The Silent and Unseen Helper
Have Carers been Forgotten?

N M Speirs
University of Edinburgh
Definitions

Unpaid carers

'Individuals who care for a friend, relative or neighbour without receiving paid income in addition to income received through the benefits system'

A carer is legally defined as;

'Someone who provides substantial amounts of care on a regular basis for either an adult or a child, where that adult or child receives, or is eligible to receive, support services under the Social Work (Scotland) Act 1968 (section 12AA) or the Children's (Scotland) Act 1995 (Section 24)'

The Scottish Executive (2005), The Care 21 Report: the Future of Unpaid Care in Scotland
The Scottish Government (2010), Getting It Right For Young Carers: The Young Carers Strategy for Scotland: 2010 - 2015 Summary
http://www.gov.scot/Publications/2010/08/16095043/1
Definitions

While a young carer is;

‘a child or young person aged under 18 who has a significant role in looking after someone else who is experiencing illness or disability.’

Young adult carers are aged between 16-24. Their experiences are often separated into those that are;

• 16-17 years of age (children)
• 18-24 (adults)

The Scottish Executive (2005), The Care 21 Report: the Future of Unpaid Care in Scotland
The Scottish Government (2010), Getting It Right For Young Carers: The Young Carers Strategy for Scotland: 2010 - 2015 Summary
# Numbers

<table>
<thead>
<tr>
<th></th>
<th>Number (2001)</th>
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<tr>
<td>England</td>
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<td>5,430,016</td>
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<td>Scotland</td>
<td>481,579</td>
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<tr>
<td>NI</td>
<td>185,086</td>
<td>213,980</td>
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<td>Wales</td>
<td>340,745</td>
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<td>UK Total</td>
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1.4 million people provide over 50 hours of unpaid care per week.

The care provided unpaid, by the nations’ carers is worth an estimated £119bn per year – considerably more than total spending on the NHS.

58% of carers are female and 42% are male.

when age is accounted for, Black, Asian and minority ethnic families are more likely to provide care for older or disabled loved ones.

Half of working age carers live in a household where no-one is in paid work.

Carers UK (2014), Policy Briefing - Facts about carers
Who is cared for?

Carers UK report via the NHS that;

- Most carers (40%) care for their parents or parents-in-law
- Over a quarter (26%) care for their spouse or partner.
- People caring for disabled children under 18 account for 8% of carers and 5% of carers are looking after adult children.
- A further 4% care for their grandparents and 7% care for another relative.
- Whilst the majority care for relatives, one in ten carers (9%) care for a friend or neighbour.

Carers UK (2014), Policy Briefing - Facts about carers
Who is cared for?

Carers UK report via the NHS that:

• 58% of carers look after someone with a physical disability
• 20% look after someone with a sensory impairment
• 13% care for someone with a mental health problem
• 10% care for someone with dementia.

Carers UK (2014), Policy Briefing - Facts about Carers
Financial Assistance

Carer’s Allowance is the main benefit for carers. Individuals may be eligible if they meet all the following conditions:

• Look after someone who gets a qualifying disability benefit.

• Look after that person for at least 35 hours a week.

• The carer is aged 16 or over.

Carers UK (2014), Carer’s Allowance Factsheet.
Financial Assistance

• The carer is not in full-time education.

• The carer earns £102 a week (after deductions) or less.

• The carer satisfies UK residence and presence conditions.

However, £1 billion in Carer’s Allowance goes unclaimed each year.

Carers UK (2014), Carer’s Allowance Factsheet.
35 hours a week

What might 35 hours of care look like?

• Time spent physically helping the person

• Time you spend ‘keeping an eye’ on the person you look after, eg preventing them coming to harm by walking out of the house

• Time spent doing practical tasks for them, eg cooking

• Time taken doing practical tasks, even if you don’t do them in the presence of the person you are looking after may also count

• Time spent travelling to and from the person you care for does not count.

Carers UK (2014), Carer’s Allowance Factsheet.
35 hours a week

- 93% said they provide practical help such as preparing meals, doing laundry or shopping.
- 87% provide emotional support, motivation or keeping an eye on someone either in person or by phone.
- 85% said they arranged or co-ordinated care services or medical appointments.
- 83% said they manage paperwork or financial matters for the person they care for.
- 71% of carers provide personal care like help with washing, dressing, eating or using the toilet.
- 57% carers were helping the person they care for with their mobility – getting in and out of bed, moving around or getting out of the house.

Carers UK (2014), State of caring survey
Challenges

Carers face multiple challenges to their health, wellbeing and quality of life simply because they are caring.

These are exacerbated by poverty, loss of employment, accumulating unmanageable debt and lack of services to support them in their caring role.

Carers are a third more likely to be in poor health than non-carers.

There are more than 660,000 people in Scotland giving unpaid care to friends or family, and this number is rising. Many are unaware of their rights, leaving millions of pounds of carers’ benefits to go unclaimed.
Breaking point

Carers UK report that 60% of carers are at ‘breaking point’.

50% of carers at breaking point had suffered a physical injury or seen deterioration in their physical health – twice the proportion of carers who said they had not been in crisis.

75% said they could not get a good night’s sleep, compared to 50% of carers who had not reached breaking point.

90% said they were stressed compared to just over half of those who were not in crisis.

Carers Scotland (2014), carers rights guide 2014-15
Carers UK (2014), Carers at breaking point.
Breaking point

79% reported anxiety compared to under half of carers who said they were coping.

Carers who say they have reached breaking point are twice as likely to say they are socially isolated by being unable to leave the house.

Nearly two thirds had suffered from depression as a result of caring.

Carers Scotland (2014), carers rights guide 2014-15
Carers UK (2014), Carers at breaking point.
Identifying carers

Carers are often only identified and supported when they are in crisis.

Carers UK believe that a duty on health and education bodies, like GP surgeries, hospitals, schools and colleges, would ensure earlier identification, advice and support.

The Scottish Government ‘recognises that identification of carers remains a challenge’ and have suggested in a consultation document;

‘there should be no legislative requirement for GP practices and local authorities to maintain a Carers’ Register’.

The National Carer Organisations believes that there should be a legislative requirement for GP practices to develop a register of carers within their practice.

Carers Scotland (2014), carers rights guide 2014-15
Carers UK (2014), Carers at breaking point.
Carers’ Legislation – consultation on proposals
The literature

Informal caring activities are often hidden, part of the private domain of the family, founded on love, attachment, duty and reciprocity, not on monetary exchange (Becker and Silburn, 1999).

However, unpaid caregiving is labour; it is care work (Brown and Stetz, 1999).

Recognizing these activities as care work is to politicize and to make public the activities, roles, value and outcomes that characterize unpaid and family-hidden caregiving, and to identify these issues as concerns for social and public policy, and for social development.

*Becker, S. Global Perspectives on Children’s Unpaid Caregiving in the Family, Global Social Policy 2007 1468-0181 vol. 7(1): 23–50;*


The literature

Children who undertake substantial or regular caring can experience significant restrictions in their development, participation and opportunities, and educational attainment, even when there may be some ‘positives’ associated with caring – such as enhanced coping mechanisms, the development of life, social and other skills, maturity, a sense of purpose and closer attachments.


The literature

Some UK commentators assert that there are no scientifically ‘proven’ differences between what young carers do within the family compared with other groups of children.

Morrow (2005) suggests that a way of differentiating what young carers do from other children is to examine tasks as Instrumental Activities of Daily Living (such as taking out the rubbish or cleaning), and as Activities of Daily Living (such as moving relatives around the house, dressing, toileting, showering and bathing, getting them in and out of bed).

Morrow (2005: 58) argues that ‘non-carers will not bath, shower and toilet a sibling or parent’.


The literature

Pakenham et al report on the psycho-social impact on young carers

*Caregiving tasks and responsibilities.*

Young caregivers take on a wide range of tasks including domestic care, general support, emotional support, personal care and child care for siblings (Dearden & Becker, 1995; Lackey & Gates, 2001). Some young caregivers have reported that others expect them to take on these tasks (Aldridge & Becker, 1993a), whereas others report a self-imposed sense of duty to undertake these roles because they perceive there to be no other choice (Bursnall et al., 2005).
The literature

Compulsion to care.

Many young caregivers have reported that they feel that they should stay in close proximity to their parent with an illness or disability and feel compelled to remain constantly responsible for their parent’s care (Bursnall et al., 2005). This compulsion or commitment to caring for their parent is sometimes driven by guilt. For example, young caregivers have described feeling guilty when they participate in non-caregiving activities (Bursnall et al., 2005).

Isolation.

Young caregivers in several studies have reported feeling isolated with respect to their caregiving role and the lack of both informal and formal support (Aldridge & Becker, 1993). The focus of most services is the care receiver; hence, many young caregivers have expressed their need for social support, primarily in the form of someone to talk to and information regarding both their caregiving duties and their parent’s illness or disability (Aldridge & Becker, 1993b).
Caregiving is time consuming and may prevent young caregivers from engaging in developmentally appropriate activities (Aldridge & Becker, 1993a). For example, young caregivers have reported missing school or experiencing difficulties concentrating at school owing to the strain of their caregiving responsibilities (Banks et al., 2002; Siskowski, 2005). Young caregivers have reported limited involvement in recreational and social activities and are less likely than most children to have their friends visit them at home because of discomfort regarding their parent’s illness or disability (Aldridge & Becker, 1993a; Lackey & Gates, 2001).
The literature

Distress.

Young caregivers have reported distress associated with their caregiving including sadness regarding their parent’s illness or disability, resentment that they have to provide care for their parent, guilt when not providing care for their parent, embarrassment about their parent’s illness or disability, and worry about their parent (Aldridge & Becker, 1993b; Bursnall et al., 2005).

Young caregivers have reported being hyper vigilant about their parent’s health and may continuously monitor their parent for signs of physical or emotional changes (Aldridge & Becker, 1993b). Indeed, researchers who have examined the impact of parental illness or disability on children have found elevated distress and related problems in several domains including anxiety, depression, intrusive thoughts, behaviour problems, and somatization (e.g., Compas et al., 1994; Fals-Stewart et al., 2004; Lester, Stein, & Bursch, 2003).
Worries

Cree (2003) reported on the worries that young carers were experiencing. They pinpointed a range of worries, some of which are commonly experienced by adolescents. Other worries can be wholly explained in terms of their lives as young carers;

81% worried about the health of the person they care for

67% worried about their own health

58% worried about the behaviour of the person they care for

53% worried about who will look after them in the future
One of the young carers (14 yo) explained;

‘Just life, it’s constantly worrying about my Mum, wondering how she is cause if she does, like, take a fit – cause she takes fits a lot – she’s only had a couple in the last couple of months, but if she takes a fit she really canny do anything, she canny get out of bed and that, and we are all at school and my Dad’s away to work so sometimes I phone home to see if she’s all right . . .’
Discussion

Curriculum for excellence is charged with producing ‘confident individuals’.

Can it deliver ‘a sense of physical, mental and emotional well-being’.

Will teachers, guidance staff and senior managers be able to deliver this for carers?

Is it reasonable to ask?
Higher Education

Using Tinto’s model of retention, to consider the position of the carer as an undergraduate student;

- **Dispositions** individuals enter with:
  - Intention
  - Commitment

- **Experiences** after entry:
  - Adjustment
  - Difficulty
  - Congruence
  - Isolation

- **External forces impinge on experience within institute**:
  - Obligations
  - Finances
Higher Education

The NUS produced their first report in carers in HE in 2013.

No national, comprehensive data exists on the numbers of students in further and higher education who are also carers.

Mature students are much more likely than young students to be student carers.

Many young adult carers do not transition between stages of education in the traditional, linear ways.

One of the key difficulties that student carers face in transition (and beyond) is managing the process of disclosing their caring responsibilities to their institution. Most participants waited until there had been an impact on their learning before disclosing to a lecturer or tutor, or until it came up naturally in conversation.

NUS (2013), Learning with care - experiences of student carers in the UK
36% of student carers felt able to balance their commitments, as compared to 53% of students without caring responsibilities.

The lack of monitoring data on student carers also means that conclusions are difficult to reach on the retention rates of student carers.

Over half (58%) of student carers had seriously considered leaving their course, compared to 39% of students without caring responsibilities.

A small but growing number of students’ unions are introducing carers’ groups as a way of providing support and social activity for student carers, sometimes grouping them together with student parents.

NUS (2013), Learning with care-experiences of student carers in the UK
Discussion

What are your recommendations?