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# What do we know about older former carers? Key issues and themes

Mary Larkin & Alisoun Milne

## Abstract

Despite a significant growth in the number older former family carers they remain largely invisible in carer-related research and literature. To begin to address this deficit, a four-stage literature review was conducted to identify existing knowledge about older former carers. Narrative synthesis of the findings yielded five themes - the concept of 'older former carer', the legacies of caring, influences on the legacies of caring, conceptualising post-caring, and support services for older former carers. Critical analysis of these findings suggests that existing evidence has a number of strengths. It highlights the terminological and conceptual confusion in the field, identifies the profound financial and health-related legacies older former carers' experience, the factors which shape these legacies and some of the complexities of bereavement older former carers face. The support needs of older former carers are also illuminated. However, the field is characterised by key weaknesses. The evidence base is fragmented and uneven. In part this reflects lack of definitional consensus and in part the fact that there is much more evidence about some sub-groups, such as carers of relatives admitted to a care home, than others. Methodology-related weaknesses include small sample sizes and a focus on a single, often condition-specific, group of older former carers. An overarching criticism relates to the narrow conceptual /theoretical purview. As post-caring tends to be viewed as one of the final temporal 'stages' of the carer's 'caregiving career', a bifurcatory model of carer/former carer is created i.e. that a carer actively provides care and a former carer is no longer caring. This constructs being a former carer – namely formerity - as a single fixed state failing to capture its dynamic and shifting nature and constrains the potential of research to generate new knowledge and extend understanding.

**Key words** older former carers, carer research, post-caring, legacies of caring, support needs, knowledge generation

## What is known about this topic

- There is a growing interest in former carers
- There is recognition of the growth in the number of older carers

## What this paper adds

- The increase in the number of older carers inevitably means a growth in the number of older former carers and yet this population are largely invisible in carer-related research and policy
- Existing research shows that older former carers experience particular post-caring legacies and have a range of ill-recognised support needs
- The current evidence base relating to older former carers is limited by a range of methodological weaknesses and a narrow conceptual scope that constrain the potential of research to generate new knowledge and extend understanding

## **Introduction**

It is well documented that there are increasing numbers of family carers both nationally and internationally (OECD 2011, Pickard 2015). Although the consequential greater numbers of ex or former carers is far less recognised, there are signs that post-caring is beginning to have a more visible public profile. Estimates of the number of carers who cease 'caring' each year for example, are beginning to emerge (Carers UK 2014a, Hirst 2014). Recent health and care policies also make reference to former carers' support needs (NHS England 2014, Carers UK 2014a) and a limited body of research is now developing (Anonymous 2009, Cronin *et al.* 2015, Cavaye & Watts 2016).

In common with many other countries, around a third of all carers in the UK are now aged 65+ years and in both absolute *and* proportional terms their number of older carers is increasing (Age UK 2016). Despite the fact that potentially a third of all former carers are 'older former carers' they remain largely invisible in carer-related research. This paper is seminal in that, for the first time, it illuminates this under-explored but growing subgroup by offering a unique review and critique of 'what is known' about older former carers. Its synthesis of existing research not only makes an important contribution to national and international knowledge about older former carers specifically, but also to the wider body of knowledge about former carers. Furthermore, such a review is of relevance to ageing societies across the globe and to gerontology.

Throughout the paper, reference is made to the universal literature about the caring post-caring experience. Whilst every attempt has been made to include international literature in the review, for reasons of brevity and consistency, examples of policy and practice are drawn from the UK.

## **Review Methods**

A review of the existing literature on older former carers, comprising four stages (see Figure 1) was conducted between February 2015 and February 2016 and updated December 2016. The overarching search question was "What is known about older former carers?"

The first stage involved a search for literature on former carers generally. This stage involved an extensive search of relevant databases including: Social Care Online, Social Policy and Research, Scopus, PsychINFO, HMIC, ASSIA (Applied Social Sciences Index and Abstracts), IBSS (International Bibliography of the Social Sciences) MEDLINE, Embase, CINAHL Plus and AMED.

In order to maximise inclusion of all relevant literature, key search terms were varied and status and roles researched. As Table 1 shows, a wide range of combinations of carer, caring, caregiving, caregiver and the prefixes former, ex, past, post and bereaved were used. The search strategy included the use of Booleans. Grey literature was identified via article reference lists and the authors' knowledge exchange networks.

**Table 1: Key search terms**

former carers	former caregivers				
ex-carers	ex carers	ex-caregivers	ex caregivers		
past carers	past caregivers				
bereaved carers	bereaved caregivers	bereaved AND former carers	bereaved AND ex-carers	bereaved AND ex-caregivers	bereaved AND former caregivers
bereavement AND carers	bereavement AND caregivers	bereavement AND former carers	bereavement AND ex-carers	bereavement AND ex-caregivers	bereavement AND former caregivers
postcaring	post caring	post-caring	postcaregiving	post caregiving	post - caregiving
postcaring experience	post caring experience	post-caring experience	postcaregiving experience	post caregiving experience	post - caregiving +experience
postcaring life	post caring life	post -caring life	postcaregiving life	post caregiving life	<a href="#">post - caregiving life</a>
postcaring transition	post caring transition	post -caring transition	<a href="#">postcaregiving transition</a>	<a href="#">post caregiving transition</a>	<a href="#">post-caregiving transition</a>
caring transitions	caregiving transitions				

All key search terms were applied to literature published since 1985; this date was chosen because it marked the first use of the term ‘ex-carers’ in the UK’s General Household Survey, thereby reflecting the emergence of an identifiable group who had ceased active caring. Whilst non-English language articles were intentionally excluded from the review, as a consequence of terminological variation, omission of a small amount of literature may have occurred. Due to the nature of former carer research i.e. it is relatively small-scale, and funded and carried out by a number of organisations, some grey literature may also have been missed.

The search yielded 176 items. The second stage involved hand searching these items for those that focused on older former carers. Whilst the initial intention was to base the definition of ‘old’ on the criteria used to define older carers, these was discarded in the light of the evidence that there is no set definition of an older carer- definitions vary from 50+ to 80+ (Anonymous, 2002, Carers Trust, 2015, Manthorpe , Moriarty , & Cornes , 2015, Greenwood & Smith 2016) . As 60+ is routinely used in data collection (United

Nations Department of Economic and Social Affairs, 2013), this was used to select items about 'older former carers'.

In the third stage, the 45 items identified in Stage 2 were analysed using the Critical Appraisal Skills Programme (CASP, 2013) in relation to their rigour, methodology and credibility. The results of the appraisal of individual items were recorded on an excel spreadsheet together with a brief synopsis of each item. Once all the items had been critically appraised, the 40 items that met the quality and relevance criteria (integral to the appraisal questions) were listed in chronological order on a 'Summary table' together with key information, such as author(s), date of publication, main findings and strengths and weaknesses. During the fourth stage of the review, this information was then topically synthesised with the aim of identifying themes. In order to capture the breadth of the review, narrative synthesis tools and techniques were adopted (Dixon-Woods *et al.* 2005, Wilson & Cordie 2013).

The five themes that emerged are discussed below. Limitations imposed by academic publishing meant that the number of references cited in these discussions had to be a strategically determined. Hence only selected references<sup>1</sup> are used.

## Themes

### *The concept of 'older former carer'*

Considerable terminological inconsistency characterises this topic area. This can be attributed to two main factors. The first is that the concept of 'former carer' is drawn from the concept of 'carer', a term now widely understood, but still contested. The fact that 'carer' is not recognised or 'owned' as a label by as many as half of those who actually 'do caring' is significant (Carers UK 2006, Lloyd 2006, Molyneaux *et al.* 2010). That carers do not belong under one definitional umbrella and are a diverse population also contributes to its differential usage. Further complexity arises in relation to older carers because some may simultaneously be service users, for example an older dementia carer with their own physical health problems (Rapaport & Manthorpe 2008, Anonymous 2014).

The second cause of confusion arises from evidence that there appears to be six possible routes to becoming an older former carer (see Table 2). This suggests that the term subsumes a number of different populations.

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<sup>1</sup> A full list of references are available from the Corresponding author upon request

**Table 2. Routes into Older ‘Former’ Caring**

When the cared-for person:
1. dies
2. is admitted to a hospital
3. is admitted to a hospice
4. is admitted to long-term care (i.e. permanently admitted to a nursing or residential care home or continuing care in hospital)
5. recovers from their health problem (e.g. hip fracture)
6. goes into remission (e.g. for cancer patients)

Research about these older former carer populations is uneven, providing no clear indication of their relative size. There are many more studies focussing on those who shift into ‘former’ caring as a consequence of the cared-for person’s death (Route 1) and/or admission to long-term care (Route 4) than there are studies about routes involving the cared-for person’s recovery or remission (Routes 5 and 6). This review inevitably reflects this proportional bias in the number of studies.

#### *The ‘legacies of caring’*

That caring is often correlated with negative outcomes for carers is widely acknowledged (Anonymous 2014, Purkis & Ceci 2015). The review showed that these outcomes do not end when older carers’ ‘active caring’ ceases and manifest themselves in the form of a number of adverse and lasting post-caring legacies. For example, care-related expenses (e.g. additional laundry, heating) are known to deplete carers’ savings and increase debt on a long-term basis (Black *et al.* 2010, Carers UK 2014a, 2014b). Older former carers’ financial hardship may be deepened by the withdrawal of carer-related benefits; these can only be claimed by ‘active’ carers (Brown & Stetz 1999).

Another cause of income reduction is being obliged to leave paid work prematurely to undertake long-term caring that extends into later life (Age UK & Carers UK 2016). This is estimated to represent a loss of at least £11,000 per annum per carer (King & Pickard 2013). Time out of the workforce reduces pension contributions, compromising post retirement income (Cronin *et al.* 2014, Carmichael & Ercolan 2016).

Long-term and intensive caring has a well-established link with increased risk of social isolation and creating, or deepening existing, physical and psychological health problems (Hutton & Hirst 2000, Eloniemi-Sulkava *et al.* 2002, Lavela & Ather 2010). These are often amplified post-caring (Anonymous 2009, Princess Royal Trust for Carers, 2011). Physical health issues that persist into post-caring life include back problems, exhaustion, skin disorders, infections, arthritis, high blood pressure and cardiac problems. In some cases, new health problems develop after caring ends, for example sleep and eating problems and increased alcohol consumption (Anonymous 2009; Grant *et al.* 2002; Rosenbloom & Whittington 1993).

The picture for psychological well-being post-caring is more complex. The majority of research suggests that older former carers experience significant distress, especially in

relation to depression (Hirst 2005, Smith *et al.* 2014). Sources of distress include loss of self-esteem, role and purpose and negative feelings such as anger, guilt, and a sense of failure (Bass and Bowman 1990, Schulz *et al.* 1997, Gaugler *et al.* 2011). Interestingly though, some evidence suggests that older carers of relatives with Alzheimer's Disease (AD) may have higher levels of well-being than non-carers after the cared-for person's death. This may be linked to a 'sense of relief' (Schulz *et al.* 1997, 2003) and/or an increase 'in (carers') sense of mastery in terms of feeling confident to handle their life alone (an important component of psychological well-being) as compared with their pre-bereaved state' (Seltzer & Li 2000, p. 166).

### *Influences on the 'legacies of caring'*

A number of the influences on the 'legacies of caring' that emerged from the review have roots in 'active caring'.

Higher levels of depression and health problems amongst older former carers are correlated with more problematic caring experiences, such as longer and/ intensive caring<sup>2</sup>; dissatisfaction with support received; isolation and/or loneliness; and a strained relationship with the cared-for person (Bass & Bowman 1990, Eloniemi-Sulkava *et al.* 2002, Boerner *et al.* 2004, Li 2005, Burton *et al.* 2008, Pruchno *et al.* 2009, Greenwood *et al.* 2013). Feelings of guilt post-caring are reduced by confidence in the quality of formal care that was provided for the cared for person (Aneshensel *et al.* 2004, Gaugler *et al.* 2011).

For carers of those who move into a care home, involvement in caring post-admission is an important influence on their sense of self and identity (Nolan *et al.* 1996, Lloyd & Stirling 2001). Most adopt a 'new' caregiving role which continues until the cared-for persons' death (Dellasega & Nolan 1997, Davies & Nolan 2006). 'New' aspects of this caring role include: visiting their relative regularly, interacting with other residents, relatives and staff, taking part in social events, and monitoring the quality of care. Other aspects may be variations on their previous caring role e.g. helping to provide personal care, offering emotional and practical support, promoting their relative's identity and managing their money (White 1994, Seltzer *et al.* 2001, Davies & Nolan 2006). However, some carers, such as spousal dementia carers, (particularly husbands) have been found to struggle with adopting a new identity post-admission (Anonymous 2003).

Bereavement can be more challenging for carers than non-carers and have longer term emotional consequences (Mullan 1992, Aneshensel *et al.* 2004). One explanation is that carers - unlike those whose relatives die without having required family care - often experience many years of 'anticipatory loss' (e.g. loss of freedom, hopes for the future) linked to a deterioration in the care recipient's health. This process can give rise to a multitude of complex emotions, both during caring and after death (Wuest *et al.* 2000, Orzeck & Silverman 2008).

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<sup>2</sup> Intensive caring is defined as caring for at least 20 hours per week

A number of influences on bereaved older carers' emotional well-being have been identified. A close relationship with the care recipient, 'good family functioning', higher levels of self-esteem, socio-emotional support and higher levels of education and income are all protective of the bereaved older carers' emotional well-being (Aneshensel *et al.* 2004, Burton *et al.* 2008, Guerra *et al.* 2016). In contrast, higher levels of distress amongst bereaved older carers' appear to be linked to specific negative care-related influences including emotional strain, role overload, lack of support during caring and dissatisfaction with caregiving, (Pruchno *et al.* 2009; Boerner *et al.* 2004).

Experiences are also influenced by the cared-for person's place of death. Over time the wellbeing of older carers whose relative is admitted to long-term care and subsequently dies appears to improve to a greater extent than older carers whose relative dies in the community. This finding may be explained by the fact that carers' whose relative is in long-term care may come to terms with a number of the psychological challenges associated with bereavement e.g. separation, loneliness, loss, *before* their relative dies. This process - conceptualised as 'anticipatory grief' or quasi-widowhood - may prepare, or even protect, carers from some of the negative effects of the cared-for person's actual death (Collins *et al.* 1993). That dementia carers are often exposed to this two stage 'bereavement' process may explain why they report higher levels of improved well-being over the longer term compared with other groups of carers (Nolan *et al.* 1996, 2003, Davies & Nolan 2004, 2006).

### *Conceptualising post-caring*

There are a number of conceptual models of caring which incorporate a post-caring phase. These are only applicable to those who are former carers because of the death (i.e. Route 1) or admission of their relative into long-term care (i.e. Route 4). The most long-standing model conceptualises caring as a continuum from pre-caring through to post-caring: post-caring is seen as integral to the 'overall caregiving career' (Orzeck and Silverman 2008, p. 212) (Schulz *et al.* 1997, Brown & Stetz 1999, Aneshensel *et al.* 2004, Cavaye and Watt 2016).

This approach is illustrated in Brown & Stetz's (1999) study of carers of people with life-threatening illnesses. They refer to the 'labor of caregiving'; caring 'begins' at diagnosis or when the care recipient first becomes symptomatic, ill, or debilitated from treatment and continues on for several months after the person dies. It comprises four phases - becoming a caregiver, taking care, midwifing the death, and taking the next step.

During the 1990s, research about dementia care took a similar path, identifying caring as taking place in a number of temporal stages - beginning pre-diagnosis and ending when the person with dementia is admitted to institutional care (Nolan *et al.* 1996). More recent work on carers of an older relative who has been admitted to a care home identifies three additional phases. The first two occur pre-admission - the 'decision making process' and the practical arrangements for 'moving into the care home'. The third phase - 'making it better' - occurs post-admission and involves the carer establishing a new 'carer role' referred to above (Davies & Nolan 2004, 2006).



Several studies specifically explore the nature of the post-care stage(s). In her work about bereaved carers, Anonymous (2009) develops the concept of a post-caring trajectory comprising three phases. The first two are the 'post-caring void' and 'closing down the caring time' whilst the third - 'constructing life post-caring' - involves getting 'life together' again, during which former carers reconnect with their families, pursue their interests, and take up new activities. Although Cronin and colleagues (2015) do not use the term 'trajectory' in their study of former carers whose relatives have either died, or been admitted to a hospice or nursing home, they conceptualise the post-caring period as a time of being 'between worlds' during which former carers experience three iterative interrelated transitions. These transitions have congruence with Anonymous' (2009) findings and are referred to as 'loss of the caring world', 'living in loss', and 'moving on'.

#### *Support services for older former carers*

Whilst research suggests that some interventions may improve the emotional wellbeing of former carers more generally their effectiveness in addressing the needs of older former carers is unexplored (Anonymous *et al.* 2004, Anonymous 2007, Relatives and Residents Association 2012, Greenwood *et al.* 2013, Greenwood & Habibi 2014).

## **Discussion**

Existing research has a number of strengths, primarily in relation to the profile, financial and health-related legacies, and the support needs of older former carers. More specifically, it provides insights into the role of caring experiences in shaping post-caring life and explores the post-caring roles older former carers adopt. Post-caring is conceptualised as an integral part of the carer's caregiving 'career' and/or as a temporal stage in the caregiving trajectory.

There are also significant deficits. A primary weakness relates to the lack of consensus about who an 'older former carer' is and how they are defined. Although six sub-populations of 'former carers' were identified, the evidence about the different sub-groups is very uneven. Some groups of older former carers are far less visible than others, namely those who become former carers when the cared-for person goes into hospital, recovers from their health problem or goes into remission. Other groups are invisible altogether. For example, those who do not 'fit' the traditional model of 'family' such as ex-partners, and those who are 'former carers' because they have chosen *not* to continue to care or have left caring behind.

Specific deficits relate to methodology. That most studies are small-scale and conducted by different bodies undermines the additive capacity of research. There is also minimal cross-fertilisation of ideas or expertise. Studies are (often) limited geographically; use small and unrepresentative sample groups and/or focus on one particular group of older former carers (e.g. those who have cared for a relative with dementia); do not allow relationship differentiation with the cared-for person (e.g. spouse, son or daughter); fail to identify 'serial' former carers (i.e. carers who move in and out of caring across their life course). Opportunities to increase knowledge about the post-caring experiences of older former carers are also constrained because there are few longitudinal studies. Most

research takes a snapshot in time or captures post-caring experiences over a short period. Additionally, further development of this body of work is undermined by the lack of inclusion of former carers in clinical studies of major co-morbidities (Lee & Gramotnev 2007). Few funding sources are a limitation too.

More fundamental deficits are linked primarily, to the absence of a theoretical lens of analysis. As post-caring tends to be conceptualised by 'adding' a 'former carer stage' to the end of the caring trajectory, a bifurcatory model of carer/former carer is created i.e. that a carer *actively* provides care and a former carer *is no longer* caring. This not only limits development of the conceptual status of former carer but constructs formerity as a single fixed state. Dementia caring illustrates the limitations imposed by this model well. Evidence suggests that dementia carers' journey from 'carer' to 'former carer' may involve at least two overlapping stages of formerity. When the person with dementia enters a care home the carer's status becomes that of former carer. However, when the person with dementia dies the carer's status shifts into a 'new' type of former carer - that of bereaved former carer. This experience of status-shift involves a series of transitions, rather than the single move from one status to another, as suggested by the bifurcatory model (Roland & Chappell 2015). Other caring experiences also challenge this unidirectional model. For instance carers of relatives regularly admitted to hospital; a carer in this situation may move in, and out, of being a carer *and* former carer. Carers who support a spouse in the community *and* a parent in a care home do not fit either as they simultaneously occupy both statuses.

## **Conclusion**

Despite a future increase in the number of older former carers they remain largely invisible in carer related research and policy. This review, intended to begin to address this deficit, has explored the contribution of existing research to understanding the profile and needs of this hidden population. Although the current evidence base has some strengths it is characterised by a number of fundamental weaknesses. These not only limit the potential of research to generate new conceptual and experiential knowledge but constrain its capacity to develop policy and service developments to meet the needs of older former carers whose situations are likely to be characterised by considerable health problems, emotional challenges and complexity. Increasing policy emphasis (in the UK at least) on self-management of long-term conditions and funding cuts to welfare services is likely to mean a greater demand is placed on older carers (Stewart & MacIntyre 2013, Vassilev *et al.* 2013) with the consequent 'on costs' post caring. Critical analysis into 'what we know' about older former carers offered by this review can be used to inform the development of a new research agenda that will extend the boundaries of knowledge and better inform national and international responses to the hidden group of carers that sit on the intersection of older and former.

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