

This is a repository copy of *Estimating the prevalence of unpaid adult care over time*.

White Rose Research Online URL for this paper:
<https://eprints.whiterose.ac.uk/1579/>

Article:

Hirst, Michael Anthony (2005) Estimating the prevalence of unpaid adult care over time. Research, Policy and Planning. pp. 1-16.

Reuse

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

Estimating the Prevalence of Unpaid Adult Care Over Time

Michael Hirst, Research Fellow, Social Policy Research Unit, University of York

Abstract

To help fulfil their responsibilities towards unpaid carers, service providers need some idea of the carer's situation and how many might require support. This paper argues that estimating the prevalence of unpaid care across service planning and budgeting cycles provides a better indication of the size and composition of the carer population than estimates at a point in time. The number of adults providing care at any time during a year is estimated for typical catchments or organisational settings, including social services and primary health care. As well as focusing on carers who are heavily involved in their caring activities, variations in their psychological well-being are assessed to provide an indication of unmet needs for support.

Key words: Carers, caregiving, gender, psychological distress, GP consultations, panel data

Introduction

Following the introduction of Invalid Care Allowance in 1975 (a social security benefit for carers now called Carer's Allowance), successive governments have increasingly recognised the role, contribution and needs of carers – family, partners or friends – who shoulder the bulk of responsibility for supporting elderly and disabled people in the community. Legislation, practice guidance and programmes to support carers in their caring role gathered pace during the 1990s, and received a further boost with the adoption of 'strategies for carers' by the UK, Scottish Executive and Welsh Assembly Governments (Department of Health, 1999; Scottish Executive, 1999; National Assembly for Wales, 2000). At the local level, Councils have been given new responsibilities for carers (Audit Commission, 2004). Social services must, when asked, assess carers' own needs and consider the sustainability of their caring responsibilities. Carers should be informed about the help and services available and consulted about the care needs of the person they look after. Local authorities can commission or provide services for carers as well as make direct payments (cash in lieu of social services) to meet carers' own assessed needs. Special grants have enabled Councils to improve the range and quality of services for giving carers a break from caring. Targets and performance indicators aim to drive further the development of local services specifically for carers.

A pre-requisite for planning and developing services is to have reliable estimates of the carer population at the local level. To inform policies that meet the needs of those providing care and

receiving care, such estimates should take account of both the diversity of carers and the dynamics of caregiving. It would also be helpful to identify the potential demand for carer assessments and a means of referring carers to social services. This paper is a step towards meeting these information needs. It provides estimates of the frequency or prevalence of unpaid carers in the adult population to inform service planners, providers and others who allocate resources and set priorities for supporting carers.

Sources of Data on Carers

The prevalence rates presented here are derived from the British Household Panel Survey (BHPS) and can be compared with estimates based on the General Household Survey (GHS) and the 2001 Census of population and housing. The GHS is widely regarded as setting the gold standard for gathering survey information about unpaid care. It provides more extensive and detailed coverage of the topic than the BHPS and, because a fresh sample is drawn for each survey, the GHS does not suffer from problems of attrition that can affect longitudinal designs like the BHPS (Maher and Green, 2002).

GHS estimates of the prevalence of unpaid care are therefore likely to be more accurate than those presented here. However, the cross-sectional design of the GHS means that no more than 'snapshot' estimates of the proportion of adult carers can be obtained, describing the prevalence of unpaid care *at a point in time*. In contrast, the BHPS offers the possibility of estimating the frequency of carers in the population *over a period of time*. Setting a time interval encompasses not only those who provide care throughout the period, but also those who cease providing care or who take on a caring role during that interval. As

described below, adopting a temporal perspective to include transitions into and out of caregiving provides useful, additional information for service planners and providers.

Like the GHS, the Census also provides snapshot estimates of unpaid care although these are likely to be the most precise figures available because they are based on a total rather than a sample enumeration of the population. Moreover, the Census provides – for the first time – estimates of the number of carers in small areas covering the whole country, and for minority population groups including children and young people who provide care. Neither the GHS nor the BHPS can match that level of detail because they are based on sample designs that limit the scale of geographical analysis to a regional level, and often misrepresent minority ethnic groups concentrated in particular areas of the country.

Despite the advantages of a complete enumeration, the coverage of unpaid care in the Census is limited to details about who provides care and how many hours a week they devote to caregiving. No information is collected about where that care is provided, the characteristics of care recipients, their relationship to the carer, the carer's responsibility for the cared-for person, or the types of care provided – all key factors that are important for understanding the diverse experiences of caregiving (Arber and Ginn, 1995a; Parker, 1992a).

Taken together, the BHPS, GHS and Census provide complementary information for investigating a variety of questions about the population of carers and the caregiving experience. However, they might produce different estimates of the nature and extent of caregiving. Responses to questions on unpaid care are influenced by survey design, how concepts are defined and presented, and the prevailing context (Hirst, 2002a; ONS, 1998; Parker, 1998). Even repeating the same questions over time, as in the GHS and BHPS, is no guarantee that 'real' trends will be identified.

The BHPS questions on unpaid care are based on those used in the GHS, and the first wave of the panel survey adopted a similar sampling design to that of the GHS. Both surveys also rely on personal interviews with all adults in the sample households. Not surprisingly, the two surveys

produce very similar prevalence rates, although the BHPS gives somewhat lower estimates of carers' involvement in caregiving (Hirst, 2000).

The Census approach to gathering information is quite different. An adult informant, who may be neither a carer nor a care recipient, usually completes the Census form on behalf of all household members without an interviewer being present. There are also marked differences between the format of the single Census question on unpaid care and the battery of questions administered in the GHS. Comparisons between the two approaches reveal striking differences. According to the GHS, around 6.8 million adults in Britain provide unpaid care compared with almost 5.6 million enumerated in the Census (Maher and Green, 2002; ONS, 2004; SCROL, 2004). The apparent discrepancy may reflect uncertainty about the threshold level of caring responsibilities. According to the Census, one in five carers provide 50 hours or more care per week, twice the proportion estimated from the GHS. These findings suggest that the detailed questions in the GHS have identified more people providing less intensive forms of practical help (for example, housework or shopping) to friends and neighbours.

How survey design and process influence estimates of the size and composition of the carer population awaits further investigation and no attempt is made here to anticipate or reconcile potential discrepancies. The remainder of this paper is devoted to presenting prevalence rates of unpaid adult care from the BHPS. The next section describes the methods used and discusses further the merits of adopting a temporal perspective. The population estimates themselves, and related figures on carer turnover and changes in the carer population, are presented in a third section with brief explanations of how they might be used and interpreted.

Methods

Data

The BHPS is an annual survey of the population living in a nationally representative sample of private households in England, Scotland and Wales, and aims to interview the same people

every year (Buck *et al.*, 2002). Data from the first ten waves, covering the period 1991 to 2000, were pooled to provide over 87,000 person-year observations and the prevalence estimates reported here represent average rates for Britain during the 1990s. The longitudinal design of the BHPS makes it possible to identify people who move into and out of a caring role between successive interview waves, as well as those who provide care throughout. All such carers are included in the prevalence estimates presented here (see further below).

Definitions

Each year respondents over 16 years are asked whether they provide care for someone who is sick, elderly or disabled. Caring is defined as looking after someone, giving special help, or providing some regular service that is not provided in the course of paid employment, and includes people with parental responsibility for a disabled child. Carers who look after clients of voluntary organisations are excluded here because what motivates them to care, and the choices available to them, are quite distinct from those of family members and friends who take on caring responsibilities (Leat, 1992). Care provided by children and young people is not recorded in the BHPS.

During the analysis, the data were stratified by *gender*, *carer status*, and *locus of care*. Analyses were conducted separately for men and women because their involvement in caregiving differs widely. Women are more likely than men to be sole or main carers, and to be more heavily involved in providing personal and physical care (Arber and Ginn, 1995b; Parker and Lawton, 1994).

Carer status distinguishes between respondents who do and do not provide care. However, carers are a diverse group of people and it is important to distinguish key sub-groups according to factors associated with variations in the experiences and impacts of caregiving (Parker and Lawton, 1994). *Locus of care* indicates where the care recipient lives in relation to the carer's usual place of residence. The term 'co-resident' covers caregiving to someone living in the same household, 'extra-resident' denotes caring for someone living elsewhere, in another private

household or in a communal establishment. People who provide care in both spheres are counted as co-resident carers.

Carers are further characterised by their relationship to the person they care for and the amount of time they devote to their caring activities. Time spent caring distinguishes between carers who provide at least 20 hours of care per week, between 10 and 19 hours, or less than 10 hours a week. Interest focuses on heavily involved carers – those devoting 20 or more hours a week to their caring activities – because they are most likely to be providing personal and physical care for someone in the same household without any help from other people (Parker, 1992a). This threshold has assumed considerable importance in identifying carers for an assessment of their own needs (Bytheway and Johnson, 1998; Social Services Inspectorate, 1996).

Six care relationships are identified, three in the same household as the carer and three where the cared-for person lives in a different household. These cover caregiving within the same generation (spouse or partner care) as well as inter-generational care (caring for a son or daughter, or looking after a parent or parent-in-law). Supporting a friend or neighbour, and caring for an undefined 'other' relative, are the remaining relationships identified here. Together, they cover the vast majority of carers. Looking after a parent or parent-in-law is the only care relationship recorded in the BHPS that can be found inside the carer's household or between different households; this distinction is important in shaping the carer's experience and is retained here.

Measuring Prevalence

The prevalence of care refers to the proportion of a population that provides unpaid care. Two approaches to measuring prevalence are commonly used:

- A 'point' prevalence estimate is based on a single assessment of who is providing unpaid care *at one point in time*. This approach is adopted in the GHS and the Census, both of which count the number of adults *currently* identifying themselves as carers.
- In contrast, 'period' prevalence is defined as

the proportion of a population providing unpaid care *at any time* within a stated period. A period prevalence estimate counts as carers those who take on a caring role or cease providing care during the period in question, as well as those who provide care throughout that interval.

Point prevalence is an appropriate measure in relatively stable situations but is unsuitable for estimating the frequency of caregiving because of considerable turnover in the carer population. More than four out of ten carers start or stop providing care during a year and the point prevalence of unpaid care is less than two-thirds the 12-month period prevalence (Hirst, 2002b). Point prevalence measures, therefore, can seriously underestimate the number of carers over time.

4

The choice of which measure to use should be guided by the purpose for which estimates are required. Here the aim is to estimate the number of carers who might benefit from advice, information, training and support. Such needs can arise at any point during a care episode as carers' circumstances, choices and resources change over time (Nolan *et al.*, 1996). Research findings indicate further that some carers have particular needs for support around the start and end of caregiving (Burton *et al.*, 2003; McLaughlin and Ritchie, 1994; Nolan and Dellasega, 2000; Schulz and Beach, 1999; Schulz *et al.*, 1997a; Schulz *et al.*, 2001; Seddon *et al.*, 2002; Seltzer and Li, 2000).

By including people who have recently started or ceased providing care, as well as those who continue in their caring role and those in long-term care relationships, period prevalence provides a better indication of the potential extent of carers' support needs. Moreover, estimating the prevalence of unpaid care across service planning, commissioning and budgeting cycles provides a more realistic indication of the size and composition of the carer population for setting priorities and allocating resources than a snapshot estimate.

The shortest interval for estimating period prevalence from the BHPS is dictated by the annual round of interview waves but beyond that it

possible to produce estimates covering any number of years. In the event, it was decided to prepare one-year prevalence rates. These include in the numerator everyone known to have provided care at some point during the year: that is, respondents who start, cease or continue to provide care between successive pairs of interview waves. The denominator includes all such carers plus non-carers; the latter are respondents who reportedly did not provide care at both interviews in each successive pair of waves. Prevalence estimates are based on the number of person-years adjusted to take account of sample attrition between waves. It is recognised that the estimates presented here understate, to a degree, the total number of carers because those who start and cease providing care between consecutive interview waves are not identified and would be counted as non-carers.

As well as taking account of transitions into and out of caregiving, identifying carers over time draws attention to changes in the involvement of those who continue in their caring role. Here, attention focuses on those who become heavily involved in their caring activities or who maintain a high level of involvement over time. As shall be observed below, carers with an ongoing involvement in providing heavy care, and those who start or cease to be heavily involved, are likely to be a priority group for service providers.

For each prevalence rate, 95 per cent confidence intervals (CI) are estimated to indicate the range that is most likely to include the findings that would be obtained if the total population were studied (Gardner and Altman, 1989).

Psychological Well-Being

In recent years, the literature has increasingly drawn attention to the rewards and satisfactions of caregiving (Nolan *et al.*, 1996). Carers' reports highlighting the positive aspects of caregiving have helped to redress an earlier emphasis on carer burden. They have also identified some of the factors that alleviate the stress of caregiving, and underlined the importance of focusing on both the carer and the care recipient when designing services and interventions (Twigg and Atkin, 1994).

An important implication is that the negative effects of caregiving for carer well-being are, in principle, avoidable and amenable to policy and practice. Caring for disabled and older people does not necessarily result in poor health outcomes or social isolation. Nonetheless, there is a wealth of studies which show that caregiving is associated with increased rates of anxiety and depression in a substantial minority of carers (Burton *et al.*, 2003; Schulz *et al.*, 1990, 1995, 1997b). There are also carers' own reports of adverse effects on their social and emotional well-being, as well as evidence of increased psychiatric illness and compromised immune response in those who feel under considerable strain (Kiecolt-Glaser *et al.*, 1991; Maher and Green, 2002; Singleton *et al.*, 2002). Thus, population estimates of psychological distress provide a useful indication of how many carers might benefit from emotional, practical or social support to boost their coping strategies.

The number of respondents in the BHPS who present high levels of emotional or psychological distress is assessed using the 12-item version of the General Health Questionnaire (Goldberg and Williams, 1991). This self-completion questionnaire asks about the incidence and severity of common mental health problems, including symptoms of anxiety and depression, social dysfunction, and loss of confidence or self-esteem.

Validity studies using the GHQ12 have shown that presenting four or more symptoms is associated with an 80 per cent probability of a formal psychiatric diagnosis (Goldberg *et al.*, 1997). This threshold is used here to identify carers with high scores who might be the focus of health promotion and support initiatives. One of the original aims of the GHQ was that it could be routinely administered in primary care settings to assist family doctors in recognising and treating patients with common mental health problems. Recent applications of the GHQ12 show that it continues to outperform doctors' unaided clinical diagnoses of depression (Henkel *et al.*, 2003).

Contact with Family Doctors

Identifying carers is the first step towards providing timely, appropriate and ongoing support yet social services have limited opportunities for

finding carers, and are often in touch with only a small minority of carers in their locality (Audit Commission, 2004). However, it is argued that general medical practitioners (GPs) and members of the primary care team, including district nurses and health visitors, could play a key role in identifying carers (Department of Health, 1999). To that end, the new GP contract, which took effect from April 2004, provides an incentive payment to GPs to have a protocol for the identification of carers and a means of referring them for social services assessment.

To investigate this further, the number of carers who talk to or visit a family doctor during a year is estimated from self-reports of GP consultations. The aim here is to indicate how readily carers might be informed of their rights to assessment and put in touch with social services, carers' centres and carer support projects.

Results

Local estimates of the carer population

The estimated number of carers in local organisational settings is shown in Table 1. These organisations were chosen because each has an important role in planning and developing services for carers and the people they care for, or providing support directly to carers. They include a social services authority, a primary care trust, and a GP partnership; a typical partnership of three doctors is assumed here. Only the more involved care situations and relationships are illustrated in Table 1, including those where the carer is at risk of poor health and adverse health changes (Hirst, 2004).

These estimates of the carer population are based on average or typical adult populations served by each organisation and assume that the socio-demographic profile of their catchment is similar to that of the country as a whole. It is further assumed that women make up around 53 per cent of the adult population. With these assumptions in mind, a typical local authority with 250,000 adults might expect to have over 15,000 adults providing co-resident care at some time during a twelve-month period, including 8,600 women and 7,200 men. The number of carers is derived by applying the prevalence rates in Appendix A to the assumed population served by each organisation.

These estimates would require some adjustment in localities with a different population size, a rapidly changing population, or a demographic structure that differs markedly from the national profile: areas with an older age structure for example, or a larger proportion of people from ethnic minorities. In addition, the prevalence rates are themselves subject to sampling errors and the confidence intervals shown in Appendix A indicate the range that is likely to include the true rate.

As an example, the prevalence of co-resident care among women is 63.4 per 1000 women, with a 95 per cent confidence interval of 61.1 to 65.7 (see Table 1). This interval indicates that the number of women providing co-resident care is expected to lie between 8,200 and 8,900 in a typical local authority, with a best estimate of 8,600. The range of estimates is no more than indicative however.

Variations in the demand for and supply of unpaid care, including alternatives to unpaid care, would need to be taken into account when estimating local carer populations. Changes in these factors over time, including the impact of new legislation, guidance and improvements in service provision, would also need to be considered.

Transitions Into and Out of Caregiving

As described above, the estimates in Table 1 indicate the number of adults providing unpaid care at some point during a 12-month period. During that year, some people will take on a caring role and others will cease to provide care. Those who report caregiving at two successive interviews are assumed to continue caring throughout the year.

Transitions into and out of caregiving can be key

Table 1 Estimates of the number of adult carers during a year by carer status, locus of care, hours caring per week, care relationship and gender

Women	Local authority	Primary Care Trust	GP Partnership	GP list
All carers	29,500	19,600	520	170
Co-resident carers	8,600	5,700	150	50
Provides 20 hours or more care a week	6,800	4,600	120	40
Caring for an extra-resident parent / in-law	8,800	5,900	160	50
Caring for a spouse / partner	3,900	2,600	70	20
Caring for a co-resident parent / in-law	1,500	1,000	30	10
Caring for a son / daughter	1,600	1,100	30	10
ALL ADULT WOMEN	135,000	90,000	2,400	800

Men	Local authority	Primary Care Trust	GP Partnership	GP list
All carers	20,000	13,900	370	120
Co-resident carers	7,200	5,000	130	40
Provides 20 hours or more care a week	4,100	2,900	70	20
Caring for an extra-resident parent / in-law	5,000	3,500	90	30
Caring for a spouse / partner	3,500	2,400	60	20
Caring for a co-resident parent / in-law	1,400	900	20	10
Caring for a son / daughter	1,200	800	20	10
ALL ADULT MEN	115,000	80,000	2,100	700

ALL ADULTS	250,000	170,000	4,500	1,500
------------	---------	---------	-------	-------

turning points for the individuals involved and occasions when they are especially likely to need advice, information and support (Nolan *et al.*, 1996). Therefore, service providers might find it useful to know how many people experience such transitions each year. The estimated proportions are shown in Table 2. For example, 24.1 per cent of women who looked after someone inside the same household had started caregiving during the year and 21.9 per cent had ceased to provide such care by the end of the year.

These proportions can be applied directly to the number of carers in Table 1. Of the estimated 8,600 women providing co-resident care in a typical local authority, just over 2,000 would have started their care episode during the year, almost 1,900 would have ceased providing care, while 4,600 (54%) are estimated to have continued caregiving throughout the 12 months.

Heavily Involved Carers

Carers typically experience considerable changes in their caring role over time reflecting changes in the needs of the person they care for, their willingness or ability to provide care, the support provided by

services, family or other informal sources, and competing demands on the carer's time (Nolan *et al.*, 1996). Devoting an increasing number of hours to caregiving may signal not only extra demands on the carer's time but also additional pressure on their coping strategies and resources.

Carers who devote an increasing amount of time to their caring responsibilities are likely to be a priority for service planners and providers, especially where they take on, or are already involved in, a heavy caring role. Heavily involved carers are most at risk of poor emotional health and adverse health changes, especially around transitions into and out of caregiving (Hirst, 2004). This section considers the extent of change and continuity associated with a heavy caring role by estimating the number of carers in three groups:

- Carers who take on a heavy caring role, defined as providing at least 20 hours of care per week,
- Carers who cease caregiving altogether after providing 20 hours or more care per week, and
- Carers who increase or maintain their caregiving above that threshold.

Table 2 Proportion of adult carers who continue, start or stop providing care during a year by carer status, locus of care, and care relationship (percent of carers by gender)

	Women	Men				
	Continue	Start	Stop	Continue	Start	Stop
All carers	48.6	26.1	25.3	45.0	28.2	26.8
Locus of care						
Extra-resident only	42.6	28.8	28.6	37.5	31.3	31.3
Co-resident	54.0	24.1	21.9	51.3	26.4	22.3
Extra-resident care relationship						
Parent / parent-in-law	42.9	29.0	28.1	34.4	32.7	32.9
Other relative	31.2	34.4	34.5	30.7	34.5	34.8
Friend or neighbour	27.3	36.3	36.4	28.1	36.5	35.4
Co-resident care relationship						
Spouse or partner	47.4	28.1	24.5	50.2	29.3	20.6
Parent / parent-in-law	50.8	20.8	28.4	39.1	30.3	30.6
Son or daughter	60.4	23.3	16.3	51.7	27.3	21.0

Table 3 Proportion of adult carers by number of hours care provided per week at the start and end of a year (percent of carers by gender)

Beginning of year	End of year							
	Women	Men						
	Non-carer	Under 10 hours	10 to 19 hours	20 hours or more	Non-carer	Under 10 hours	10 to 19 hours	20 hours or more
Non-carer	–	19.5	3.4	3.6	–	21.9	3.5	3.3
Under 10 hours	18.2	21.6	3.8	1.9	20.8	22.0	2.8	1.4
10 to 19 hours	3.6	3.1	3.3	2.0	3.2	2.6	2.5	1.7
20 hours or more	3.7	1.3	1.6	9.4	3.0	1.2	1.4	8.5

8

Table 3 summarises the changes in carers’ involvement during a 12-month period: it covers all adults who provide care at some point during a year comparing their level of involvement at the end of the year with what it was at the beginning. For example, almost one in five women in the carer population (19.5%) takes on a caring role (from being a non-carer) that involves no more than 10 hours of care per week, while 3.8 per cent increase the amount of time they devote to caregiving from under 10 hours to between 10 and 19 hours a week.

Overall, around four out of ten carers take on or increase their involvement in caregiving during a year: 40 per cent of women and 39 per cent of men.¹ However, many of these carers experience

relatively small increases in their caring responsibilities, including those who provide fewer than 10 hours care per week. To focus on those who might be considered a higher priority for service support, the shaded cells in Table 3 identify the three sub-groups of carers described above: those who take on a heavy caring role, cease altogether providing 20 hours or more care per week, or maintain or increase their caregiving above that threshold.

Summing the proportions in the shaded cells of Table 3 indicates that a substantial minority of carers experience changing or continuing responsibilities associated with a heavy caring role. Around 21 per cent of women and 18 per cent of

Table 4 Proportion of adult carers experiencing changing or continuing responsibilities in a heavy caring role during a year by carer status, locus of care, and care relationship (percent of carers by gender)

	Women	Men
All carers	20.5	18.0
Locus of care		
Extra-resident only	8.2	4.9
Co-resident	55.4	45.5
Extra-resident care relationship		
Parent / parent-in-law	11.9	4.5
Other relative	8.5	8.1
Friend or neighbour	2.4	3.9
Co-resident care relationship		
Spouse or partner	56.8	56.5
Parent / parent-in-law	48.8	26.1
Son or daughter	69.9	44.6

men take on or cease providing at least 20 hours care per week, or they increase or maintain their caregiving above that threshold.

Table 4 shows further that these proportions (covering the shaded cells in Table 3) vary considerably between different care situations. The most striking contrast is between within-household and out-of-household care: around half of co-resident carers experience changing or continuing responsibilities in providing heavy care compared with fewer than one in ten extra-resident carers. Spouse carers and parents looking after a sick or disabled child are most likely to be faced with the

demands of a heavy caring role, men and women alike. Almost half the women heavily involved in looking after a parent or parent-in-law in the same household experience changing or ongoing caring responsibilities, more so than their male counterparts.

The proportions shown in Table 4 can be applied directly to the population estimates in Table 1. For example, around 57 per cent of spouse carers take on, relinquish or maintain a heavy caring role during a year. Of the estimated 7,400 spouse carers in a typical local authority, these findings indicate that 2,200 women and 2,000 men may

Table 5 Proportion of adult carers who present four or more GHQ symptoms once or twice during the year they continue, start or stop providing care by carer status, locus of care, and care relationship (percent of carers by gender)

	More than 3 GHQ symptoms	Women			Men		
		Continue	Start	Stop	Continue	Start	Stop
All carers	Once	11.1	6.8	6.6	8.8	5.5	4.9
	Twice	7.2	3.2	3.5	4.6	2.2	2.0
Locus of care							
Extra-resident only	Once	9.6	7.2	7.3	6.8	6.0	5.8
	Twice	4.9	3.3	3.6	3.8	2.2	2.1
Co-resident	Once	12.2	7.4	6.2	10.3	5.8	4.5
	Twice	10.9	4.2	4.7	5.4	2.6	2.4
Extra-resident care relationship							
Parent / parent-in-law	Once	9.7	7.5	7.7	6.3	6.5	5.6
	Twice	4.9	3.4	3.6	2.7	1.9	2.3
Other relative	Once	6.4	8.9	8.2	5.3	6.2	7.8
	Twice	5.0	4.8	4.8	1.5	3.2	2.0
Friend or neighbour	Once	5.5	8.5	8.0	5.0	7.0	5.3
	Twice	2.4	2.9	3.9	3.3	1.6	2.4
Co-resident care relationship							
Spouse or partner	Once	10.6	8.2	7.5	9.3	5.8	4.9
	Twice	8.8	5.4	6.0	4.7	3.0	2.0
Parent / parent-in-law	Once	11.0	5.2	5.5	7.4	4.9	3.7
	Twice	6.3	3.6	5.8	3.4	1.5	2.5
Son or daughter	Once	16.1	7.8	4.9	12.0	7.0	2.0
	Twice	13.4	3.7	2.2	4.0	3.3	3.3

present particular support needs associated with change or continuity when heavily involved in looking after a spouse or partner.

Psychological Distress in Carers

The proportions of women and men within each care situation who present high distress scores are shown in Table 5. This table distinguishes between those who report four or more symptoms of distress twice during a year, or at one interview only. Recurrent or persistent distress may indicate a need to explore the factors that underlie carers' emotional health and review their coping strategies and resources, including opportunities to take a break from caregiving. The estimates show that substantial minorities of carers report high distress scores, especially among those looking after someone in the same household.

The proportions of carers with high distress scores can be applied directly to the population estimates in Table 1. Thus, social services might expect to find 1,700 women (19.8% of 8,600) and 750 men (10.4% of 7,200) providing care inside their own household who report recurring symptoms of psychological distress during a year. They include those reporting high levels of distress before and

after starting or ceasing co-resident caregiving, as well as those providing such care throughout the year. The individual percentages in Table 5 produce estimates for each of these situations. For example, around 360 women taking on a co-resident caring role report recurring distress, as do 400 women who cease providing such care, and 940 women who look after someone inside the same household throughout the year (representing 4.2, 4.7 and 10.9% of women providing co-resident care within a typical social services area).

Carers' Contact with GPs

Table 6 shows the proportions of women and men within each care situation who consult a GP about their own health during the year they provide unpaid care. Irrespective of the care situations described here, the vast majority of carers contact a GP each year: over 80 per cent of women and more than 70 per cent of men. These findings indicate that GP surgeries provide a potentially fruitful setting in which to identify adult carers during or around transitions into and out of a caregiving role (Arksey and Hirst, 2004).

The proportions shown in Table 6 can be applied directly to the population estimates in Table 1. In a

10

Table 6 Proportion of adult carers in contact with a GP during the year they continue, start or stop providing care by carer status, locus of care, and care relationship (percent of carers by gender)

	Women			Men		
	Continue	Start	Stop	Continue	Start	Stop
All carers	39.4	21.2	21.1	33.1	20.5	19.3
Locus of care						
Extra-resident only	34.9	23.2	23.6	26.8	22.3	22.3
Co-resident	43.0	19.9	18.8	39.5	19.9	16.3
Extra-resident care relationship						
Parent / parent-in-law	34.3	22.3	22.7	23.3	23.0	22.1
Other relative	25.5	29.1	28.9	22.2	22.8	24.1
Friend or neighbour	24.5	29.5	30.8	18.5	27.6	26.4
Co-resident care relationship						
Spouse or partner	39.5	23.2	21.4	40.0	23.0	16.2
Parent / parent-in-law	36.3	16.9	23.8	30.1	21.2	19.6
Son or daughter	45.9	18.7	14.8	34.4	19.4	14.7

typical GP partnership for example, 120 out of 150 women (81.7%) who look after someone in the same household, and 100 out of 130 men who provide co-resident care (75.7%), would be expected to contact one of the GPs at some point during the year. The individual percentages in Table 6 will break down these estimates into those who start, cease or continue providing care during the year. However, it is not possible to determine whether carers consult a GP immediately before or soon after starting or ceasing to provide care because the timing of these transitions and GP contacts is not precisely known.

Conclusions

Implementation of the *Carers Act 1995*, which gave carers the right to an assessment of their own needs for information, advice and support, has been patchy and positive outcomes for carers are difficult to detect at the population level (Arksey, 2002). History seems to be repeating itself with the implementation of the *Carers and Disabled Children Act 2000* in England and Wales, and the *Community Care and Health (Scotland) Act 2002*, both of which extend carers' rights to an assessment independently of the person they look after (Carers UK, 2003). Lack of additional funding for local authorities to carry out carer assessments, develop the new services envisaged under the legislation, and engage more fully with the health service, has been blamed for the disappointing progress (Cozens, 2002). Part of the problem stems from difficulties in identifying carers and uncertainty about how many of them are entitled to request a needs assessment.

This paper provides prevalence and population estimates of unpaid adult care to inform service planners and providers with responsibilities for supporting carers. Although prevalence estimates of unpaid care are readily available from other sources, notably the General Household Survey and the recent Census, the value of the estimates presented here is that they cover adults who provide care at any time during a 12-month interval. These estimates, which include people who take on or relinquish their caring role during that interval, are considerably higher than those relating to a single point in time because of considerable turnover in the carer population (Hirst, 2002b).

The rationale for including former and would-be carers is that both groups frequently present particular or additional needs for advice, information and support when moving into or out of their caregiving role (Nolan *et al.*, 1996). The implication is that resources cannot be readily switched from those whose care episodes end to those about to take on a caring role, even if the total number of carers were static. Therefore, the number of would-be and former carers should be considered, alongside those who currently provide care, when estimating service needs. Estimates of the number of carers over time are likely to give a more realistic indication of the health care and support needs associated with caregiving across budgeting cycles.

Not all carers present such needs however, or require them to be met through the development of support services in the public or independent sectors. A further contribution of this paper is to identify those carers who are most at risk because of the demands of a heavy caring role, or who present clinically significant levels of anxiety and depression. The proportion of carers at risk varies across different care situations and the estimates presented here should help inform resource allocation decisions and the targeting of services.

Many carers do not readily identify themselves especially where they regard caring as part of their normal everyday activities, as simply fulfilling family obligations (Leat, 1992; Parker, 1992b; Twigg and Atkin, 1994). The findings indicate that the vast majority of carers contact a GP each year suggesting that GP surgeries are likely to be the most productive setting within which to provide information to carers, advise them of their rights to a social services assessment, and help them maintain their own health and well-being (Arksey and Hirst, 2001a).

The challenge is to develop effective methods for identifying carers that are acceptable to GPs (Keeley and Clarke, 2003). Progress towards genuine partnerships between primary care and social services is opening up new possibilities for jointly commissioned and jointly provided carer services, and for improved collaboration between frontline staff around carer support (Coleman and Glendinning, 2002). Introducing social care staff or carer support workers alongside GPs can

improve the identification of carers and boost service responses to their particular needs (Arksey and Hirst, 2001b; Lankshear and Hodges, 1999). Improved access for carers to primary care may also be required, especially for minority ethnic groups facing language and communication barriers, culturally inappropriate services, and implicit or explicit racism (Katbamna *et al.*, 2002). Carers who are not in regular contact with a GP require alternative approaches. School nurses are well placed to identify and support young carers. Another possibility is to involve community pharmacists in identifying hidden or hard-to-reach carers (Princess Royal Trust for Carers, 2003). The time is ripe for a trial of methods for the identification and referral of carers. The population estimates developed here could provide a yardstick against which to assess their efficacy.

Note

1. Table 3 masks the full extent of annual changes in hours caring because only three categories are shown. The estimates in the text are based on movements between all seven categories defined in the survey questionnaire: under 5, 5 to 9, 10 to 19, 20 to 34, 35 to 49, 50 to 99, and 100 or more hours per week. Those who respond 'other' are assigned 5 to 9 hours; those who respond 'varies under 20 hours' are assigned 10 to 19 hours and those who respond 'varies over 20 hours' are assigned 20 to 34 hours.

Acknowledgements

The research on which this paper is based was funded by the UK Department of Health. I am grateful to members of the project advisory group for reading an earlier draft of this paper and offering valuable comments, and for the advice of two anonymous reviewers. Data from the British Household Panel Survey were made available through the Data Archive in accordance with current ethical guidelines and data protection regulations. The data were originally collected by the ESRC Research Centre on Micro-Social Change at the University of Essex. Neither the original collectors of the data nor the Archive bear any responsibility for the analyses or interpretations reported here. The views expressed are those of the author and are not necessarily shared by any individual, government department or agency.

References

- Arber, S. and Ginn, J. (1995a) 'Gender Differences in the Relationship between Paid Employment and Informal Care', *Work, Employment and Society*, 9: 446-71.
- Arber, S. and Ginn, J. (1995b) 'Gender Differences in Informal Caring', *Health and Social Care in the Community*, 3: 19-31.
- Arksey, H. (2002) 'Rationed Care: Assessing the Support Needs of Informal Carers in English Social Services Authorities', *Journal of Social Policy*, 31: 81-101.
- Arksey, H. and Hirst, M. (2001a) 'Why GPs are Best Placed to Support the Work of Carers', *General Practitioner*, 20 April, 34-35.
- Arksey, H. and Hirst, M. (2001b) 'Taking Care of the Carers', *General Practitioner*, 27 April, 36-37.
- Arksey, H. and Hirst, M. (2004) 'Unpaid Carers' Access to and Use of Primary Care Services', *Primary Health Care Research and Development*, 5.

- Audit Commission (2004) *Support for Carers of Older People: Independence and Well-Being 5*. London: Audit Commission.
- Buck, N., Burton, J., Laurie, H. and Lynn, P. (2002) *Quality Profile: British Household Panel Survey Waves 1 to 10: 1991–2000*. Colchester: Institute for Social and Economic Research, University of Essex.
- Burton, L., Zdaniuk, B., Schulz, R., Jackson, S. and Hirsch, C. (2003) 'Transitions in Spousal Caregiving', *The Gerontologist*, 43: 230-41.
- Bytheway, B. and Johnson, J. (1998) The Social Construction of 'Carers', in A. Symonds and A. Kelly (eds) *The Social Construction of Community Care*. Basingstoke: Macmillan. 241-53.
- Carers UK (2003) *Missed Opportunities*. London: Carers UK.
- Coleman, A. and Glendinning, C. (2002) 'Primary Care Partnerships: Progress and Problems', *MCC: Building Knowledge for Integrated Care*, 10: 3-8.
- Cozens, A. (2002) *Findings of the ADSS survey on the implementation of the Carers and Disabled Children Act 2000*. London: Association of Directors of Social Services.
- Department of Health (1999) *Caring About Carers: A National Strategy for Carers*. London: Department of Health.
- Gardner, M. and Altman, D. (1989) *Statistics with Confidence*. London: British Medical Journal.
- Goldberg, D. and Williams, P. (1991) *A User's Guide to the General Health Questionnaire*. Windsor: NFER-Nelson.
- Goldberg, D., Gater, R., Sartorius, N., Ustun, T., Piccinelli, M., Gureje, O. and Rutter, C. (1997) 'The Validity of Two Versions of the GHQ in the WHO Study of Mental Illness in General Health Care', *Psychological Medicine*, 27: 191-97.
- Henkel, V., Mergl, R., Kohlen, R., Maier, W., Möller, H-J. and Hegerl, U. (2003) 'Identifying Depression in Primary Care: A Comparison of Different Methods in a Prospective Cohort Study', *British Medical Journal*, 326: 200-01.
- Hirst, M. (2000) *Informal Care in Ethnic Minorities. Working Paper No. 1731*, York: Social Policy Research Unit, University of York.
- Hirst, M. (2002a) *Costing Adult Care. Working Paper No. 1883*, York: Social Policy Research Unit, University of York.
- Hirst, M. (2002b) 'Transitions to Informal Care in Great Britain During the 1990s', *Journal of Epidemiology and Community Health*, 56: 579-87.
- Hirst, M. (2004) *Carer Distress: A Prospective, Population-Based Study. Working Paper, No. 1947*, York: Social Policy Research Unit, University of York.
- Katbamna, S., Bhakta, P., Ahmad, W., Baker, R. and Parker, G. (2002) 'Supporting South Asian Carers and those they care for: The Role of the Primary Health Care Team', *British Journal of General Practice*, 52: 300-05.
- Keeley, B. and Clarke, M. (2003) *Primary Care – Identifying and Providing Support to Carers in Primary Care*. London: Princess Royal Trust for Carers.
- Kiecolt-Glaser, J., Dura, J., Speicher, C., Trask, O. and Glaser, R. (1991) 'Spousal Caregivers of Dementia Victims: Longitudinal Changes in Immunity and Health', *Psychosomatic Medicine*, 53: 345-62.
- Lankshear, G. and Hodges, V. (1999) 'The Placement of a Social Services Care Manager in a GP Surgery as a Way to Improve Carer Access to Services and Improve Liaison Between Statutory Agencies', *Health and Social Care in the Community*, 7: 206-15.

- Leat, D. (1992) 'Innovations and Special Care', in J. Twigg (ed) *Carers: Research and Practice*. London: HMSO, 94-125.
- Maher, J. and Green, H. (2002) *Carers 2000*. London: The Stationery Office.
- McLaughlin, E. and Ritchie, J. (1994) 'Legacies of Caring: The Experiences and Circumstances of Ex-Carers', *Health and Social Care in the Community*, 2: 241-253.
- National Assembly for Wales (2000) *Caring About Carers: A Strategy for Carers in Wales*. Cardiff: National Assembly for Wales.
- Nolan, M., Grant, G. and Keady, J. (1996) *Understanding Family Care: A Multidimensional Model of Caring and Coping*. Buckingham: Open University Press.
- Nolan, M. and Dellasega, C. (2000) 'Supporting Family Carers During Long-Term Care Placement for Elders', *Journal of Advanced Nursing*, 31: 759-67.
- ONS, Office for National Statistics (1998) *Disability and Care: Questions and Needs Considered*. Proceedings of a Conference held on 15 June 1998, London, Office for National Statistics.
- ONS, Office for National Statistics (2004) See website: www.statistics.gov.uk for 2001 census results relating to England and Wales.
- Parker, G. (1992a) 'Counting Care: Numbers and Types of Carers', in J. Twigg, (ed) *Carers: Research and Practice*. London: HMSO, 6-29.
- Parker, G. (1992b) *With This Body: Caring and Disability in Marriage*. Buckingham: Open University Press.
- Parker, G. (1998) 'Trends in Caring 1985-1995', in O. Rowlands *Informal Carers*. London: The Stationery Office, 39-48.
- Parker, G. and Lawton, D. (1994) *Different Types of Care, Different Types of Carer: Evidence From the General Household Survey*. London: HMSO.
- Princess Royal Trust for Carers (2003) *Focus on Carers and the NHS – Identifying and Supporting Hidden Carers: Good Practice Guide*. Glasgow: Princess Royal Trust for Carers.
- Schulz, R. and Beach, S. (1999) 'Caregiving as a Risk Factor in Mortality', *Journal of the American Medical Association*, 282: 2215-19.
- Schulz, R., Beach, S., Lind, B., Martire, L., Zdaniuk, B., Hirsch, C., Jackson, S. and Burton, L. (2001) 'Involvement in Caregiving and Adjustment to Death of a Spouse', *Journal of the American Medical Association*, 285: 3123-29.
- Schulz, R., Newsom, J., Fleissner, K., Decamp, A. and Nieboer, A. (1997a) 'The Effects of Bereavement after Family Caregiving', *Aging and Mental Health*, 1: 269-82.
- Schulz, R., Newsom, J., Mittlemark, M., Burton, L., Hirsch, C. and Jackson, S. (1997b) 'Health Effects of Caregiving: The Caregiver Health Effects Study', *Annals of Behavioural Medicine*, 19: 110-16.
- Schulz, R., O'Brien, A., Bookwala, J. and Fleissner, K. (1995) 'Psychiatric and Physical Morbidity Effects of Dementia Caregiving: Prevalence, Correlates, and Causes', *The Gerontologist*, 35: 771-91.
- Schulz, R., Visintainer, P. and Williamson, G. (1990) 'Psychiatric and Physical Morbidity Effects of Caregiving', *Journal of Gerontology*, 45: 181-91.
- Scottish Executive (1999) *Strategy for Carers in Scotland*. Edinburgh: Health Department, Scottish Executive.
- SCROL, Scottish Census Results On Line (2004) See website: www.scrol.gov.uk for 2001 Census results relating to Scotland.
- Seddon, C., Jones, K. and Boyle, M. (2002) 'Carer Experiences after a Relative goes into Nursing or Residential Care', *Quality in Ageing: Policy, Practice and Research*, 3: 16-26.

Seltzer, M., Li, L. (2000) 'The Dynamics of Caregiving: Transitions during a Three-Year Prospective Study', *The Gerontologist*, 40: 165-78.

Singleton, N., Aye Maung, N., Cowie, A., Sparks, J., Bumpstead, R. and Meltzer, H. (2002) *Mental Health of Carers*. London: The Stationery Office.

Social Services Inspectorate (1996) *Carers (Recognition and Services) Act 1995: Practice Guide*. London: Department of Health.

Twigg, J. and Atkin, K. (1994) *Carers Perceived: Policy and Practice in Informal Care*. Buckingham: Open University Press.

Address for Correspondence:

Michael Hirst,
Research Fellow
Social Policy Research Unit
University of York
Heslington
York
YO10 5DD
UK
Tel: 01904 321950
Fax: 01904 321953
Email: spru@york.ac.uk

APPENDIX

Table A.1 One-year prevalence rates by carer status, locus of care, hours caring per week, and care relationship (carers per 1000 adults by gender)

	Women	Men		
	Prevalence	(95% CI)	Prevalence	(95% CI)
Carer status				
Carers	218.2	(214.3 to 222.1)	174.0	(170.2 to 177.9)
Locus of care				
Extra-resident only	158.6	(155.2 to 162.1)	114.9	(111.6 to 118.1)
Co-resident	63.4	(61.1 to 65.7)	62.5	(60.0 to 64.9)
Hours caring per week				
Under 10 hours	145.5	(142.2 to 148.8)	121.5	(118.2 to 124.8)
10 to 19 hours	43.6	(41.6 to 45.5)	29.7	(28.0 to 31.4)
20 hours or more	50.7	(48.6 to 52.7)	35.6	(33.8 to 37.5)
Extra-resident care relationship				
Parent / parent-in-law	65.1	(62.7 to 67.4)	43.8	(41.7 to 45.9)
Other relative	32.0	(30.3 to 33.6)	23.0	(21.5 to 24.6)
Friend or neighbour	36.2	(34.5 to 38.0)	25.3	(23.7 to 26.9)
Co-resident care relationship				
Spouse or partner	28.7	(27.1 to 30.3)	30.4	(28.6 to 32.1)
Parent / parent-in-law	11.3	(10.2 to 12.3)	11.8	(10.7 to 13.0)
Son or daughter	12.0	(11.0 to 13.0)	10.1	(9.1 to 11.1)

