Caring in Later Life
Reviewing the Role of Older Carers
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Executive Summary

Considerable research has been undertaken to identify the needs and experiences of carers. However, much of it either regards carers as a homogeneous group or focuses on those in the 45–59 age group. Little specific attention has focused on older carers, despite the fact that they have unique needs which may have been hidden in previous research.

This review, commissioned by Help the Aged, with support from Carers UK, brings together existing evidence and supplements it with fresh analysis of the General Household Survey 1995, to draw out the particular needs of carers over the age of 60. The picture of older carers that emerges from this study is significantly different from that of carers overall.

This review suggests that more should and can be done to improve the health and quality of life of older carers and to develop a deeper understanding of the nature and consequences of caring in later life. The National Service Framework for Older People provides a unique opportunity for health and social services agencies to review the support they offer to older carers.

Review findings

- Nearly 2 million carers (out of an estimated 5.7 million carers in the UK) are aged over 60. Four-fifths of them are aged 65–74 and one-fifth are aged 75 and over. The proportion of male to female carers is about 50/50.
- The number of older carers is increasing, and they form an increasing percentage of all carers, presumably as a reflection of policies designed to enable older ill or disabled people to remain in their own homes for as long as possible. This pattern is expected to continue.
- Older carers predominantly look after older people. One-third of older carers support spouses, one-fifth care for parents or parents-in-law, one-fifth for friends and/or neighbours and under one-fifth care for ‘other relatives’. Just under one-tenth are parents caring for an adult child with a disability.
- Over 40% of older carers live in the same household as the person they care for. The vast majority of these are spouses. This care is often interdependent in nature and the carer/cared-for roles are sometimes indistinguishable from each other.
- Those caring outside the home offer care to a number of different groups: parents, friends/neighbours and ‘other relatives’. They tend to care for fewer hours per week, to offer more practical support and to be involved on a more limited basis.
- Older carers are likely to offer higher levels of personal and physical care than other carers. A third of older carers are
providing personal care such as washing and dressing to the person they care for.

- Over two-thirds of those being cared for by older carers have physical disabilities. Just over one-tenth have ‘physical and mental impairments’, just under one-tenth have ‘mental impairments only’.

- Nearly 40% of older carers are providing support for over 20 hours a week. Half of those are providing care for over 50 hours a week.

- The older a carer is, the more likely they are to be spending long hours providing care. Whilst about one-fifth of carers aged 60–74 provide 50+ hours per week, one-third of carers aged 75 and over provide this amount of care. This suggests that significant numbers of fourth age older carers are providing very high levels of personal care.

- Many older carers are not only caring intensively for many hours per week, but they have been caring over a long period of time. Well over one-quarter of older carers have been caring for 10 years or more. There is a particular concern about carers aged 75+ who are likely to be in poor health themselves.

- The consequences of caring in older age are far reaching and long-term:
  - Older carers are one of the poorest groups in the UK. In particular, if caring begins before retirement age it impacts upon the carer’s earning capacity and in turn pensionable status. There are also additional costs related to caring.
  - The benefits system does not recognise the effects of long-term caring and long-term poverty amongst older people. Older carers may have little access to welfare rights advice.
  - Many older people are caring for others while suffering from a serious health condition themselves. Over half of older carers report a long standing illness or disability.
  - Older carers experience increased stress and depression. Between one-third and one-half of all spousal carers of people with dementia suffer from depression.

- One-third of intensively involved older carers who have been caring for between 5-14 years have not had a break of two days or more since they started caring.
  - Services associated with improved well-being among carers are respite care, day care, community nursing and sitting services.
  - Carers also benefit from contact with other carers. Carer support groups may be particularly valued by carers of people with dementia.
  - Satisfaction with the help received from family and friends is one of the most significant ways in which carers manage. Networks seem to act as ‘stress buffers’ for carers and protect them against social isolation.

- Many older carers are physically and socially restricted by their caring commitments. They become detached from their interests and social networks.

- Older carers welcome support from health and social care services, but the policies which target help towards those who live alone overlook their needs. Three-quarters of older carers living with the cared-for person receive no regular visits from health or social services.

- Older carers from minority ethnic communities. There are many gaps in the present understanding of the structure and dynamics of informal care within ethnic communities. In particular little is known about the nature and the experience of informal care amongst black communities.
  - Evidence suggests that the need for support among older carers from minority ethnic communities is as great – or greater – than it is for white carers, particularly for respite care.
  - Linguistic, economic and cultural factors can adversely affect the take-up of health and social care services by older people and older carers.
  - Older carers from minority ethnic communities looking after a relative with dementia seem to have particular difficulties accessing appropriate services.
Rural carers. Current research identifies rural carers as ‘hard to reach’. Evidence suggests that rural carers receive fewer services because they are often dispersed across a wide area. Myths about the self-help nature of rural communities also limit investment in services.

Former carers, who have looked after someone before that person died or was admitted to a care home, require special consideration.

Most people want to remain involved after their relative is admitted to a care home. Many remain ‘a carer’ in an emotional and psychological sense. In spite of this, care staff frequently fail to involve carers in the care of their relative.

The impact on the carer following the death of the cared-for person has received very limited research attention, although it is evident that the transition from caring intensively to not caring at all is very emotionally unsettling and difficult.

Recommendations

It is evident that more overall support is needed for older carers. The cumulative impact of the physical, financial, social and emotional consequences of caring in older age is insufficiently understood and requires further work. Policies and services need to work preventively to alleviate the impact of these consequences on carers.

Based on the evidence of this study, we recommend the following action to enhance the status and quality of life of older carers.

Policy

Tackling poverty among older carers

- Older carers need access to sufficient financial support. Age barriers associated with financial benefits are discriminatory in their effect and should be removed.

- Outreach work and points of access for benefits advice are needed.

At present older carers do not receive Invalid Care Allowance. The age barrier should be removed (in line with government plans) so any carer of any age can apply for ICA.

The benefits system does not recognise that caring takes place over different periods of time or that different levels of care may be needed. Two levels of ICA could be created; a lower level paid to carers for the first three months of caring and thereafter to carers giving fewer hours of care; and one at the level of the basic retirement pension available after three months to all carers giving greater levels of care.

The level of Invalid Care Allowance should be raised in line with long-term benefits such as Invalidity Benefit and Retirement Pension.

There is a strong view that carers should be compensated for the actual costs of caring. This could take the form of a carer’s allowance which could be non-means tested and paid to all carers in all circumstances.

As credits for contributions to the basic state pension are related to the qualifying criteria for ICA, measures to increase access to ICA would also improve pension rights for carers including older carers.

Proposals aimed at improving pensions for women, recognising that they make up the majority of those whose pensions are affected by broken employment and reduced contributions, could be extended to all carers. These measures include improving basic pensions; scrapping contributions for pensions and linking increases in state pensions to earnings not prices.

Improving housing

- Poor housing is strongly related to long-term poverty and is more prevalent among those aged 75 and over. Improving housing is a key aim of the Government’s initiatives to support carers. Good accommodation can make a considerable difference to the lives of disabled people and their carers, as do adaptations such a stair lift.
Injury prevention and health promotion

- Many of the physical injuries suffered by carers could be prevented by the provision of training in lifting and moving the person they care for. Sometimes carers will need special equipment installed in their home to help them do this.

Services

- Local authorities need to be proactive in seeking out and working with older carers to support them throughout their caring role. Preventive early intervention services for older carers should be developed.
- Agencies should take account of the changing pattern of caring and review the support they offer to older carers and to older couples. They should ensure:
  - that older people living at home as part of a couple are not discriminated against in the provision of home care, community nursing and GP services;
  - that older carers automatically receive a Carer's Assessment in their own right (in line with the Carers and Disabled Children Act 2000). Assessments should address changing needs quickly and flexibly;
  - that older people and their carers have equal access to respite and sitting services and other forms of support;
  - that older carers are enabled to retain their own networks of friendship and interests, to relieve stress and ensure they still ‘have a life’.
- Local authorities should be proactive in developing the option of offering older carers direct payments as a substitute for direct services (as allowed under The Carers and Disabled Children Act (2000)) so that it is a realistic and positive alternative option to receiving services commissioned by the local authority.
- Partnerships between care homes and carers and services for former carers should be developed.
- New approaches to meeting the needs of rural carers should be developed – for example, developing outreach work, providing transport, and publicising services effectively.
- Services for older carers from minority ethnic communities should be developed which are culturally and socially acceptable.

Areas for further research

The review highlights a number of research deficits. In particular, attention needs to be given to:

- The needs and experiences of carers about whom little is known:
  - older couples
  - older carers from minority ethnic groups
  - older gay and lesbian carers
  - former carers
- The finding that older people provide a lot of care to ‘other relatives’. Changing family patterns may be creating new bonds and obligations between individuals (between ex- or step-relatives for example) which need to be acknowledged and supported
- The finding that older people provide significant amounts of help to others outside their own families. The significance of friendship and neighbourliness in the lives of older people has not been widely explored. The role of older people in providing the glue that holds communities together has significant implications for policies of urban regeneration and neighbourhood renewal
- Understanding the experience of ‘being an older carer’
- Qualitative data about the process and meaning of spousal care.

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