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Hearts & Minds

The health effects of caring

S | P | R | U
SOCIAL POLICY RESEARCH UNIT
THE UNIVERSITY of York

In association with

CARERS UK
the voice of carers
CARERS Scotland

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Around 6 million adults in Britain help and support family, partners or friends who are ill, frail or disabled. The care they provide is unpaid. They include over 1.5 million carers who devote at least 20 hours a week to their caring activities.¹ However, most adults provide that level of care at some point in their lives.²

The UK, Scottish Executive and Welsh Assembly Governments have adopted strategies that aim to support carers in their caring role and enable them to continue caring for as long as they wish to do so.³ Ensuring that carers' health needs are met, and helping them maintain their own health and well-being, are key elements of those strategies.

New research, based on interviews with people before, during and after a period of time spent caring, shows that unpaid carers experience health inequalities compared with the general population. This leaflet summarises the findings and recommends a more thoroughgoing approach to tackling carers' needs by those responsible for improving the nation's health.

Carers' health problems

The study found that emotional and mental health problems are more often associated with caregiving than physical health problems. Carers are more likely than non-carers to report high levels of psychological distress, which can include anxiety, depression, and loss of confidence and self-esteem.

Carers report that emotional health problems interfere with their everyday activities and work. Restrictions on personal, family and social life also take their toll on carers' health. Indeed, heavily involved carers may not have enough time or energy to look after their own health.

Diminished immune response, and susceptibility to physical illness and infection such as flu, may result from the stress associated with providing round-the-clock care. Injuries sustained while lifting and moving the person they are looking after also limit or prevent the carer's ability to provide care and fulfil their other roles.

Taken together, the findings draw attention to the physical, psychological, social and financial stress that some carers face, and the isolation that often accompanies a demanding caring role. Maintaining carers' health, and ensuring their access to health services, are important in their own right. Promoting carers' health may also bring health and other benefits to the person they care for.

Carers who do not experience psychological distress are likely to be better able to cope with the demands of care, and more willing to continue providing care. Consequently, poor health in the carer population has important implications for health and social services:

- Carers who experience distress often have unmet support needs and may require help from service providers, including services for carers to take a break from caring.
- Poor health in carers can often lead to older people's greater use of health services, including admission to, delayed discharge from, or unplanned readmission to hospital; referral to a day hospital or geriatric unit; and admission to residential care or nursing homes.

- If caregiving ends because of carer ill health, the health service may be faced with two patients where previously there was only one, supported by an unpaid carer.

Which carers are most at risk?

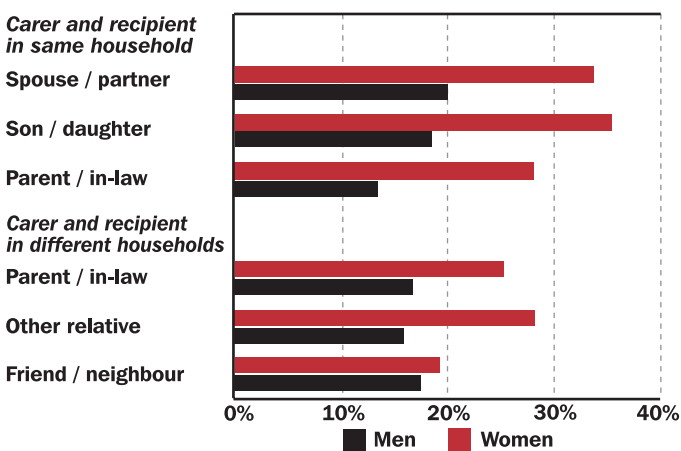
Although mental and emotional health problems are associated with caregiving, providing care for disabled or elderly people does not automatically result in psychological distress. Most carers rate their health as 'good', and overall only a minority faces increased risk of poor health outcomes.

Psychological distress is most likely to occur where carers have a particularly close relationship with the person they look after. Those caring for a spouse or partner, and parents caring for a sick or disabled child, are most at risk of distress, followed by carers looking after an elderly parent and other close kin. Figure 1 also shows that more women than men experience distress, especially where they look after someone living in the same household.

Figure 1

Proportion of carers who experience distress

Level of distress varies according to the care situation.

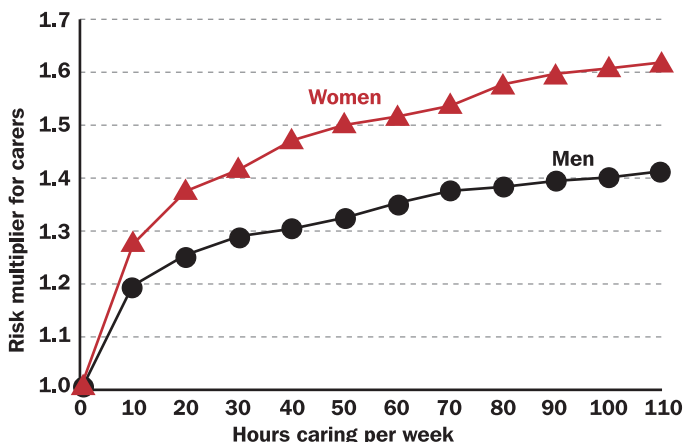


Spouse carers and others in the high risk groups are often heavily involved in caring activities. Thus, risk of distress increases progressively with the number of hours devoted to caregiving (Figure 2). Compared with non-carers, full-time 'active' care (16 hours a day or 112 hours a week) increases the risk of distress in women by a factor of 1.6 (that is, 60 per cent higher), and by a factor of 1.4 (or 40 per cent higher) in men providing similar levels of care.

Figure 2

Carers' risk of distress relative to non-carers

Risk of distress increases with intensity of caregiving.



Jean & her mother, Ella

Jean cares for her 84-year-old mother, Ella, who is very frail and widowed. Jean manages her mother's care on her own after her own husband died of a heart attack 6 months ago. Ella finds it very difficult to move around the house and use the stairs. Jean is frightened to leave her alone in the house as she falls a lot and can't get back up without help.

Jean's own health is poor and she feels under some considerable stress.

Carers who devote long hours to their caring activities are likely to be providing the more demanding types of assistance, including help with personal care (for example bathing, dressing and using the toilet) and mobility. Although these heavily involved carers form a minority of the carer population, they provide the bulk of unpaid care hours:



- Just under 25 per cent of carers provide 20 hours or more care a week but account for over 75 per cent of the total time devoted to unpaid caregiving.
- Fewer than one in ten carers provide round-the-clock care but almost half of all care hours.

Were these more intensive caring relationships to break down because the carers are unable to cope, the cost of replacing the care they provide by community health and social services would be disproportionate and potentially considerable.

Taking on a caring role

Although each caring relationship is different, it is possible to identify similar stages in the evolution of caring responsibilities and activities, and the transitions or turning points between them:⁴

- From the beginning, there is growing awareness of the need to provide care, and recognition of new or changed obligations and responsibilities towards the cared-for person. Caring about someone with advancing frailty or impairment can be at least as stressful as providing hands-on care, and a major cause of anxiety before taking on the role and identity of a carer.
- The transition to caregiving is marked by decisions, often implicit, about providing physical and personal assistance. Taking on a demanding caring role with all the changes and tensions in personal, family and social life that may arise, can be especially stressful for carers. Anxieties about caregiving may be fuelled by lack of advice, emotional support and the information to make informed choices.
- As caregiving extends, most carers adapt to their caring role and cope with the extra demands alongside their other activities. Indeed, many carers tell of the rewards and satisfactions of caregiving. However, the physical and emotional demands of ongoing care, and the sacrifice of personal and social goals such as having to give up paid work, are associated with increased risk of chronic distress.

Levels of distress before, during and after starting to provide 20 hours or more care a week are plotted in Figure 3. These can be compared with the relatively constant rates of 23 per cent in women and 16 per cent in men who do not provide care:

- Before caregiving begins, people who will shortly take on heavy caring responsibilities present higher than expected rates of distress. Women especially report significantly higher distress levels at this stage.
- The start of heavy caregiving is marked by a significant increase in distress rates. Women face almost a threefold increase in the risk of experiencing distress when starting an episode of heavy care; men face a twofold increase in the risk of distress.
- Although distress levels fall after the first year of heavy caregiving, rates of distress in carers remain above those of non-carers, and rise again among men when their caregiving lasts for more than four years.

Moreover, heavily involved carers are likely to report recurring episodes of distress:

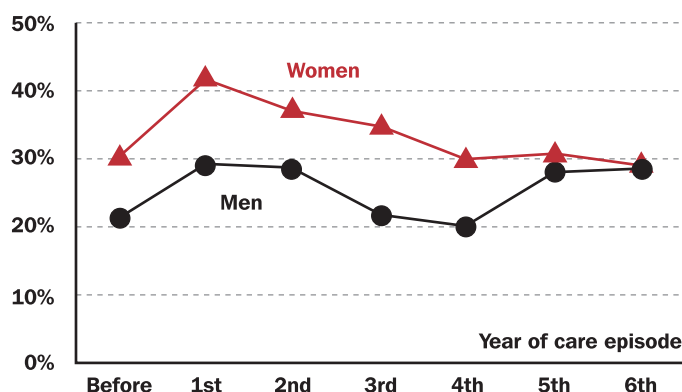
- 32 per cent of women and 18 per cent of men who provide 20 hours or more care per week report high distress scores every year during the care episodes monitored here. Comparable figures for recurring distress in the general population are 21 and 13 per cent for women and men respectively.

In contrast, adverse health consequences are not observed in carers who are less heavily involved. Distress rates in those who provide under 20 hours care a week fluctuate within a narrow band only marginally above those of non-carers, and do not increase around the transition to caregiving.

Figure 3

Prevalence of distress before and during heavy caregiving episodes

Distress levels rise around the start of care.



When caregiving ends

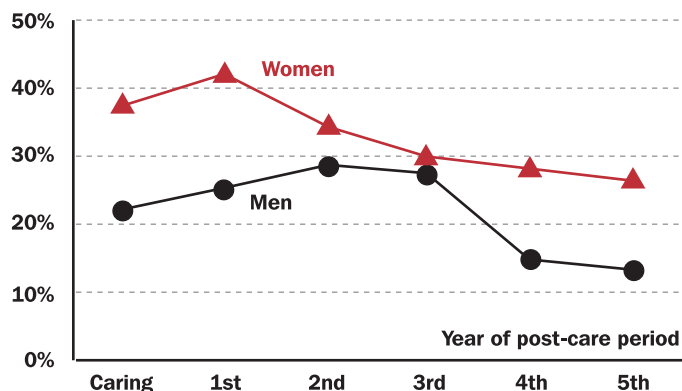
Although the end of caregiving brings relief from day-to-day caring activities, social isolation and other sources of stress are not easily remedied. Some carers experience traumatic grief and prolonged depression following the death of the person they were caring for. Admission of the care recipient to a residential care or nursing home may also be stressful for carers, especially when associated with feelings of guilt or failure.⁴ Loss of a significant role, and a need to fill the void left by caregiving with meaningful alternatives, can undermine a sense of self-worth and identity.⁵

Women especially face increased risk of distress when heavy caregiving ends, followed by steady improvement in their emotional health (Figure 4). By comparison, the post-care experience of men points to a more prolonged period of adjustment for many of those who were formerly heavily involved. However, for women and men alike, distress rates return to levels similar to those of non-carers by the fourth or fifth year after heavy caregiving ends. Distress levels in those who cease providing less than 20 hours care per week do not change when caregiving ends, and are little different to those of non-carers around that transition and beyond.

Figure 4

Prevalence of distress before heavy caregiving ends and after

Distress levels eventually decline after caregiving ends.



Carer diversity

Carers are a diverse group of people. The findings indicate that the extent of psychological distress among carers, and the varying responses of women and men to caregiving, differ between those who:

- Are more or less heavily involved in caring,
- Have different relationships with the person receiving care,
- Provide care for someone in their own home or elsewhere, and
- Are at different stages in their caregiving episode.

Mrs Green & her husband, David

Mrs Green has been caring for her husband for the past 10 years. Her husband, David, has had a stroke. She is needed day and night to provide physical care. She also needs to provide emotional support as David's confidence has been badly affected by his illness. She feels that she cannot leave David alone without arranging for someone else to be there.

Physically, she often suffers from pain aggravated by her caring role. This pain is made worse by often being tense and stressed. She also feels her emotional wellbeing is also affected; often feeling tired, stressed and depressed.

People providing relatively few hours of care each week, mostly for someone living in a different household, often do not present significantly higher rates of distress than non-carers.

To understand the health effects of caregiving, and develop services that promote carers' health, it is important to differentiate the carer population according to these factors. Failure to distinguish key groups of carers, or to consider their location in the care episode, is likely to obscure unmet health needs and unlikely to produce positive outcomes.

Identifying carers

Identifying carers is the first step towards providing timely, appropriate and ongoing support. GPs and members of the primary care team, including district nurses and health visitors, are expected to play a key part in supporting carers, and the GP surgery is probably the best place to identify them:

- Over 80 per cent of women and more than 70 per cent of men consult a GP within six months before or after starting to provide care; heavily involved carers contact GPs more often.
- Hospital discharge arrangements also provide an important opportunity to identify and support family carers, and community pharmacists can signpost carers to sources of advice, information, and support.⁶

Recognising the diverse care situations described above could form part of a protocol for identifying carers in primary care settings, and following up those most at risk of poor health. Once identified, carers can be informed of their rights to assessment and put in touch with social services, carers' centres and carer support projects.

Carer distress during the 1990s and beyond

Despite growing recognition of the importance of carers, the introduction of legislation and guidance to support them, and improvements in local service provision, positive outcomes are difficult to detect in the population of carers. Inequalities

in rates of psychological distress between carers and non-carers did not diminish in the ten years to 2000, indicating that the case for supporting carers is as compelling as it ever was.

The persistence of caring-related inequalities shows the challenges for public health policy that tackling carer distress represents. The findings also provide a national baseline against which to monitor the impact of measures to promote carers' health and well-being, and prevent ill health in the future.

It might be anticipated that devoting more resources to effective support services would reduce distress levels in the carer population \bar{n} at least in the medium term. Set against that goal is a projected increase in the number of people who will be caring for a partner or an elderly parent, which are among the more stressful care situations identified here.⁷ High turnover in these carer groups points to a recurring need to support carers around the transitions into and out of caring.² Thus, caregiving will be an important public health issue for the foreseeable future.

How important is caregiving in shaping health inequalities?

Everyone's mental health is potentially affected by a number of factors.⁸ A key question for public policy is: how important is caregiving alongside the wider determinants of health like poverty, education and employment?

To investigate this further, the effect of caregiving on psychological distress was compared with that of other factors more commonly associated with health inequalities, for example gender, socio-economic group, and the material conditions of people's lives. This analysis showed that caregiving is independently associated with distress on top of other key health determinants such as financial strain, physical health problems, age, marital status, educational qualifications, ownership of consumer durables, smoking behaviour, employment status, and social class. Among these factors:

- Caregiving is the fifth most significant factor associated with women's distress rates and the ninth most important factor influencing distress levels in men.

Particular care situations have a relatively substantial effect on distress levels, especially in women. Looking after someone in the same household, for instance, has more influence on raising women's risk of distress than being a widow, or not having paid employment.

Caregiving also increases more generally observed health inequalities. For example, the gap between female and male distress rates in the general population is around seven percentage points (23 per cent of women against 16 per cent of men). However, this gender gap is much greater among carers living in the same household as the person they care for:

- 35 per cent of women who care for a partner experience distress, compared with 20 per cent of male spouse carers, a difference of 15 percentage points.
- 36 per cent of mothers caring for a disabled child experience distress, compared with 19 per cent of fathers, a percentage difference of 17 points.

Main recommendations

The adverse effects of caring on health are, in principle, avoidable and amenable to policy and good practice. Although this study was not designed to evaluate policy options, the findings have implications for carer support, and could inform service planning and resource allocation decisions. Key messages for policy and practice include:

- Early identification of carers is likely to be important for increasing the effectiveness of health promotion and prevention initiatives, and tackling carers' needs for information, training and personal development to help them balance caring responsibilities alongside their other roles.
- Improved access to services and emotional support should target people providing substantial amounts of care; these carers are likely to benefit from advice, information, education and training around the start of caregiving, and at regular intervals where heavy care giving continues for some years.
- Opportunities for low-level health measures should not be missed. Examples include: community groups and activities, free flu vaccinations, and alternative therapies to reduce stress. Investing small amounts of resources in carer support could prevent serious deteriorations and crises in health and well-being that might otherwise have costly implications for health and social services.
- Recurrent or persistent distress indicates a particular need to explore the factors that underlie carers' emotional health, and enhance their coping strategies and resources. Each source of stress will often require different types of intervention, geared to individuals' circumstances and to differences in the way women and men respond to the care situation.
- When substantial amounts of care are provided over an extended period, carers' health should be checked at least once a year, or whenever a suitable opportunity arises.
- Emotional support, bereavement care, and practical advice (on getting a job, finances and benefits, for example) may be beneficial when caring ends, especially for spouse carers and others who have been heavily involved in their caring activities.
- Carers in the high risk groups should be counted in local health needs assessments to inform policy development, resource allocation and the commissioning of carer support. Explicit recognition and inclusion of carers in health improvement programmes could increase their effectiveness and acceptability.
- Services for disabled and frail older people should take account of the support needs of carers and their choices around caregiving, including alternatives to providing unpaid care. Carers should be actively involved in decisions about the care of the person needing care when planning discharge from hospital and in the community.
- Protocols in primary care and other settings for identifying carers at risk should be developed and tested to boost take up of carers' right to an assessment of their own needs.

- Primary care trusts should increase awareness in primary care settings of the role, contribution and needs of carers; improve carers' access to services; and commission carer services in partnership with social services and local carers' centres.
- Take-up of an incentive payment in the new GP contract to introduce a protocol for identifying carers should be monitored, and the level of incentive should be reviewed periodically.
- There is a need to evaluate the effectiveness, costs and acceptability of services to carers in reducing the adverse effects of caregiving, including use of direct payments to meet carers' own assessed needs, and measures enabling them to combine paid work with caring, or to find a job when caring responsibilities cease or permit.
- Health inequalities associated with caregiving should be monitored at the national level to track the impact of changes in the carer population, identify emerging needs, and inform policy.

Conclusions

Carers often have additional health care needs because of their caregiving responsibilities. Risk of psychological distress increases with intensity of caring activities. Adverse effects on carers' psychological well-being are most pronounced around the start of care episodes and when caregiving ends. Ongoing care increases the risk of recurring distress, and adverse health effects can persist beyond the end of caregiving.



Several groups of carers face increased health risk, especially those looking after a partner, and women providing long hours of care to a disabled child or parent in the same household. Although they form a minority of the carer population, these high risk groups provide the bulk of unpaid care.

Taken together, the findings underline the importance of health promotion, prevention strategies and service responses to the health care needs of carers. Accordingly,

- **Caregiving should be recognised as a public health issue.** This means that additional health care resources need to be allocated for developing carer support services and encouraging a more thorough going approach to promoting carers' health and preventing ill health.
- **Care giving should be on the agenda for reducing health inequalities.** This move would have two important consequences: first, it would require consideration of care giving alongside other social determinants when tackling health inequalities, and monitoring health trends and outcomes. Secondly, it would encourage key government departments to assess the health impacts of their policies and programmes on carers, and to consider whether and how they can reduce caring-related health inequalities.

The challenge is to develop policies, programmes and practices that are acceptable to carers and care recipients alike, improve the quality of both their lives, and are effective in alleviating and preventing the adverse health effects of caring.

About the research

The research uses data from the British Household Panel Survey (BHPS) covering the period 1991 to 2000. Each year, over 9000 adults living in a nationally representative sample of around 5000 private households in England, Scotland and Wales are interviewed. Neither the original collectors of the data nor the Data Archive bear any responsibility for the analyses or interpretations reported here. Full details of the BHPS can be viewed at <http://www.irc.essex.ac.uk/bhps/index.php>

The *General Health Questionnaire* was used to assess psychological distress.⁹ It asks respondents about their recent experience of twelve symptoms known to be indicative of anxiety and depression, social dysfunction, loss of confidence and self-esteem. The proportion reporting four or more symptoms is used to represent those who experience distress because that threshold indicates probable clinical diagnosis.

The research was carried out by Michael Hirst and funded by the UK Department of Health. The views expressed are those of the author and are not necessarily shared by any individual, government department or agency.

The full report, 'Health Inequalities and Informal Care', is available (price £3.50) from:

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