sup>	-	80	-
Other relative	63	67	-
Friend/neighbour	75	67	11
All <sup>2</sup> (100%)	61	54	11
	$\chi^2=21.00, df=5, p<.01$	$\chi^2=53.90, df=6, p<.001$	

1. As previously defined

2. Not coded separately in GHS

Table 16 suggests that there has been change in who reports having had a break. In 1985, spouses were least likely and those caring for a parent in-law most likely to report having been able to take a break of two days or more since starting caring. By 2009/10, these differences between different types of caring relationships were even greater. Fewer than a third of spouses reported having taken a break, compared to almost nine out of ten of those caring for parents-in-law; indeed those caring for parents-in-law were the only group in which the proportion reporting having had a break had increased.

Table 17 shows that formally provided respite care played a very small part in supporting the few carers in the SCH who reported having had a break of two days or more since starting to care. However, with no comparable information about how breaks were provided in the 1985 survey, we do not know whether formal arrangements have become more or less prevalent as a source of support for carers.

**Table 17: Arrangements reported by carers in SCH that allowed them to take a break**

<b>Type of arrangements used to provide a break. Cared for person goes to:</b>	<b>% of carers who had had a break reporting this type of arrangement</b>
Nursing or residential home	5
NHS hospital	1
Local authority hostel	1
Arranged holiday for cared for person only	1
Arranged holiday for cared for person and carer	2
Stay with volunteer family	1
Stay with relatives or friends	24
Friend or relative stays with cared for person	48
Paid help/carers n.f.s.	3
Family/neighbours/friends visit but do not stay	6
Family/friends looked after cared for person n.f.s.	6
Respite home	1
Holiday together	3
Other	4
<b>Total (n)</b>	<b>234</b>

n.f.s. – not further specified

Numbers are too small for further statistical analysis, but examining the frequencies did suggest that carers who helped parents or parents-in-law were most likely and spouse carers least likely to report informal arrangements with family, friends or neighbours as a source of support for taking a break. By contrast, spouse carers were most likely to report that they got a break from caring by going on holiday with their spouse. Those caring for a child were most likely to report that they got a break by the person they cared for going on holiday (without the carer) or staying with a volunteer family.

## Chapter 5: Focus on change: caring for a child and caring for a spouse or partner

In this next section of the paper, we focus specifically on the two groups of carers where the most change seemed to have occurred – those caring for a dependent or adult child and those caring for spouses/partners.

### Caring for a child

In 1985, there were 129 carers and in 2009/10 278 carers who reported that the main person they cared for was their child (including adult children). Of these, the majority (89% in 1985; 87% in 2009/10) lived in the same household as their child.

The sex distribution among main carers of a child has shifted between the two surveys. In 1985 36 per cent of carers in this group were men; in 2009/10 29 per cent were men.

The age of carers in this group has also changed over time. Table 18 shows both that there was a higher proportion of younger parents (under 35) and a somewhat smaller proportion of older parents (55 and over) in 2009/10 compared to 1985.

**Table 18: Age of those caring for their child: 1985 and 2009/10**

Age of carer	% of carers in this age group (1985)	% of carers in this age group (2009/10)
16-24	<1	2
25-34	19	17
35-44	23	30
45-54	23	23
55-64	19	12
65 and over	15	18
N (100%)	129	278

These changes seem likely to be explained in part by changes in the age profile of children being supported. In 1985, 44 per cent of the children being supported were under 16, but in 2009/10 51 per cent were in this youngest age group. By contrast, in 1985, almost 40 per cent of children being supported by parents were aged between 16 and 34, compared to just over 30 per cent in 2009/10. At the other end of the age distribution, five per cent were

45 or over in 1985. In 2009/10, nine per cent were in this age group. These differences in age distribution of the children may reflect different types of change, some of which we outlined earlier.

On the one hand, medical and technological innovations mean that children with significant impairments both survive infancy more often and live longer than in the past. Further, those with considerable support needs (for example, continuous oxygen supply, nasogastric feeding) are now able to live at home rather than in hospital or long-term care settings (Parker et al., 2013). While children with such impairments do live shorter lives than those without, living longer than they would have done in the 1980s and more often living at home may account for some of the change in age distribution seen between the two surveys. Policy has also changed since the 1980s, with the closure of many (though not all) long-stay hospitals and schools where disabled children often lived out their lives in the past (Morris, 1995).

On the other hand, changes in the younger adult age range may reflect changes in opportunities for adults who disabled since birth or childhood (Beresford, 2004). 1985 was only 15 years after legislation first guaranteed education to **all** disabled children and the disabled people's movement in the UK was then still in its early years. Since then, opportunities for disabled young people and adults to live lives that are independent of their parents have increased and both policy and practice have encouraged this.

There was virtually no difference in the age range of female and male carers supporting a child in 1985. In 2009/10, women were slightly more likely to be aged 25-34 years compared to men (18% and 13% respectively) while men were somewhat more likely than women to be in the 45-54 age group (29% and 19% respectively), but these differences were not large enough to achieve statistical significance. This may help in part to explain the change in overall sex distribution we saw above, if in 1985 there were more older fathers who were main carers and in 2009/10 there were more younger mothers.

In 1985, over three-quarters (81%) of carers said that they were married, 10 per cent widowed, and the remainder (9%) divorced or separated. By 2009/10, marital status reflected changes in marital status in the population as a whole, with 12 per cent of carers reporting themselves as single and 14 per cent as divorced or separated. Only 68 per cent said that they were married or in partnerships and six per cent that they were widowed, the latter reduction presumably reflecting the younger overall age of the carers.

The GHS asked how the person being supported was 'affected' by their condition. Main carers for children reported that their child was affected mentally (22.5%), physically (37%) or both mentally and physically (36%). By 2009/10, a third (34%) of children were said to be affected mentally and 32 per cent both mentally and physically. Most of the remainder

(31%) were affected only physically. The category that covers mental effects is likely to include both mental illness and learning disability, and is acknowledged as an unfocussed indicator of type of impairment. The change here may also reflect increasing rates of diagnosis of autism spectrum disorders (Baird et al., 2006; Brugha et al., 2012).

Almost two-thirds of parents in 1985 who were the main carer reported helping for 20 or more hours a week and were most likely to be providing personal and physical care (28%) or personal care (33%). In 2009/10, almost three-quarters of parents (71%) said that they cared for 20 hours or more, and they were somewhat more likely to be involved in both personal and physical care (31%), and less likely to be involved in personal care without physical care (27%). These changes likely reflect the younger age of the children being supported, compared with 1985, as well as the possibility that children living at home now have greater support needs, for the reasons suggested above.

Given the age range of the children in the 1985 survey, it was not surprising to find that many parents reported caring for many years; over a fifth (23%) said that they had been caring for 20 years or more. However, despite the slightly younger age profile of the children in 2009/10, the proportion reporting caring for 20 years or more was almost the same (24%).

We saw earlier that the level of service support to those caring for a child was lower in 2009/10 than it had been in 1985 in all categories of service other than 'other'. We also explained there that differences between the two surveys probably reflected the wider range of services specifically asked about in the later survey.

### **Employment status of carers supporting a child**

Given both the younger age profile of the carers in 2009/10 and the substantial changes in women's labour market participation since 1985, one might expect to see different patterns of paid employment for both male and females caring for a child between the two surveys. This was, indeed, the case.

First, a higher proportion of all those caring for a child in 2009/10 reported being employed (42%, compared to 36% in 1985). However, while this increase was evident for both male and female carers, female carers' labour market participation had increased most (from 24% in 1985 to 35% in 2009/10) compared with no change among men (59% in both surveys). Despite this change, mothers in 2009/10 were still significantly less likely to report being in paid work than fathers.

Secondly, there were other differences; for example, no men reported that they were 'keeping house' in 1985, compared to 55 per cent of women. In 2009/10, by contrast, some

12 per cent of men reported this as their economic status, compared to 40 per cent of women.

Thirdly, although there was a slightly younger age profile for those caring for a child in 2009/10 the proportions reporting themselves as retired was higher: 10 per cent in total in 1985 and 16 per cent in 2009/10. But here again, sex differences were very evident over time. In 1985 only seven cent of women, compared to 15 per cent of men reported being retired. In 2009/10, the proportions doing so were much closer (16 per cent for men and 15 per cent for women).

As we saw above, these differences are unlikely to be explained by differential change over time in the ages of male and female carers. However, it seemed possible that the increase in men reporting keeping house in 2009/10 was associated with the slight excess of male carers in the 45 to 54 age group. Further analysis, however, did not support this possibility.

### **Explaining employment status of carers supporting a child**

We know that being a carer, of itself, reduces labour market participation among both women and men, particularly when carers are heavily involved and/or live in the same household as the person being supported (Heitmuller, 2007). However, among carers supporting a child what other factors might influence whether or not they participate in paid work? In this part of our work we used a similar statistical approach to that used to examine service receipt, but here we explored the impact of carers' sex, age and marital status, the age of the child they were supporting, and the number of hours of care they provided on whether they were in paid work. Analysis was confined to carers under 65, for reasons articulated earlier.

**Table 19: Relative probability (odds ratio) of carer being in paid employment when under the age of 65 years and caring for a disabled or ill child (GHS and SCH)**

		1985 GHS <sup>1</sup>		2009/10 SCH	
		<i>Odds ratio</i>	<i>95% CI</i>	<i>Odds ratio</i>	<i>95% CI</i>
Sex of carer:	Male	1.00		1.00	-
	Female	.175***	.065 - .425	0.414**	.217 - .787
Age of carer:	16-24	-	-	1.00	-
	25-34	1.00.		.336	.055 - .2.067
	35-44	-	-	.533	.090 – 3.163
	45-54	.563	.172 – 1.838	.393	.061 - .2.525
	55-64	.347	.059 – 2.036	.107*	.014 - .845
Marital status	Married	1.00		1.00	
	Not married	.996	.257 – 3.869	.446*	.229 - .867
Age of child:	Under 16	1.00		1.00	-
	Over 16	1.114	.342 – 3.634	2.397*	1.091 – 5.269
Hours of help provided a week	Under 20	1.00		1.00	-
	20 or more	.475	.191 – 1.181	0.457*	.228 - .916

1. Smaller numbers of parents in this survey made it necessary to reduce the carer age categories to get an adequate fit.

\* significantly different from comparison category at .05 level

\*\* significantly different from comparison category at .01 level

\*\*\* significantly different from comparison category at .001 level or beyond

Table 19 suggests that in 1985, the only included factor that significantly affected whether someone caring for a child was in paid employment, once the other factors were taken into account, was the carer's sex. Females under the age of 65 who were caring for a child were more than 80 per cent less likely to be in paid employment than men. In 2009/10, sex of the carer was still important, but other factors also played an independent part in the likelihood of being in paid employment. The oldest group of carers (55-64 years), those who were not married and those providing 20 or more hours of care were significantly less likely to be in paid employment, while those whose child was 16 or older were much more likely to be in paid work.

Exploring the factors associated with paid employment for *all* carers under the age of 65 in the SCH allows us to understand whether those who care for children *currently* experience different constraints on their paid work. To do this we looked at all carers under the age of 65 and added into the logistic regression a variable that described the relationship of the person being supported to the carer. We also explored whether or not the person being supported lived in the same household as the carer but this did not add significantly to explanation of paid employment and is therefore not reported here.

Table 20 shows that both the age of the carer and that of the person being supported are important in relation to the carers' labour market status.

As might be expected, those aged between 25 and 54 are much more likely to be in paid work than the comparison category of 16 to 24 year olds, where many are still in education. Those caring for someone over 16 are also much more likely than those caring for someone under this age to be in paid work, particularly if the person being supported is 75 or over. Independent of their age, those caring for a child or a parent are more likely to be in paid work than those caring for a spouse or partner.

On the negative side, we can see that being female, unmarried, and caring for 20 or hours or more a week all independently and significantly reduce the likelihood of a carer being in paid work.

**Table 20: Relative probability (odds ratio) of carer being in paid employment when under the age of 65 years (all main carers, SCH)**

		2009/10 SCH	
		<i>Odds ratio</i>	<i>95% CI</i>
Sex of carer:	Male	1.00	-
	Female	.697**	.552 - .881
Age of carer:	16-24	1.00	-
	25-34	2.279**	1.337 – 3.886
	35-44	2.867***	1.724 – 4.770
	45-54	2.539***	1.542 – 4.180
	55-64	.841	.504 – 1.404
Marital status	Married	1.00	
	Not married	.535***	.410 - .698
Age of person being supported:	Under 16	1.00	-
	16-74	2.063**	1.205 – 3.533
	75 and over	3.571***	1.886 – 6.763
Hours of help provided a week	Under 20	1.00	-
	20 or more	.377***	.295 - .482
Relationship of person being supported to carer	Spouse/partner	1.00	
	Child	1.853*	1.118 – 3.073
	Parent	1.513*	1.022 – 2.238
	Parent-in-law	1.685	.987 – 2.878
	Other relative	1.134	.681 – 1.889
	Friend/neighbour/ other	.972	.578 – 1.636

\* significantly different from comparison category at .05 level

\*\* significantly different from comparison category at .01 level

\*\*\* significantly different from comparison category at .001 level or beyond

Overall, then, independent of their sex or age, the age of the child they are supporting, their marital status, or hours of care provided each week, those supporting a child are more likely to be in work than those caring for a spouse or partner. This may reflect a ‘spare adult’ effect for married or partnered couples with children, where one of them can substitute for the paid work and/or the caring activity of the other. Where a spouse or partner is being cared for, such substitution is not possible. A similar ‘spare adult’ effect may also be evident for those married or partnered people caring for parents.

### Supporting a spouse or partner

The other group that seemed, on the face of it, to have changed much between 1985 and 2009/10 was of those caring for a spouse (or partner). As we would expect from the analysis presented at the beginning of this paper, the number of spouse/partner carers in the 2009/10 survey was much higher than in the 1985 survey (see foot of Table 21 for totals). The carers in this sub-group were relatively evenly divided between women and men with the proportions the same in both surveys (53% women and 47% men). The age distribution of spouse carers differed between the two surveys, however (Table 21). Here we can see an increase over time in the youngest age groups (up to the age of 34), a reduction in the middle years (45 to 64) and an increase in the oldest age group (75 and over). This means that the increase in spousal caring between 1985 and 2009/10 does not explain all of the increase in caring activity in mid-life that Evandrou and Glaser (2002) identified.

**Table 21: Age of carers supporting a spouse/partner: 1985 and 2009/10**

Age of carer	% of carers in this age group (1985)	% of carers in this age group (2009/10)
16-24	<1	1
25-34	2	5
35-44	7	7
45-54	14	11
55-64	30	20
65-74	29	27
75 and over	17	29
N (100%)	237	629

**Table 22: Age of person being supported by a spouse: 1985 and 2009/10**

Age of person being supported	% of carers supporting a spouse/partner this age (1985)	% of carers supporting a spouse/partner this age (2009/10)
<35	3	5
35-44	6	7
45-54	12	10
55-64	27	20
65-74	27	23
75 and over	25	36
N (100%)	237	629

The pattern of ages of the people being supported by a spouse/partner, and changes between 1985 and 2009/10, largely mirror those found among all carers (Table 22). There was a small increase in the proportions supporting a spouse/partner under the age of 45, a reduction in the proportion supporting a spouse/partner aged between 55 and 74, and a substantial increase in the proportion supporting a spouse/partner aged 75 or over. The mean age gap between spouses at marriage has stayed largely constant over the last 100 years at around 2.5 years, so this mirroring of the ages of carers and their spouses/partners in the two surveys is not, perhaps, surprising (Bhrolcháin, 2005). However, what is clear is that spousal care for those over the age of 75, provided by those who are themselves over the age of 75 has increased substantially in this group. In 1985, 14 per cent of spouse carers were 75 or over and supporting a partner who was 75 and over. By 2009/10 this proportion had risen to 25 per cent.

In 1985 all spouse carers reported themselves as 'married'; by 2009/10 this had changed, as might be expected given the more general change in marriage patterns between the two surveys, although the vast majority of spouse carers (97%) still reported themselves as 'married', with two per cent reporting themselves as 'single' and two per cent as 'separated/divorced'.

There was some change between the two surveys in how carers reported the condition of their spouse/partner. In both, the person being supported was most likely to be affected physically by their condition (77% in 1985 and 74%, in 2009/10). The proportions reporting that the person was affected mentally or both physically *and* mentally increased from 20 per cent in 1985 to 25 per cent in 2009/10. These increases, coupled with the increased numbers of older partners being supported, suggest the increased presence of dementia. It

is not possible to test this directly as, unlike the 2009/10 survey, the 1985 survey did not ask specifically about dementia. However, the proportion of spouses supporting someone 75 and over who reported that their partner was affected mentally increased from three per cent in 1985 to six per cent in 2009/10, while those reporting both physical and mental effects rose from 12 per cent to 14 per cent.

The level of involvement of spouse carers increased between the two surveys. In 1985, 69 per cent reported that they cared for 20 or more hours a week; by 2009/10 this had increased to 74 per cent. If we examine hours of care by age of the carer we see, again, the burden that older spouse carers carry. In 1985, 75 per cent of spouse carers caring for 20 or more hours a week were aged 75 and over; in 2009/10 the equivalent proportion was 78 per cent; the respective figures for all spouse carers were 69 per cent and 75 per cent.

Finally, and as would be expected given the overall ageing of this sub-group of carers between the two surveys, the number of years for which carers had been supporting their spouse/partner increased between 1985 and 2009/10. In the earlier survey, 8.5 per cent of spouses had been caring for 15 or more years; in 2009/10 this was the case for 17 per cent. The proportions of those who had been caring for between 10 and 15 years had also increased – from 11 per cent to 18 per cent. As a corollary, there were reductions in the proportions reporting caring for five or fewer years (from 52% to 43%) and for between five and 10 years (from 29% and 23%).

We saw earlier that those being supported by a spouse/partner were less likely to receive a range of supportive services in 2009/10 than similar carers in 1985. The carers were also less likely to report having been able to take a break of two or more days since starting to care for their spouse/partner.

Overall, then, between 1985 and 2009/10 we have seen the growth of a sub-group of carers who are potentially more vulnerable by virtue of age (75 and over) caring for spouses/partners who are themselves potentially more vulnerable because of their age; and a sub-group that as a whole is apparently less well supported than it was in 1985. Are there any further links between these factors?

As we saw earlier, logistic regression allows us to calculate the relative probability of a carer supporting someone who receives specific services, all other things being equal. In the following tables (Tables 23 to 27) we can see the contribution of type of care provided, whether or not the carer is a spouse/partner of the person being supported, whether he or she is aged 75 or over, and whether the person being supported is aged 75 or over. The analysis is presented separately for the GHS and the SCH and, as in the earlier analysis of service receipt, the GHS data were filtered to make them comparable with the SCH.

Table 23 examines medical support. This shows that, in both surveys, those being cared for by a spouse/partner were around half as likely as those being supported by someone else to receive medical support. The only other factor that significantly influenced such visits was the type of care being provided, although the relationship between ‘heavy end’ caring and medical support has apparently weakened between 1985 and 2009/11.

**Table 23: Relative probability (odds ratio) of medical support to the main person being cared for (GHS and SCH)**

	GHS		SCH	
	<i>Odds ratio</i>	<i>95% CI</i>	<i>Odds ratio</i>	<i>95% CI</i>
<b>Type of care:</b>				
Personal	1.565**	1.167 to 2.100	1.518*	1.040 to 2.217
Physical	2.299***	1.556 to 3.396	1.351	0.783 to 2.332
Other	1.00	-	1.00	-
<b>Spouse:</b>				
Yes	0.530**	.343 to .820	0.511**	0.318 to .820
No	1.00	-	1.00	-
<b>Carer over 75:</b>				
Yes	1.754	.966 to 3.184	1.595	0.865 to 2.937
No	1.00	-	1.00	-
<b>Person being cared for over 75:</b>				
Yes	0.999	0.771 to 1.295	1.167	0.815 to 1.672
No	1.00	-	1.00	-

\* significantly different from comparison category at .05 level

\*\* significantly different from comparison category at .01 level

\*\*\* significantly different from comparison category at .001 level or beyond

Table 24, which examines personal care support, shows a similar pattern in both surveys in relation to spouses/partners. Again, those being supported by a spouse/partner were half as likely as those supported by someone else to be getting this type of service, all other things being equal. In 1985, those receiving personal or physical care from the carer were twice as likely as others to be receiving personal care visits; by 2009/10 this relative ‘advantage’ had disappeared for those receiving physical care and had weakened considerably for those whose carer provided personal care.

**Table 24: Relative probability (odds ratio) of personal care support to the main person being cared for (GHS and SCH)**

	GHS		SCH	
	<i>Odds ratio</i>	<i>95% CI</i>	<i>Odds ratio</i>	<i>95% CI</i>
<b>Type of care:</b>				
Personal	2.590***	1.910 to 3.513	1.480*	1.072 to 2.044
Physical	2.077**	1.335 to 3.233	1.391	0.882 to 2.192
Other	1.00	-	1.00	-
<b>Spouse:</b>				
Yes	0.516**	0.320 to .832	0.507**	0.330 to .778
No	1.00	-	1.00	-
<b>Carer over 75:</b>				
Yes	1.470	0.778 to 2.780	1.427	0.837 to 2.431
No	1.00	-	1.00	-
<b>Person being cared for over 75:</b>				
Yes	1.625**	1.221 to 2.164	2.141***	1.556 to 2.945
No	1.00	-	1.00	-

\* significantly different from comparison category at .05 level

\*\* significantly different from comparison category at .01 level

\*\*\* significantly different from comparison category at .001 level or beyond

Table 25 looks at the likelihood of receiving support from some kind of advisor. As with other services, we see that those being supported by spouse or partner were significantly less likely to be receiving this type of support.

**Table 25: Relative probability (odds ratio) of advice support to the main person being cared for (GHS and SCH)**

	GHS		SCH	
	<i>Odds ratio</i>	<i>95% CI</i>	<i>Odds ratio</i>	<i>95% CI</i>
<b>Type of care:</b>				
Personal	1.465	0.974 to 2.204	2.322***	1.506 to 3.579
Physical	2.089**	1.230 to 3.549	1.542	0.800 to 2.975
Other	1.00	-	1.00	-
<b>Spouse:</b>				
Yes	0.405**	0.210 to .779	0.332***	0.192 to 0.573
No	1.00	-	1.00	-
<b>Carer over 75:</b>				
Yes	2.040	0.915 to 4.545	1.524	0.719 to 3.230
No	1.00	-	1.00	-
<b>Person being cared for over 75:</b>				
Yes	0.780	.545 to 1.115	0.723	0.484 to 1.080
No	1.00	-	1.00	-

\* significantly different from comparison category at .05 level

\*\* significantly different from comparison category at .01 level

\*\*\* significantly different from comparison category at .001 level or beyond

As we explained earlier, in the section of the report that examined service support for all carers, there were some differences in the way home care support was asked about in the two surveys. It is therefore difficult to know whether the different patterns revealed between the two surveys in Table 26 are real or artifactual. However, what the results do show is that, regardless of how defined, home care support was significantly less likely to be received when a person was being cared for by their spouse or partner. The difference was particularly striking in the SCH, given that both the age of the carer and the age of the person being cared for were controlled for. By contrast, and unlike the services examined so far, the type of care being provided by the carer seemed more or less irrelevant to receipt of home care, once these other factors were taken into account.

**Table 26: Relative probability (odds ratio) of home care support to the main person being cared for (GHS and SCH)**

	GHS		SCH	
	<i>Odds ratio</i>	<i>95% CI</i>	<i>Odds ratio</i>	<i>95% CI</i>
<b>Type of care:</b>				
Personal	1.121	0.838 to 1.498	1.210	0.894 to 1.639
Physical	1.317	0.877 to 1.978	0.897	0.565 to 1.426
Other	1.00	-	1.00	-
<b>Spouse:</b>				
Yes	0.610*	0.383 to 0.971	.281***	0.173 to 0.454
No	1.00	-	1.00	-
<b>Carer over 75:</b>				
Yes	1.575	0.878 to 2.828	1.825*	1.063 to 3.133
No	1.00	-	1.00	-
<b>Person being cared for over 75:</b>				
Yes	2.739***	2.101 to 3.571	3.077***	2.249 to 4.210
No	1.00	-	1.00	-

\* significantly different from comparison category at .05 level

\*\* significantly different from comparison category at .01 level

\*\*\* significantly different from comparison category at .001 level or beyond

Finally, Table 27 looks at the likelihood of people receiving visits from ‘other’ services. Again, it is difficult to make direct comparisons between the two surveys here, for reasons explained in the earlier examination of service receipt. In 1985, although those being supported by a spouse or partner were somewhat less likely to receive visits from other services, this difference did not reach statistical significance, all else being equal. The only factor that was significant in 1985 was the age of the person being supported, where those over the age of 75 had a greater chance of having other support services. In the 2009/10 survey, however, there was a substantially lower likelihood of those being supported by a spouse or partner receiving other services. This was also true for those who were over the age of 75.

**Table 27: Relative probability (odds ratio) of other visits to the main person being cared for (GHS and SCH)**

	GHS		SCH	
	<i>Odds ratio</i>	<i>95% CI</i>	<i>Odds ratio</i>	<i>95% CI</i>
<b>Type of care:</b>				
Personal	1.475	0.973 to 2.237	1.369	0.926 to 2.024
Physical	1.283	0.690 to 2.385	1.255	0.697 to 2.260
Other	1.00	-	1.00	-
<b>Spouse:</b>				
Yes	0.625	0.318 to 1.232	0.292***	0.176 to 0.482
No	1.00	-	1.00	-
<b>Carer over 75:</b>				
Yes	1.143	0.458 to 2.851	1.432	0.677 to 3.029
No	1.00	-	1.00	-
<b>Person being cared for over 75:</b>				
Yes	1.740**	1.179 to 2.569	.344***	0.231 to 0.512
No	1.00	-	1.00	-

\* significantly different from comparison category at .05 level

\*\* significantly different from comparison category at .01 level

\*\*\* significantly different from comparison category at .001 level or beyond

## Chapter 6: Limitations, strengths and conclusions

### Limitations and strengths of our work

We outlined in our methods section some of the limitations that came about from analyzing the GHS and the SCH alongside each other. However, having to deal with these issues rigorously means that we can be sure that we are comparing like with like. However, this approach to ensuring comparability does mean that we cannot say whether our findings apply to Wales and Scotland or to people who are caring for more than one person.

Also as outlined in the methods section, the authors of the SCH have suggested that, compared with the GHS, it may have under-represented carers who provide relatively low levels of support. Certainly, we found that the 2009/10 survey included higher proportions of carers providing high levels of support, but it is difficult to know how much of this is due to real change and how much to this possible under-representation. However, our use of our caring typology in the multivariate analyses has allowed us to compare like with like here too; this was particularly important when we were examining factors related to service receipt.

A limitation of both the GHS and the SCH is their focus on services for the person being supported rather than for the person who is the carer. When the 1985 GHS was devised there were few services *for* carers, as such and therefore focusing on services for the person being supported was the most sensible approach. Subsequent GHS modules and the SCH have followed this pattern. The SCH did include questions about assessment and review of carers' own needs and whether any services were received as a result; but obviously, there was nothing comparable in the GHS. However, both surveys did ask about respite care, which might be construed as a service for carers, rather than the person being supported (although see our earlier discussion of this issue). None of the analysis of this material suggested any wholesale increase in service support to carers via this route. Indeed, care provided via other informal sources (family members and friends) was the predominant model reported by carers in the SCH.

The final limitation of our work is, of course, its cross-sectional nature; we were comparing the results of a survey carried out with one group of people in 1985 with those of a survey carried out with another group of people in 2009/10. However, our careful back-fitting of the GHS data onto the SCH does allow us to interpret our findings as a quasi-cohort analysis. Further, there is nothing in the headline changes in the population of carers that we have observed that contradicts conclusions that might be drawn from the more limited data and comparisons possible from examining Census data from 2001 and 2011.

## Conclusions

The comparisons presented here suggest considerable change between 1985 and 2009/10 in the population of people who are carers - particularly in relation to their greater average age and whom they are supporting. Carers in England are, overall, now older, caring for people who are themselves older, and more heavily involved than they were when the first nationally representative data became available. The proportions supporting spouses/partners or children (whether young or adult) increased between the two surveys, while the proportion supporting parent or parents-in-law was almost the same.

At the same time, service receipt for the people that carers were supporting also changed. On the one hand, smaller proportions overall were receiving any services, compared to 1985, despite the heavier average level of involvement of carers in 2009/10. Of course, the latter could explain the former: if services do not substitute for carers' input, then one might expect to see fewer services when carers are, on average, more heavily involved. Yet, when services *were* in place, there appeared to be an increased focus on those who were receiving personal care from the carer. Further, in relation to some types of services, those who lived in the same household as the carer seemed to be even less likely to receive service support than they did in 1985. The conclusion then, looking across all services, however, is that heavily involved carers are less well supported (via services for the person they cared for) than they were in 1985.

Within the population of carers we have also observed an apparent intensification of the experience of both those who care for their children (whether young or adult) and those who care for a partner or spouse. In both cases, more report providing personal care (the type of care most associated with long hours and other types of impact) and for longer hours.

The period since 1985 has seen a substantial increase in policy focus on carers, both through policy discussion and actual legislation. In part, we can see what may be the impact of this focus in some of our results. So, for example, there is a hint that some services may have become more focussed on situations where carers are or could be participating in paid employment. For the most part, however, our results indicate no major refocussing of resources across the board on services for people who are supported by carers. Rather, our evidence suggests a sustained movement away from substitution of services for carers' input, and particularly when carers are beyond retirement age. While outright discrimination against carers on the basis of gender is now largely absent from data on service provision, there is still a clear balance of provision in favour of those who do not live in the same household as their carer.

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Data for analysis of the GHS were from:

Office of Population Censuses and Surveys. Social Survey Division. (1988). *General Household Survey, 1985*. [data collection]. UK Data Service. SN: 2349, <http://doi.org/10.5255/UKDA-SN-2349-1>

Data for analysis of the SCH were from:

GfK NOP, Information Centre for Health and Social Care. (2011). *Survey of Carers in Households, 2009-2010*. [data collection]. UK Data Service. SN: 6768, <http://doi.org/10.5255/UKDA-SN-6768-1>

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## Appendix 1

**Table A1: Type of care provided by type of caring relationship (GHS)**

Caring relationship	% providing type of care			N (100%) <sup>1</sup>
	<i>Personal</i>	<i>Physical</i>	<i>Other</i>	
Relative, under 16, same household	77	10	13	62
Relative, 16-74, same household	47	13	40	244
Relative, 75+, same household	43	14	43	129
Relative, 16-74, different household	10	8	92	399
Relative, 75+, different household	17	8	75	589
Total (%)	25	10	65	1423

1. May sum to more than 100 because of rounding  
 $\chi^2 = 278.93$ ,  $df=8$ ,  $p<.0001$