

# Informal care over time

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RESEARCH FINDINGS FROM THE  
SOCIAL POLICY RESEARCH UNIT

SPRU

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The government's strategy, *Caring for carers*, aims to support carers in their caring activities, sustain their other roles including paid employment, and improve their long-term financial security. This project explored these policy goals using existing data sets to inform service developments and the allocation of resources for supporting adult carers. The research also provides baseline findings at the national level which could be used to monitor the impact of the strategy and related policy initiatives. Key findings include:

- ▶ The carer population is constantly changing, greatly complicating the assessment of carers' needs, resource targeting and service developments.
- ▶ Most people can expect to provide informal care at some point in their lives.
- ▶ The number of heavily involved carers looking after spouses, elderly parents or disabled children is increasing.
- ▶ Transitions to informal care are associated with the onset of emotional distress and prolonged or recurring symptoms of anxiety and depression.
- ▶ As care episodes lengthen, carers' likelihood of being in paid work decreases compared with non-carers, for those looking after someone in the same household. Although labour market income is correspondingly lower, household and total personal incomes are less affected. Heavily involved carers are particularly likely to withdraw from work and least likely to enter or return to work after caregiving has ceased.
- ▶ Incomes in retirement from state and private pensions are lower for those currently caring for someone in the same household, and retired women carers are particularly likely to be in the lowest pensioner income band. Those who provided a substantial amount of care earlier in their lives also face lower incomes in retirement than those not previously involved in informal care.

## Background

When this research began our knowledge of informal care at the population level came from cross-sectional surveys, providing valuable snapshot pictures of the prevalence and nature of caregiving, who cares for whom and the support services received. These surveys provide little insight, however, into the dynamics of caregiving yet analysing change is vital to understanding how caring relationships develop. Outcome measurement is also concerned with detecting changes over time.

Drawing on time series and longitudinal data, this project aimed to:

- ▼ Investigate the effects of caring on adult carers' health, economic activity and financial circumstances.
- ▼ Estimate the likelihood of becoming a carer and how this varies across population subgroups.
- ▼ Examine the timing of care episodes in relation to family and household circumstances.
- ▼ Chart trends in the population of carers and caring relationships over time.

## Findings

### The population of carers

The public policy importance of informal care stems from the irreplaceable care that almost six million individuals provide for the vast majority of disabled, ill or frail elderly relatives and friends living in private households. Even that figure understates the total volume of caregiving in Britain. The population of carers is constantly changing as individuals stop providing care and others take on a caring role, or vary their level of involvement. More than a third start or cease caregiving each

year and over half are replaced by another cohort of carers every five years. Heavily involved carers providing 20 hours or more informal care per week are even more transient.

High rates of carer turnover have two important consequences:

- ▼ More individuals are involved in caregiving than shown in cross-sectional surveys. At any time, around 34 per 1000 women and 24 per 1000 men provide at least 20 hours care a week but these figures rise to 50 and 36 per 1000 respectively during a 12 month period. Twice as many individuals provide care sometime during a five year period as during one year.
- ▼ Over the life course, most individuals can expect to provide informal care at some point in their lives: by age 75 years, almost two thirds of women and close to half of men will have provided one or more spells of at least 20 hours of care per week.

Caring for children with chronic illness or disability commences mainly during the child-rearing years, before parents reach their mid-40s. The need to look after disabled or elderly parents occurs across a wider age span but starts mainly when carers are in their mid-30s to mid-50s. The likelihood of providing informal care for a spouse or partner increases with age; most caring relationships that start after age 55 are between spouses.

### Recent trends in informal care

Although the population of adult carers in Britain declined during the 1990s, the proportion of those heavily involved in providing informal care increased. This trend towards more intensive caregiving is associated with an increasing number of caring relationships that typically make heavy demands on carers: caring

for a spouse, child or elderly parent. At the same time, less intensive caregiving between households declined, particularly between friends and neighbours. However, elderly parents were increasingly looked after in their own homes by non-resident daughters.

Until the early 1990s most spouse carers were women. Subsequently more men than women took on the role of a spouse carer and by the end of the decade as many men as women provided informal care for a spouse or partner.

These trends reflect broader changes in society including: rising numbers of frail older people, increased chances of living with a spouse in old age, higher rates of home ownership among more recent cohorts of older people, and continuing improvements in the life expectancy of severely disabled children.

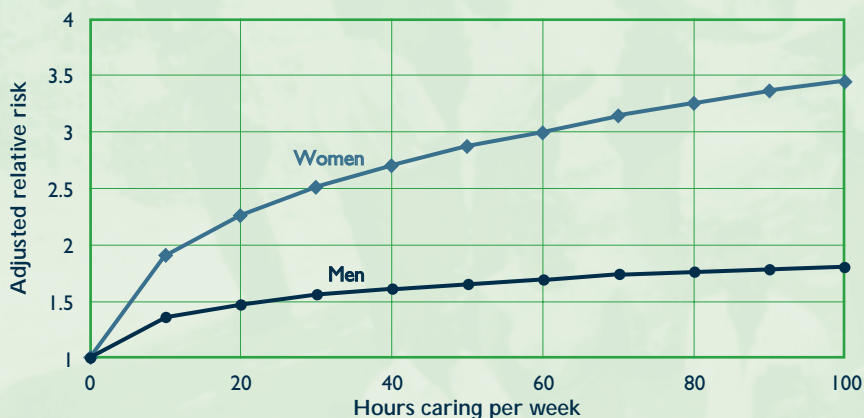
### Health outcomes of caring

By investigating representative samples of carers and non-carers over time, the research produced new evidence on the risk of common mental health problems:

- ▼ Taking on caring roles is associated with adverse effects on carers' mental health including risk of onset of and delayed recovery from symptoms of anxiety and depression.
- ▼ Distress levels in the carer population increase during the first year of caregiving and do not return to former levels as caring continues.
- ▼ The risk of anxiety and depression rises progressively with the number of hours devoted to caring each week.

Figure 1 shows the estimated risks associated with taking on a caring role by plotting net changes in respondents' scores for psychiatric distress. Relative to non-carers (=1),

**Figure 1: Change in psychiatric distress scores relative to non-carers following transition to informal care (adjusted for prior score and potential confounders)**



scores increased (worsened) following transition to informal care by a factor of 1.90 for women providing 10 hours of care and by 2.26 for 20 hours a week. Risk estimates for male carers are 1.36 and 1.48 respectively, indicating a weaker though still significant association with increasing involvement in caregiving.

Although the explanatory factors are imperfectly understood, the findings draw attention to differences in women's and men's responses to their caring roles, the types of care they provide and the support they receive. Among those taking on full-time or continuous care, women are almost twice as likely men to report increased distress.

**Effects of informal care on employment**

A major policy objective is to encourage carers to remain in paid work as this enables them to have an independent life and avoid hardship. It is also considered to help sustain the caring role.

In general employment status changes little immediately following the transition to informal care: 83 per cent under pension age remain in the same position as before care started. Generally eighty-five per cent of those in paid work remain in work, but fewer, 70 per cent, of those working part time (mostly women) did so.

As the duration of caregiving increases, however, there is a significant reduction in the likelihood of being in paid work compared with non-carers. After the third year of informal care those providing 20 or more hours care per week are considerably less likely to be in paid work.

Combining employment and informal care substantially decreases the spare time available: estimates of the time devoted to caregiving, paid work and travel to work show that a quarter of carers spent 12 hours or more per day on these activities compared with seven per cent of non-carers. Because more men work full-time, 54 per cent of men compared with 39 per cent of women spent ten or more hours per day on paid work, travel and caregiving.

Part-time workers looking after someone in the same household are less likely to be in permanent jobs and jobs with annual increments than non-carers. The private sector is less likely to employ those with caring responsibilities.

Looking after a spouse or partner reduces the likelihood of remaining in paid work compared with other caring relationships.

Heavily involved carers are significantly less likely to be

in paid work when caregiving ends; not only do they take longer to return to work but the number in paid work continues to decline beyond the caring episode.

For women, working part-time while providing informal care increases their chances of being in work after caregiving ends relative to those not working; working full-time increases them even more.

**Effects of informal care on income**

Differences in the employment patterns of carers and non-carers influence their relative incomes.

Caregiving chiefly affects labour market incomes which decline relative to similar non-carers for longer episodes of care.

Personal and household incomes are less affected, and benefit and pension incomes seem to compensate for lack of earnings. However, although the household incomes of carers and non-carers appear similar, the living standards of carer households would be lower by the costs of disability of the cared-for person.

There is little evidence in the relatively short time period available in the data that incomes catch up after caregiving ends.

**Pension arrangements and informal care**

If carers withdraw from paid work they are less likely to be able to sustain the necessary contributions for pension provision in retirement. The result is that incomes in retirement from state and private pensions are lower for both current carers and those who provided informal care earlier in their lives. Women over retirement age caring for someone in the same household are particularly likely to be in the lowest income band compared with other pensioners.



The pre-retirement years are the peak time for taking on a caring role and it was thought that people would take early retirement in order to provide care. However the main source of income during these years is from benefits rather than occupational pensions.

## Implications

### Local services

Identifying carers in primary care settings should explore the extent of involvement in caregiving and the nature of caring relationships to identify those at risk of adverse health effects. Empathy, support and understanding will often be the most appropriate response to carers' emotional needs and would be consistent with the largely undifferentiated distress detected here.

Primary care trusts and social services authorities need to be responsive to carers' varying needs for support and take account of changes in the population of carers. Evaluations of service performance might usefully include indicators of the time between referral, needs assessment and service provision, and the timeliness of these processes.

The turnover of carers has financial and administrative implications for social services authorities. Underestimates of turnover would result in the needs of many carers, and the people they care for, not coming to the authorities' attention and a risk that formal service support is slow, inflexible and therefore inappropriate. Overestimates of turnover could lead to wasteful care management resources and higher unit costs.

### National government

If the trends identified here continue, increasing resources will be required for identifying heavily involved carers, assessing their needs and supporting them in their caring activities, including services for carers to take a break from caregiving.

Heavily involved carers are vulnerable in the labour market which has implications for their current and long-term financial security. A way forward would be through commitment to family friendly employment policies and practices that help people balance paid work and other aspects of their lives.

It is a poor reward for providing informal care that carers have such low incomes in retirement. Special provision during the working life and beyond will often be necessary to provide carers with incomes in retirement comparable with others.

## Methods

The project was funded by the Department of Health as part of its *Outcomes of Social Care for Adults* initiative. It was carried out over 28 months commencing September 1997.

The research was based on nationally representative samples of carers and non-carers in three data sets: the *British Household Panel Survey* (1991 to 1995), the *General Household Survey* (1985, 1990, 1995), and the *Family and Working Lives Survey* (1995) made available through The Data Archive, University of Essex. Neither the original collectors of the data nor the archive bear any responsibility for the analyses or interpretations reported here. These data were analysed using the *Statistical Package for the Social Sciences*. Psychiatric morbidity was assessed by the *General Health Questionnaire*.

### Further information

Copies of the report *Caring relationships over time* by Sandra Hutton and Michael Hirst are available from SPRU's Publications Office, price £7.00.

Contact Ruth Dowling on 01904 433608 or email [spruinfo@york.ac.uk](mailto:spruinfo@york.ac.uk)

#### Related publications:

Hirst, M. and Arksey, H. (2000) 'Informal carers count', *Nursing Standard*, 14, 42, 33–34

Hirst, M. and Hutton S. (2000) 'Informal care over time', *Benefits*, 28, 9–12

Hirst, M. (2001) 'Trends in informal care in Great Britain during the 1990s', *Health & Social Care in the Community*, 9, 6, 348–357

The government's strategy for informal carers and associated policy developments can be viewed at:

<http://www.carers.gov.uk>

The data archive can be visited at:

<http://dawwww.essex.ac.uk>

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