Retirement age caregivers and deprivation of area of residence in England and Wales

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Abstract Many countries in Europe are beginning to acknowledge the essential contribution of informal caregivers, as policy changes leave more people with greater needs being cared for in the community. Carers who are themselves retired are a vulnerable group. Compared to caregivers in younger age groups, a higher proportion have pre-existing disease; they may be more vulnerable to the adverse effects of caregiving on health, and many survive on low incomes. This study investigated whether ill health amongst older carers and hours of caregiving were greater in disadvantaged areas of England and Wales. We also estimated the cost of replacing this care with formal services. Data were analysed from the 2001 UK census, relating to 9.2 million males and females of pensionable age living outside of communal establishments in England and Wales. Thirteen percent of people over retirement age (1.2 million) provided care for others, more than half of whom (742,182) reported poor health. Pensioners provided care in all areas; the proportion giving care was higher in low deprivation (advantaged) areas, but both the numbers and proportion of pensioners in poor health providing many hours of care were greater in disadvantaged areas. The annual cost of replacing all informal with formal social care was estimated to lie between 14.8 and 43.9 billion

Euros. Older carers are an essential support to welfare systems. If demographic shifts require any substitution of formal for informal care, this will place a significant burden on all areas, with the greatest needs likely to be in the disadvantaged areas.

Keywords Caregivers · Social class · Health care costs

Introduction

Informal care is an essential, but often overlooked, support to welfare provision across Europe. In the UK, recent changes in health and social policy have had important effects on the amount and type of informal care provided: closure of national health service long term care beds, changes to eligibility rules for residential and nursing care, and financial constraints on local authority community care have combined to produce a situation where there are more people with greater needs outside of institutions (Carers UK 2004). The targeting of resources to the most needy inevitably means that those with less urgent or intense needs may not be eligible for formal care, leaving a gap to be filled by relatives and friends. In 2006 the King's Fund, one of the most influential health policy 'think tanks' in the UK, commissioned a review 'Securing Good Care for Older People' which predicted an increasing role for informal care in the future, and a need for greater support for carers (Wanless 2006). There are strong social justice arguments for facilitating informal care, but governments also recognise that supporting informal carers is likely to be a cost effective and popular strategy. This means that identifying the most vulnerable carers and characterising their needs will be essential

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Ethical permission was not required.

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for the planning and provision of appropriate support services (Carers UK 2002; Leontardi and Bell 2002).

In this paper, we focus on the more than one million ‘informal’ carers in England and Wales who are over retirement age (65 years for men, 60 years for women), in relation to the level of deprivation of the area in which they live. The reasons for studying pensioners by level of deprivation are based on strong theoretical considerations. Carers of pensionable age are more likely than those in younger age groups to have pre-existing disease, and may be more vulnerable to the adverse effects of caregiving on mental and physical health (Hirst 2005; Pinquart and Sorensen 2003; Savage and Bailey 2004; Schulz and Beach 1999). In addition, academic endeavours to assess needs for care in the UK have long acknowledged that deprivation may signal additional needs for public support, over and above the needs indicated by the health and demographic characteristics of the population (Smith et al. 1994; Carr-Hill et al. 1996; Diderichsen et al. 1997). Coupled with the fact that most of the public resources for health and social services in the UK are allocated to administrative areas to cater for their respective resident populations, area-based analyses of differential need are required to inform planning and provision of services. The specific features of the 2001 UK census offer unique opportunities to study a whole population (not a sample) of older caregivers by deprivation of their area of residence—this analysis is not possible with other available surveys.

Although clear geographical differences in informal caregiving across England and Wales have been found, the 2006 King’s Fund review considered that the existing evidence on caregiving and material deprivation was conflicting (Wanless 2006). Analyses of UK survey data have suggested positive associations between the intensive provision of informal care and poverty or manual occupational groups (Hutton 1998; Arber and Ginn 1993), but no effect for income if other factors are constant (Glaser and Grundy 2002). In England and Wales, the highest proportions of people providing 20 or more hours of care were found in local authorities with the greatest deprivation (as measured by the index of multiple deprivation) (Leontardi and Bell 2002).

To understand more fully the association of informal caring at older ages and socioeconomic disadvantage, further small area analyses are needed. This study utilises data from the 2001 UK census at electoral ward level, and looks at the relationship between hours of caring, health of carers and area disadvantage within a complete population. We ask whether the hours of caring and ill-health amongst pensioner carers vary with

area level deprivation in England and Wales, and go on to estimate the cost of replacing informal with formal care.

Methods

For the first time in 2001, the UK census included a question which asked whether each person looked after or gave help or support to family members, friends, neighbours or others, because of long-term physical or mental ill-health or disability, or problems related to old age. Anything done as part of paid employment was not to be counted.

The office for national statistics supplied data from the 2001 census relating to all electoral wards in England and Wales (mean population 5,500 per ward [Office for National Statistics 2005]). The data comprised the number of people of pensionable age resident in each ward, disaggregated by sex; self reported health status (‘not good’ will be referred to as ‘poor’ health throughout), presence of limiting illness and hours spent providing care for others (see box 1 for census questions). Scores for the deprivation of the area of residence of the carers were calculated using the Townsend index, using the original definition of the scores (see box 2) (Townsend et al. 1988; Office for National Statistics 2003). The wards were then divided into quintiles (which contained equal number of wards, but different numbers of people), on the basis of their Townsend score, with the first quintile representing the least disadvantaged wards and the fifth quintile the most disadvantaged wards. People resident in communal establishments were excluded, as they would not be providing care for others.

Costs

We assumed that the pensioners in our study were providing care for one or more adults, rather than children, and that they took on tasks that might otherwise be undertaken by a social care worker. We made no allowance for the possibility that the pensioners worked at a slower speed than a paid worker, nor that they might be able to do more than one task at a time. The census question on caregiving gives three options for the amount of care provided; 1–18, 19–49 and 50 or more hours. Costs were estimated from the perspective of third party payer (i.e. the body paying for services, such as the local authority). The replacement hourly rate was calculated, using data from the costing model produced by Tribal Sector for the Department of Health and UK Home Care Association (Unit costs of

Health and Social Care 2005 produced by Personal and Social Services Research Unit (PSSRU) at the University of Kent) (Curtis 2006). Secondly, we used the social services costs from the Evaluating Community Care for Elderly People Project community care package costs estimated by PSSRU (Curtis 2006). This describes typical packages that are of low, high and median cost. Where people were providing 50 or more hours of informal care, the cost of residential care was substituted, using the PSSRU estimates for local authority and private residential and nursing home care.

Results

Just over 1.2 million people of pensionable age (13.1%) provided care for others, approximately two thirds of caregivers were women. Of the pensioners who provided any care, the majority (0.66 million) spent between 1 and 19 h per week as carers.

Area deprivation and pensioner carers

There were clear patterns in the level of care giving, according to deprivation of area of residence (Table 1). With increasing area disadvantage, the proportion of high level (50 or more hours per week) carers increased (from 3.7% in the first quintile to 4.9% of pensioners in the most deprived quintile), whilst the proportion of lower level carers (who provided care for between 1 and 19 h per week) fell from 9.3 to 5.4% from quintiles 1 to 5.

Health of carers and non-carers of pensionable age, by area level deprivation

Irrespective of caring status, the numbers and proportions of pensioners who were in poor health increased in a stepwise manner from least to most disadvantaged quintiles. 103,871 (53%) of carers in the most advantaged wards were in fair or poor health, compared to 199,409 (69.6%) of carers in the most disadvantaged wards. Longstanding limiting illness (LLI) was reported by 542,494 (54%) of carers and 3,805,220 (47%) of non carers. The numbers of people with LLI were greater in the more disadvantaged areas (74,865 (38.3%) of all carers in the advantaged areas reported LLI, compared with 147,125 (31.4%) of all carers in the more disadvantaged areas). Considering all pensioners within each deprivation quintile, the proportion of carers with LLI rose with increasing disadvantage (Table 2).

Table 1 Care provided by men and women of pensionable age by deprivation of area of residence, England and Wales 2001

	Deprivation quintile 1 (most advantaged 20% of wards) (No. carers [% of all pensioners in quintile])	Quintile 2 (No. carers [% of all pensioners in quintile])	Quintile 3 (No. carers [% of all pensioners in quintile])	Quintile 4 (No. carers [% of all pensioners in quintile])	Deprivation quintile 5 (most disadvantaged 20% of wards) (No. carers [% of all pensioners in quintile])
Male carers	73,794 (5.4%)	80,782 (5.2%)	102,931 (5.0%)	90,123 (4.9%)	108,341 (4.5%)
Female carers	121,931 (8.9%)	133,355 (8.6%)	169,540 (8.3%)	147,248 (8.0%)	177,937 (7.3%)
Hours of care provided per week					
0	1,171,672 (85.7%)	1,341,217 (86.2%)	1,773,027 (86.7%)	1,596,901 (87.1%)	2,138,600 (88.2%)
1–19	126,675 (9.3%)	131,105 (8.4%)	154,710 (7.6%)	122,381 (6.7%)	131,026 (5.4%)
20–49	18,380 (1.3%)	21,126 (1.4%)	29,345 (1.4%)	27,614 (1.5%)	36,710 (1.5%)
50+	50,670 (3.7%)	61,906 (4.0%)	88,416 (4.3%)	87,376 (4.8%)	118,542 (4.9%)
All males ≥ 65 years	523,026 (38.2%)	586,409 (37.7%)	753,618 (36.8%)	662,500 (36.1%)	877,278 (36.2%)
All females ≥ 60 years	844,371 (61.8%)	968,945 (62.3%)	1,291,880 (63.2%)	1,171,772 (63.9%)	1,547,600 (63.8%)

The table shows the number of men and women of pensionable age (% within each deprivation quintile) and the hours of care they provide (Deprivation quintiles range from 1 least disadvantaged electoral wards to 5, most deprived)

Table 2 People of pensionable age reporting poor health or long term limiting illness: hours of informal care provided by men and women according to area level deprivation, England and Wales 2001

	Deprivation quintile 1 Most advantaged 20% of electoral wards	Quintile 2	Quintile 3	Quintile 4	Deprivation quintile 5 Most disadvantaged 20% of electoral wards
Pensioner carers reporting long term limiting illness					
Caregivers	74,865 (5.5%)	87,317 (5.6%)	119,904 (5.9%)	113,283 (6.2%)	147,125 (6.1%)
Non-caregivers	462,542 (33.8%)	568,099 (36.5%)	811,371 (39.7%)	802,122 (43.7%)	1,161,086 (47.9%)
Pensioners reporting poor health					
Hours of care provided per week					
0	191,264 (14.0%)	243,616 (15.7%)	366,762 (17.9%)	388,084 (21.2%)	610,137 (25.2%)
1–19	11,843 (0.9%)	13,676 (0.9%)	18,602 (0.9%)	17,293 (0.9%)	23,309 (1.0%)
20–49	2,848 (0.2%)	3,693 (0.2%)	5,853 (0.3%)	6,148 (0.3%)	9,301 (0.4%)
50+	10,599 (0.8%)	13,833 (0.9%)	21,764 (1.1%)	24,025 (1.3%)	36,187 (1.5%)

No. (% of all pensioners in quintile)

More of the wards with the highest proportion of pensioner caregivers (>14% for wards in the upper quartile) were drawn from the less disadvantaged Townsend quintiles. Thirty six percent of the wards in the upper quartile for the proportion of carers were amongst the most advantaged, whereas 5.3% were from the most disadvantaged. In contrast, there were more disadvantaged wards in the upper quartile for the proportion of carers in poor health (>22% of pensioner carers in poor health). Forty nine per cent of wards in the upper quartile for the proportion of carers in poor health were drawn from the most disadvantaged quintile of wards, 5.4% were from the most advantaged.

Pensioners in poor health

A total of 218,974 (18.2%) of carers reported poor health. Irrespective of hours of care, proportionately more carers in poor health were found in the more disadvantaged areas. Within each deprivation quintile, the number of male caregivers in poor health providing 50 or more hours, as a proportion of all males in poor health, increased with increasing disadvantage. The opposite trend was seen for the low level (1–19 h) male carers. For female carers in poor health, an upward trend in the proportion of pensioners in poor health with increasing disadvantage was seen at all levels of care (Data not shown, available on request).

Costs

In Table 3, some possible alternatives to informal care are presented. The hourly cost of home care is shown in each group. At the mid and high level care groups, it sometimes exceeds the cost of residential care, and is therefore not included in the calculation of the median

costs. The low, high and median costs in each band of caregiving hours is multiplied by the number of carers to produce the estimated costs shown in Table 4.

The replacement costs for the three hourly bands of caregiving overlap. The lowest number of caregiving hours is costed at Euros 38 to 444 per week, 20–49 h at Euros 200–1,018 and 50 or more hours of care may cost between Euros 573 and 1,018 per week. The total replacement cost for the care provided by people of pensionable age in England and Wales is estimated to lie between 14.8 and 43.9 billion Euros. These figures are equivalent to 50–160% of the gross expenditure in England (2004–5) of 27 billion Euros on personal social services for all age groups (Health and Social Care Information Centre 2006). The estimated mean costs (in wards grouped by deprivation quintile) increased significantly with increasing disadvantage of area of residence.

Discussion

Interpretation of key findings

There is a distinct and consistent pattern between caregiving by pensioners and socioeconomic disadvantage in England and Wales. Pensioners from more disadvantaged areas are more likely to provide 50 h or more of care, and to report longstanding limiting illness or poor health themselves. Many of the census wards with high proportions of pensioner carers are found in well off areas, whereas wards with the highest proportion of caregivers in poor health were found more often in disadvantaged areas. Hence, the burden of caregiving and the carer's own ill health may combine to produce the most intensive needs in poorer areas.

Table 3 Typical replacement services for different levels of informal care, England and Wales

	Weekly cost Euros
Community care packages ^a to substitute for up to 19 h of informal care	
Very low cost package (2 h per week)	38
Low cost package (4.5 h home care, two frozen meals)	98
Median cost package (7.25 h per week)	105
High cost package (2.5 h home care, 2 visits to day care, 2 respite stays of 7 and 14 days to residential care home)	298
Very high cost package (13.25 h home care, including weekends, one day per week at day centre)	444
Community, residential or nursing care to substitute for 20–49 h of informal care	
Home care at Euros 19 per hour for 20 h	380
Local authority day care (Euros 40/half day) for 5 half days	200
Very high cost community care package (13.25 h home care, including weekends, one day per week at day centre)	444
Voluntary residential care	573
Private residential care	578
Private nursing home care	801
Local authority residential care	1018
Community, residential or nursing care to substitute for 50 + hours of informal care	
Home care at Euros 19 per hour for 50 h	950
Local authority residential care	1018
Voluntary residential care	573
Private residential care	578
Private nursing home care	801

^a Costs derived from the Evaluation Community Care for Elderly People: the ECCEP Project, PSSRU, University of Kent at Canterbury, GB pounds converted to Euros at 10/2006 exchange rates

Table 4 Average replacement costs of informal care (pensionable age carers), England and Wales

	Weekly cost Euros	Annual cost per carer Euros	Total annual costs for all elderly carers in England and Wales Euros (billion)
1–19 h of informal care per week ($n = 665,897$ elderly carers)			
Low	38	1,976	1.3
Median	105	5,460	3.6
High	444	23,088	15.4
20–49 h care per week ($n = 133,175$ elderly carers)			
Low	200	10,400	1.4
Median	573	29,796	4.0
High	1,018	52,936	7.0
50 or more hours per week ($n = 406,910$ elderly carers)			
Low	573	29,796	12.1
Median	801	41,652	16.9
High	1,018	52,936	21.5

Costs (2005) derived from the Evaluation Community Care for Elderly People: the ECCEP Project, PSSRU, University of Kent at Canterbury

The number of elderly caregivers identified is great, and it is unlikely that formal services would be required, or have the capacity to respond to anything other than small changes in the amount of informal care provided. The 2006 King's Fund review has recommended a substantial increase in funding for social care in the coming years, to keep pace with demographic changes and improve care (Wanless 2006). Support for informal caregivers would be a crucial part of any changes. Our findings emphasise the economic importance of the carers' contributions, and could inform policy-making to support and maintain the health and welfare of caregivers.

Our findings suggest that support for pensioner carers is needed particularly in disadvantaged areas. Young and colleagues found that when carers of all ages are considered, local authorities with high deprivation scores (using the index of multiple deprivation) had both higher proportions of carers and higher proportions of carers in poor health (Young et al. 2005). This finding differs from our study, in which many of the wards with the highest proportions of pensioner carers were in better-off areas. Whilst it is likely that caregiving behaviour amongst pensioners differs from the general population of carers, there were also differences in study design. Young and colleagues' analyses

were at local authority level and excluded caregiving under 20 h per week. The authors also acknowledged that the five health and disability indicators within the deprivation index that they used—the IMD were a potential cause of the correlation between deprivation and caregiving. Nevertheless, current carers may not have adequate access to services, however disadvantaged the area. Shaw and Dorling have described an ‘inverse care law’ for informal carers, where the provision of formal health services is inversely related to the population prevalence of poor self rated health. The proportion of informal carers (providing 50 or more hours of care per week) was more closely related to need (Shaw and Dorling 2004).

Limitations

There are several possible methods to estimate the economic burden of informal care (Andersson et al. 2002; van den Berg et al. 2004; McDaid 2001). All have limitations, and in putting a monetary value on care, issues such as the emotional and social value of informal care will inevitably be overlooked. Our replacement cost approach was appropriate to the aim of this study, but neglects a number of important perspectives, and shared the limitations, common to other costing studies, arising from difficulties in estimation of the time spent caregiving and the cost of the care (Pickard 2004). If, for example, informal caregivers work more slowly than paid carers, or combine the provision of care with an unrelated task, then wide ranging assumptions have to be made to put a consistent monetary figure on such activities. In this age group, the opportunity costs of caregiving by pensioners are likely to be very important to individuals, particularly as more of them will lie in leisure time lost, rather than production. In addition, out of pocket costs may be more difficult for a carer to find, if they rely on a limited pension.

Although our estimates do not take into account the disability levels of the care recipients, or other issues such as benefit payments, the level of costs estimated is in keeping with a recent report for Carers UK (Carers UK 2002). This study estimated the replacement costs for carers of all ages in Britain to be in the region of Euros 85 billion per annum, or around Euros 1,500 per capita each year. That figure is based on data from the general household survey and an hourly rate of Euros 15. In Scotland, the annual cost of informal care of the elderly was estimated at Euros 296 million, or Euros 60 per inhabitant (Leontardi and Bell 2002). The Scottish calculation used an hourly rate for up to 28 h of care, above which the hours of informal care were discounted. Our approach of using typical packages of

care costed from recent fieldwork should give a close approximation to real costs, which take into account the requirement for local authorities to minimise expenditure. This is similar to the approach adopted by the UK’s 1996 House of Commons Select Committee on the Future and Provision of Funding in Long Term Care (House of Commons Health Committee 1996), and, as with the 2006 King’s Fund review, is based on the PSSRU data.

Ideally, it would have been preferable to analyse the influence of both area deprivation and individual social class. However, the study was limited to the analysis of area deprivation, as no reliable measures of individual socioeconomic status at older ages were available from the 2001 census. The Townsend Index was chosen for the deprivation analysis because of its sound theoretical basis. It combines only direct indicators of material deprivation, and excludes both indirect measures (such as groups at risk of deprivation) and measures of health, which would skew or confound any correlations between deprivation and health-related outcomes (Townsend et al. 1988; Morris and Carstairs 1991; Whitehead 1992). The Townsend score has been shown to be a reliable measure of area level deprivation over two decades and has been found to perform particularly well in explaining the observed variations in health indicators in the UK (Morris and Carstairs 1991). If access to formal services varies with material deprivation, then this will distort any social patterning of need for informal care. From previous studies, we know that access to formal services is less of a problem in relation to primary care in systems with universal coverage (and access to social services follows similar patterns), though there are more concerns about equitable access to secondary care (Hanratty et al. 2007). Another limitation of our study was the concern over confidentiality, which meant that the Office for National Statistics was unable to provide information on both the age and area of residence of the census respondents. Hence we could not comment on the relationship between area deprivation and age related patterns in care needs. Similarly, the data did not identify who was caring for whom, though evidence from the General Household Survey in 2000 for Great Britain does suggest that the majority of elderly carers do care for other elderly people (Maher and Green 2002). Implicit in our analysis is the assumption that self rated health and long standing limiting illness are reported in a similar manner across different socioeconomic groups and areas at older ages. At working ages, self rated health has been shown to be a strong predictor of subsequent mortality across different socioeconomic groups in Sweden, and this relationship appears to hold

for older ages (Burström and Fredland 2001; Idler and Benyamini 1997). Census data have many advantages over other surveys. They are not prone to any sampling biases, as the whole population is obliged to participate and questions are subject to rigorous piloting before being used. However, it is possible that older adults may respond to particular questions in a unique way. For example, in this study the number of pensioners reporting 20–49 h of care is low across all wards. The reasons for this are unclear.

Conclusion

This study has provided a baseline description of the elderly informal caregiving population in England and Wales, and shown that in addition to receiving care, older adults provide care that is a major support to the welfare system. The census evidence that there are more carers in disadvantaged areas working for longer

hours and with poor health themselves should inform the resourcing of services for carers on a locality basis. Our estimates indicate that the costs to the public sector of any shifts from informal to formal care will fall disproportionately on more disadvantaged areas. This means that health and local authorities serving deprived populations—already the most overstretched—will be the ones facing the heaviest cost consequences of replacement services.

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Appendix

Box 1 2001 UK Census questions on general health, caring and long-term illness

- Q11 Over the last twelve months would you say your health has on the whole been:
- ☐ Good?
 - ☐ Fairly good?
 - ☐ Not good?
- Q12 Do you look after, or give any help or support to family members, friends, neighbours or others because of:
- Long-term physical or mental ill-health or disability, or
 - Problems related to old age?
 - Do not count anything you do as part of your paid employment
 - ✓ time spent in a typical week
 - ☐ No
 - ☐ Yes, 1–19 hours a week
 - ☐ Yes, 20–49 hours a week
 - ☐ Yes, 50+ hours a week
- Q13 Do you have any long-term illness, health problem or disability which limits your daily activities or the work you can do?
- Include problems which are due to old age
 - ☐ Yes ☐ No

Box 2 Derivation of Townsend deprivation score at ward level

Each of the four indicators was calculated as per the original definitions given by Townsend. Because of the confidentiality measures in the Census output, the fewest number of cells were used in calculating values. As per the original Townsend calculations, unemployment and overcrowding were log transformed before standardising. The final Townsend value is the sum of the four standardised values:

$$\text{townsend} = \text{unemptown} + \text{nocartown} + \text{renttown} + \text{hocctown}$$

Unemployment: The percentage of economically active residents aged 16–59/64 who were unemployed

Table CAS028	Sex and age by economic activity
Economically active:	$\text{ecactive} = 0002 - 0082 - 0252$
Unemployed:	$\text{Unemploy} = 0005 - 0085 - 0255$
Percentage unemployed:	$\text{perunem} = \text{unemploy}/\text{ecactive} \times 100$
Log transformation:	$\text{Lnperunem} = \ln(\text{perunem} + 1)$
Standardising:	$\text{unemptown} = (\text{Lnperunem} - 1.6385)/0.43067$

Non-ownership of a car: The percentage of private households not possessing a car

UV62 Cars or Vans

All households:	hhlds62 = 0001
No car:	nocar = 0002
Percentage no car:	per0car = Nocar/hhlds62 $\times$ 100
Standardising:	Nocartown = (per0car – 22.1533)/12.98354

Non ownership of a home: The percentage of private households renting rather than owning or buying a home

Table UV63 Tenure (households)

Owned:	own = 0002
Households:	hhlds63 = 0001
Percentage not owned:	perrent = (hhlds63 – own)/ hhlds $\times$ 100
Standardising:	renttown = (perrent – 28.1071)/14.19010

Overcrowding: The percentage of private households containing more than one person per room

Table UV58 Persons per room

Overcrowded:	hocc = 0004 + 0005
Households:	hhlds58 = 0001
Percentage overcrowded:	perhocc = hocc/hhlds58 $\times$ 100
Log transformation:	lnperho = ln(perhocc + 1)
Standardising:	hocctown = (lnperho – 0.7440)/0.44057

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