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# Former carers: issues from the literature

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How to cite:

Cavaye, Joyce and Watts, Jacqueline H. (2018). Former carers: issues from the literature. Families, Relationships and Societies, 7(1) pp. 141–157.

For guidance on citations see FAQs.

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Version: Accepted Manuscript

Link(s) to article on publisher's website:
http://dx.doi.org/doi:10.1332/204674316X14676464160831

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## Introduction

This article will focus on the experiences of former carers; individuals who were previously unpaid carers but for whom caregiving has come to an end. It is estimated that the UK has 6.5 million carers of whom, almost 2 million become former carers each year (Carers UK 2014). At the same time, another 2.1 million individuals take on a caregiving role for the first time and become members of a 'marginalised population' (Hash and Cramer, 2003: 50) providing increasing amounts of unpaid care (Carers UK 2014). Furthermore, numbers of carers are projected to rise in the UK due to an increasing ageing population and a reduction in the availability of formal service provision. Thus, the number of former carers will also increase. Little attention has, however, been paid by policymakers or practitioners to the needs of former carers in the post-caregiving period.

Recent policy has raised the profile of carers and established their importance in providing health and social care (HMG, 2010). Current legislation introduces new rights and entitlements for carers which are underpinned by the concepts of wellbeing, empowerment and personalisation. For example, the newly enacted Care Act 2014, which came into force in England in April 2015, provides carers with a new legal entitlement to support. In particular, Clause 20 of the Care Act places a duty on local authorities to meet carers' needs for support provided that certain residency and eligibility criteria are met (HMG, 2014).

In this context, carers are viewed as an important resource, which is essential to the success of current care policies. However, this policy is directed only at carers who are still actively providing care. There is currently no policy that explicitly addresses the needs of former carers. This creates an increasingly large population of former carers to whom little or no support is provided in the post-caregiving period (Orzeck and Silverman, 2008). Yet, former carers comprise a relatively large proportion of society and are potentially, a valuable and underused resource.

## Temporal dimensions of caregiving

Caregiving research in the last two decades has tended to focus on the 'active' phase when carers are providing care while the care recipient is still alive (Seltzer and Li, 2000). The key components of caregiving are defined by Stetz and Brown (1997) as the guiding, giving and doing for the care recipient to meet his or her needs. This encompasses a very wide range of tasks and processes at different times including what Brown and Stetz (1999: 191) call 'midwifing the death' and 'taking the next step'. These terms illustrate that caregiving is a

dynamic process that changes over time. A process that has been conceptualised as an 'unplanned and unexpected career' (Aneshensel et al, 1995), caregiving comprises various phases of which the post-caregiving period is only one of many that carers experience.

A number of temporal models of caregiving identify transitions in the caregiving career (Pfeiffer, 1999; Nolan et al, 1996; Cavaye, 2006). Despite each author using a different term, common to each model is the identification of a beginning, a discernible temporal direction and an end of caregiving. Identification of the end or post-caregiving stage is not new. It was acknowledged in the early literature (George and Gwyther, 1986) but described as the "ignored phase of caregiving careers" (Pearlin and Zarit, 1993: 155). Theorists have ascribed it various labels including: "exit stage" (Lindgren, 1993), "a new beginning" (Nolan et al, 1996), "taking the next step" (Brown and Stetz, 1999) and "new horizons" (Cavaye, 2006). Whatever the term used, the post-caregiving trajectory (Larkin, 2009) is an integral part of the caregiving career that all former carers experience (Orzeck and Silverman, 2008).

The detrimental effects of caregiving are well documented with family carers reporting poor health, high levels of depression, stress and anxiety and social isolation as a result of their role (Pinquart and Sorenson, 2003; Hanratty, 2007; Hoffman et al, 2012). However, relatively little is known about the experiences of former carers in the post-caregiving period. The purpose of the review was, therefore, to explore the existing knowledge about former carers.

**Methods**

The first step in the review process was the development of a search strategy to collect relevant research studies. The search was limited to papers written in the English language and published between 1995 and 2015 to reflect current knowledge. Eight electronic databases: ONCL First Search, ASSIA, PsychInfo, CINAHL, MEDLINE, EMBASE, British Nursing Index and AMED were searched using the term 'former carer'. This identified only 19 studies of which, one was the authors' conference paper, 4 were not relevant and 8 were duplicates, leaving just 6 studies. This was regarded by the authors as too limited for the purposes of a literature review. A second search was therefore conducted using the terms 'ex-carer', 'bereaved carer', 'end-of-caregiving', 'post-caregiving' combined with Boolean search terms 'AND' and 'OR'. The term 'bereaved' carer was included because they are by virtue of bereavement, also former carers. The search was extended by scanning reference lists of located papers and exploring the most recently published editions of key journals.

Following the second search, a total of 323 records were identified for potential inclusion. The first author reviewed each title to assess eligibility and removed duplicates and papers

which did not meet the inclusion criteria. The abstracts and full text of 138 articles were then scrutinised independently by both authors to verify they met the inclusion criteria. Inclusion criteria were studies reporting on primary and secondary research with former or bereaved carers whether or not these were the terms used by authors. Exclusion criteria were studies that focused only on current carers, evaluation of services and clinical or research method tools.

*Data Evaluation*

Two approaches to data evaluation were used to enhance rigour in this review. Firstly, the quality of studies was determined by methodological or theoretical rigour and relevance of data. See Table 1 for the methodological dimensions that were considered important. Secondly, each study was coded on a 2-point scale (high or low) as suggested by Whittemore and Knafl (2005) and only those that scored 'high' were included in this review. The 'coding' element of the evaluation was undertaken independently by each author, decisions discussed and agreement reached on the final selection of articles to be included.

**Table 1: Summary of methodological quality evaluation**

| **Methodological dimensions** | **Number of studies that met criteria (n=30)** |
|---|---|
| Research aims / question / hypothesis clearly stated | 28 |
| Research design clearly outlined | 26 |
| Methodology suitable to answer research question | 29 |
| Recruitment strategy appropriate | 29 |
| Participant sampling and sample size justified | 27 |
| Ethical considerations addressed | 18 |
| Data collected in a way that addresses the question | 29 |
| Data analysis that addressed study aims | 30 |
| Clear statement of findings | 30 |
| Findings answer the research question/aim/ hypothesis | 30 |
| Discussion and conclusions consistent with study results | 30 |
| Limitations of study discussed | 15 |

*Data Analysis*

Qualitative content analysis as described by Bryman (2008) was used to analyse the data. This involved each author reading and rereading the articles and preparing short descriptive summaries. In order to enable the findings to be compared within and between the articles, codes were generated based on the short descriptive summaries, themes identified and agreed upon after review and discussion.

*Findings*

From a possible 138 articles identified, 31 articles from 30 studies met the inclusion criteria and are included in the review. Two articles reporting on one study were included as each of these focused on different aspects and were thus considered to be relevant. The methodological approaches of studies are summarised in Table 2 below.

| **Table2: Methodological approaches** | |
|---|---|
| **Methodology** | **Number of studies (n=30)** |
| Qualitative | 13 |
| Quantitative | 1 |
| Mixed method | 1 |
| Cross-sectional | 1 |
| Longitudinal – quantitative | 3 |
| Longitudinal – qualitative | 2 |
| Longitudinal – mixed methods | 9 |

The studies were conducted in the UK (n=7), USA (n=10), Australia (n=6), Sweden (n=3), Canada (n=2), Belgium (n=1), and Ireland (n=1). The majority of studies were set in the community (n=25) with five set in care homes or dementia units. Eight studies sampled carers of people with dementia and related conditions. Seven sampled carers of people with various types of cancer. Three studies focused on end-of-life and palliative care but failed to provide details of specific health conditions as did two studies of older people. Other condition specific studies included heart failure (n=1), chronic obstructive pulmonary disease (n=1), Parkinson's disease (n=1), Motor Neurone Disease (n=2) and HIV/AIDS (n=2). Further key characteristics of each study are shown in Table 3.

Three emergent themes were identified during syntheses of findings and are presented in the following sections.

## Psychological wellbeing

Strongly emphasised in the literature is the perception that most individuals become former carers through bereavement (Burton et al, 2006; Keene and Prokos, 2008; Waldrop, 2007). Thus a key theme in the literature is the psychological wellbeing of former carers. For example, Hash and Cramer's (2003) small study found that the post-caring period was

characterised by loneliness and depression with activities such as engaging with the community and establishing new relationships challenging. However, findings from this study concerning isolation and loneliness might be connected to the nature of the sample of gay/lesbian former carers with this social grouping still, in many contexts, being stigmatised and marked out for derision. It is thus difficult to judge from the findings the extent to which isolation in the post-caring period is shaped by stigma or feelings of loss leading to loneliness.

The literature also discusses a range of stress and grief reactions of former carers in response to the transition to post-caring that Cronin et al (2015) in their small exploratory study, characterise as being 'between worlds', particularly in the early post-caring phase. Stress can be theorised as a continuum across active and post-caring roles with bereavement acting as a significant stress transition in a caring career from a life-course perspective (Aneshensel et al, 2004; Masterton et al, 2015). Cumulative stress theory argues that the burden and emotional demands of caring precipitates significant distress post bereavement (Aneshensel et al, 2004). This argument, however, is countered by the stress reduction theory that proposes that former carers experience a reduction in stress. For example, in Bond et al's (2003) longitudinal study former carers' stress reduced after the death of the care recipient enabling them to adjust more readily to the loss.

In Burton et al's (2006) study of spousal carers, discussion focuses on the post-caregiving experience of older carers in relation to expected and unexpected loss of their spouse. They found that for participants in the 'unexpected' death group, there was worsening depression after bereavement while for those in the 'expected' death group, depression levels remained stable. Keene and Prokos (2008), drawing on the same longitudinal mixed methods study as reported by Burton et al (2006), also consider the impact of the cessation of spousal caregiving and argue for greater attention to be given to both the duration and situation of caregiving as factors that may influence adjustment to a post-caring role. Their findings reveal that a longer duration of caregiving is associated with lower depressive symptoms in bereavement than those experienced by spouses engaged in shorter-term caregiving. A longer period for adjustment towards the end of caregiving is suggested as one explanation; enough time to 'say goodbye' is another. In both these articles based on the same US study, no information is given about the health conditions of those who are being cared for. Other studies, however, such as those by Aoun et al, 2011 and Phillip et al, 2014 discussed later, indicate that the post caregiving period can be impacted in different ways by stress related to difficult symptoms experienced by those being cared for with specific diseases.

Sanderson et al's (2013) research into the experiences of 32 caregivers (spouses or daughters) bereaved through the expected death of a loved one from ovarian cancer, found high levels of distress amongst this group consistent with Post Traumatic Stress Disorder. In all cases, participants' accounts used the language of shock and trauma when they were interviewed six months after the death. For bereaved caregivers in Sanderson et al's (2013) study their lives in the period following the expected death were characterised by shock, numbness, pain, intense sorrow and incredulity at what had happened. Similar to the experiences of caregivers in Waldrop's (2007) study, their overwhelming responses were triggered by images of the suffering they had witnessed during the later stages of their loved one's illness giving rise to persistent distress (Sanderson et al, 2013). These studies are similar in terms of size and methodology and, therefore, a larger study over a longer time span would be beneficial in developing understanding about the duration of this period of intense distress.

These findings challenge the suggestion that carers who expect and are assumed to be prepared for the death of the care recipient, have less distress in bereavement, supporting Hebert et al's (2006) contention that the relationship between preparedness and bereavement mental health is inconclusive. Some carers experience increasing levels of distress following bereavement and might benefit from professional support, while others show stable distress symptoms over time (Haley et al, 2008; Larkin, 2009). Thus, exploring features of the pre-loss and post-loss periods together with whether or not the death was expected reveals that there are multiple trajectories and it is, therefore, difficult to generalise or define a reliable trajectory for levels of stress/distress for former carers.

**Significance of the care recipient's illness**

The nature of the illness of the care recipient is another feature emerging from the literature that has an impact on carers in the post-caregiving period. A number of small-scale studies demonstrate that carers' experiences differ depending on the care recipient's illness (Aoun et al, 2011; Phillip et al, 2014; Small et al, 2009). The larger longitudinal study by Bernard and Guarnaccia (2003) also found that the nature of the illness of the care recipient was significant in impacting on adjustment in the post-caregiving period. The illness trajectory is another significant factor; this may progress swiftly with largely predictable demarcations or it may be slow and haphazard with an uncertain timeline (Brown and Stetz, 1999; DiGiacoma et al, 2013).

The literature suggests that caring for a person with dementia for example, may be qualitatively different from caring for persons with other conditions. Gradual loss of cognitive and physical function eventually results in the social death of the dementia sufferer leaving the carer to mourn the loss of the person they knew before their death (Bond et al, 2003). Thus dementia results in the loss of relationships and its inevitable trajectory towards death is not always made clear to carers by health professionals (Penders et al, 2015). Given the scale of dementia in the older population, the potential impact on carers is, therefore, significant.

Mourning by the caregiver before physical death is a form of anticipatory grief that is widely experienced by those caring for someone with dementia. Carers of palliative care patients dying from other conditions are also said to grieve anticipatorily but whether this is to a greater or less extent is unclear. This situation illustrates the complex nature of both the caregiving career and the bereavement process (Haley et al, 2008).

Another long-term condition which has a lasting impact on carers is HIV/AIDS as the stigma surrounding this condition exposes caregivers to judgemental attitudes which negatively impact upon their post-bereavement adjustment (Brown and Stetz, 1999). However, Cadell and Marshall (2007) who focus on the experience of HIV/AIDS carers after the death of their partner, report that for many the positive effect on their self-concept of caring in the context of HIV was characterised as strength and service. These qualities contributed to a sense of personal congruence despite the negative and stigmatised attributes associated with AIDS. Dumont et al (2008), in their longitudinal mixed methods study of 18 bereaved carers, also found that congruence, characterised by them as the carer having done everything they could for their loved one, had a major positive impact on grief reactions. The finding from Cadell and Marshall's (2007) study can be aligned with the concept of 'the modified self' discussed by Carlander et al (2010) in relation to family caregivers' experiences of caring for a dying family member at home. Being close to life-threatening illness may contribute to an extended self of the carer (Cadell and Marshall, 2007) but it also can have the opposite impact resulting in the reduced self of the carer. The theorisation of the 'modified self', particularly in the early post-caring period, makes a useful contribution to understanding this phase as one of potentially multiple trajectories. Some former carers look back on caregiving as fulfilling contributing to personal development whilst others may feel a sense of being diminished by the experience (Brown and Stetz, 1999; Bond et al, 2003).

Hasson et al (2010) discuss the experience of bereaved carers who have cared for someone with Parkinson's disease. Their qualitative study of the experience of 15 former carers

highlights a trajectory of loneliness both during the period of providing care and in bereavement. Former carers in their study felt abandoned by health and social care professionals, noting their immediate withdrawal as soon as the patient had died. Also discussed in relation to this group is the very limited access to palliative care services that offer support to both patients and carers that includes the specific goal of providing bereavement care to families (Hasson et al, 2010). Resources for this kind of formal support are not readily available with DiGiacomo et al (2013) arguing that to be effective, professional bereavement support for former carers should entail holistic assessment and should be both practical (meeting information needs) and pro-active. The perception by carers in Hasson et al's (2010) study that palliative care and hospice services are only available to patients with cancer was exacerbated by the lack of referrals for Parkinson's disease patients by primary care professionals.

In the context of Motor Neurone Disease (MND) the final days of life can be devastating for both the care recipient and the carer because, as explained by Whitehead et al (2012), the disease is complex and can result in rapid decline of the sufferer leaving carers unprepared and traumatised. Because the final stage of MND often involves complete bodily breakdown including the loss of the ability to communicate, the suffering of the dying person can have a lasting impact on carers. Whilst carers are likely to have gained competence in care functions such as controlling feeding and fluids, managing medical equipment and transferring and repositioning the person with MND as disability increases, this can be at the expense of their physical and emotional wellbeing (Aoun et al, 2011) leaving them depleted and less able to cope with the dying process. Whilst both the Aoun et al (2011) and Whitehead et al (2012) studies had a similar qualitative design and small numbers of participants, their findings are different. Former carers in Whitehead et al's (2012) study, reported feelings of relief at the death of their loved one mixed with guilt and anger resulting in high levels of carer distress, this contrasting with findings in Aoun et al's (2011) study. Thus, the final stages of caregiving for individuals with MND are experienced by the carer as difficult both on a practical and emotional level. It is not surprising therefore, that for many carers the support provided for the care recipient at the end of life is a source of both positive and negative reflection in the post-caring period (Grande and Ewing, 2009; Wong and Ussher, 2009). A specific finding that emerges from Wong and Ussher's (2009) cross-sectional mixed methods study of 22 former carers was that the carer being present at the point of death is instrumental in the process of coming to terms with loss and grief in the post-caregiving period.

**Shifting caring roles and identities**

Another theme emerging from the literature is how carers' identity and roles are challenged with the transition to institutional care (Cronin et al, 2015; Johannson et al, 2014). This move is characterised by Johannson et al (2014: 1033) and Bond et al (2003) as a 'relinquishing of care' and suggests a transfer of assumed responsibility. A number of factors influence these care decisions including a carer's health, employment, other family responsibilities and stretched personal resources (Davies and Nolan, 2006; Grande and Ewing, 2009). Cronin et al (2015: 3) note that the "placement of a relative is often a 'last resort'" giving rise to carers experiencing loss and grief coupled with a sense of failure that they may not have 'done enough' (Dellasega and Nolan, 1997).

Feelings of grief and guilt can also result where carers are not confident that they have secured the best care for their relative. Cronin et al's (2015) qualitative exploratory study of 40 former carers found that moving the care recipient into a care setting was characterised as failure associated with feelings of inadequacy. Carers place great importance on their loved one receiving the best possible care, particularly in the last stage of life (Bond et al., 2003). Sometimes this involved relocating the care of a relative from home to a formal institutional setting and this may occur earlier or later in the illness trajectory (Johannson et al, 2014). The additional strain of travelling to and from the new care setting may create another burden for carers, adding to feelings of exhaustion and a change of routine in the post-caregiving phase (Andren and Elmstahl, 2002).

Following the move of the care recipient to a formal care setting, family carers may feel uncertain what their role should be (Davies and Nolan, 2006; Hennings et al, 2013). Continuing engaged involvement based on the carer's biographical knowledge of the care recipient aimed at establishing high quality personalised care may be the goal of the carer, with this as one way of remaining connected despite separation (Johansson et al, 2014). However, a primary and visible role as a carer may be replaced by a more support oriented one with responsibility now formally shared with health care professionals and power over day-to-day decision-making mainly devolved to them. Adjustment by carers to this modified role that may positively result in them being recognised as partners in care (Johannson et al, 2014) can be a stressful transition and this may not be readily acknowledged by health professionals (Davies and Nolan, 2006). Hennings et al (2013) highlight from their longitudinal small-scale narrative study the particularly stressful nature of this 'institutional' transition for spouse carers who, they argue, may struggle with their changed role and status both within and outside the care setting.

The question is thus raised - when is a carer no longer a carer, particularly as there are a number of different routes to becoming a former carer? Underpinning this question is evidence from the literature of different 'kinds' of former carers, with some being more distinctly ex-carers (through bereavement, for example) than others. In conceptual terms, carers whose relatives move to be cared for in an institutional care setting occupy a more ambiguous status as a former carer. This is a sensitive area because as Dellasega and Nolan (1997) note, the admission of a relative to a long-term care facility remains a taboo subject, largely because of the widely held negative perceptions of institutional care alternatives. Although some studies (Hennings et al; 2013; Penders et al, 2015) encourage carers to continue to see themselves as carers once the cared-for person is admitted to a care home, no clear picture emerges from the literature. Others conceptualise these individuals as former carers (Bond et al, 2003; Cronin et al, 2015).

Given the life-changing nature of the decision (for both the caregiver and the care recipient) to change the location of care, the process can be conceptualised as moral burden not least because it contradicts the idealised and dominant paradigm of 'home' as the best and last place of care. The placement of the care receiver into a formal care setting can create a situation equally as stressful as that experienced during active caregiving involving a radical temporal re-orientation for the caregiver (Andren and Elmstahl, 2002).

**Discussion**

In its aim to explore the extent and nature of existing knowledge about former carers, this review has drawn out the dynamic and temporal features of the post-caregiving experience. The aftermath of caregiving has been shown to be a period shaped by situational, temporal and relational factors giving rise to a fluid and diverse experience landscape.

Being a carer is a divergent role (Molyneaux et al, 2011) and its cessation is mainly due to the death of the care recipient or admission to institutional care, with this strongly emphasised in the post-caring literature. Carers are not uniform in their responses to the end of their caregiving with poor psychological wellbeing associated with the nature, duration and chronicity of the illness of the care recipient and pre-existing relationships. Grief and distress are inextricably coupled with the loss that has evoked it, with increasing acknowledgement of the significance of 'good' and 'bad' deaths for those who are bereaved being able to adjust to the loss.

Also emerging from the literature is that bereavement is not perceived by the former carer as an endpoint but as a transition within an ongoing care-related life-course trajectory. Cronin et al's (2015) theorisation of this transition as 'living in loss' encompasses practical as well as emotional issues – the loss of the carer allowance is one example. Development of further conceptual frameworks to understand and capture former carers' experiences of such a profound transition is needed in order to recognise their distinctive needs.

Provision of carer support has also been highlighted in the literature as potentially beneficial where the carer's role is changed at the point when the care recipient moves to an institutional care setting. The literature suggests that feelings of guilt and grief by former carers that they may have 'failed' to keep their loved one at home can be overwhelming and lead to elevated levels of distress. Perception by others that the carer has 'outsourced' to institutions the care of their loved one, and this associated with emotional withdrawal from the relationship can further exacerbate a sense of failure and inadequacy. Recognition of the ambiguous nature of the caregiving role and that the accompanying practical and emotional burden does not necessarily decrease in these circumstances, is the first step towards considering the kinds of services and support that could be beneficial.

Whilst there is evidence that many former carers would benefit from more supportive interventions, particularly in bereavement, this is by no means universally illustrative of the multiple domains of bereavement outcomes. Informal caring is very much contingent upon opportunity and capacity all inflected by class, gender, culture and kinship ties - powerful forces in shaping the post-caregiving experience.

This review has added to our understanding of the dynamic and temporal dimension of caregiving. It has shown that former carers have unmet needs. Despite the raised profile of carers and the policy initiatives that have been developed, service support remains problematic and recent reforms do not address the post-caregiving period when formal support is immediately withdrawn and only bereavement services are available to former carers. Resources for formal post-caregiving support should be made available and targeted, time-limited and needs-based interventions developed. The post-caregiving period should be viewed as an integral part of the caregiving career, with recognition that former carers continue to have practical and psychological needs once caregiving comes to an end. Improving support for them should be a policy priority.

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| Reference | Sample | Study Design | Aims | Findings |
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| Andren and Elmstahl 2002<br><br>Sweden | 42 former carers | Longitudinal mixed methods study. | Explore if burden differed significantly according to care setting. | Admission to care home created new burdens; travel to and from new setting was change in routine and exhausting; carers expressed guilt and grief after the transition to long-term care. |
| Aneshensel et al 2004<br><br>USA | 291 bereaved carers | Six-wave longitudinal mixed methods study. | Understand emotional wellbeing following end of caregiving. | Caregiver stress is a continuum across caregiving; bereavement causes significant stress; pre-loss feelings of stress and burden predict differential unfavourable and differential trajectories post-caregiving. |
| Aoun et al 2011<br><br>Australia | 16 bereaved carers | Qualitative exploratory study. | Explore experiences of MND spouse carers during and after caregiving. | Carers gain competence in clinical care tasks; experience deterioration in physical and emotional wellbeing leaving them less able to cope emotionally and physically with death and bereavement; prolonged grief exhibited by carers who had accessed palliative care at a late stage. |
| Bernard and Guarnaccia, 2003<br><br>USA | 213 bereaved carers | Secondary analysis of data from longitudinal quantitative *National Hospice Study*. | Determine whether relationship to patient with breast cancer influences adjustment to bereavement. | Daughters experienced more anxiety and depression because of the specific nature of their mother's breast cancer; greater pre-loss levels of anxiety, depression and strain, predicted worse adjustment to bereavement than for husbands. |
| Bond et al 2003<br><br>Australia | 150 spouse carers<br>60 active, 53 former and 37 | 2 wave longitudinal quantitative study. | Explore changes between continuing, widowed and former carers whose spouses with dementia | Positive changes in wellbeing and increase in social activities as result of relinquishing of care; change in role led to reduction in stress; former carers perceived caregiving as fulfilling; others experienced anticipatory |

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| | bereaved | | moved into care home. | grief and felt diminished by the role. Importance placed on quality of care provided at end of life. |
| Brown and Stetz 1999<br><br>USA | 26 carers | Longitudinal mixed method study; article reports on qualitative data only. | Explore the influence that potentially fatal illness, cancer or AIDS has on caregiving. | Conceptualises post-caregiving as 'taking the next step' and 'moving ahead'; experiences influenced by pace of illness and interactions with service providers; caregiving was personally fulfilling for some but less satisfying for others. Death brought sense of relief, focus on tying up loose ends, dealing with regrets and moving ahead. |
| Burton et al 2006<br><br>USA | 193 spouse carers | Changing Lives of Older People, a prospective longitudinal mixed methods study. | Explore relationship between expected and unexpected death to bereavement response. | Unexpected death of spouse was associated with marked increases in depression; expected death brought stable depression levels; except for highly stressed caregivers, all showed improvements in social activity after bereavement. |
| Cadell and Marshall 2007<br><br>Canada | 7 bereaved carers | Qualitative exploratory study | Explore individuals self-constructs after the loss of partner from HIV/AIDS. | Despite loss of relationship and purpose, caregiving had positive effect on self-concept; qualities of strength and service contributed to good bereavement outcomes despite stigma associated with illness. |
| Carlander et al 2010<br><br>Sweden | 10 bereaved carers | Qualitative descriptive study | Explore challenges to carers self-image when caring for dying relative at home | Positive concept of 'modified-self' due to caregiving; others experienced negative impact and reduce sense of self; factors challenging carers' self-image were: forbidden thoughts, intimacy and decreasing personal space. |
| Cronin et al 2015<br><br>Eire | 40 former carers | Qualitative exploratory descriptive study | Explore experiences and needs of former carers. | Post-caring transition conceptualised as 'loss of caring world', 'living in loss', 'moving on', and as being 'between worlds'. Care home admission was last resort and accompanied by feelings of failure, guilt and grief. |
| Davies and | 37 carers of | Qualitative descriptive study | Understand carers' | Carers' decisions on care home admissions influenced |

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| Nolan 2006<br>UK | older people | | perspectives on nursing home placement. | by various personal factors; admission accompanied by stress, uncertainty over role and identity change; perceived role now as maintaining continuity. |
| Dellasega and Nolan<br>2007<br><br>US and UK | 48 UK and 54 US carers | Qualitative cross-national exploratory study. | Examine carers' responses to care home placement. | Decisions to enter care homes taken in haste and without information; admission is significant stressor on carers with feelings of loss, grief and sense of failure at not having done enough; carers require proactive support to move towards a 'new beginning'. |
| DiGiacoma et al 2013<br><br>Australia | 21 bereaved female spouse carers | Longitudinal qualitative study. | Ascertain experiences of spousal caregiving and the transition to widowhood. | Pace of illness trajectory and poor quality death influences wellbeing, grief and adjustment. Carers were critical of lack of communication, post-bereavement follow-up and lack of support from professionals. |
| Dumont et al 2008<br><br>Canada | 18 bereaved carers | Longitudinal mixed methods study; article reports only on qualitative data. | Identify dimensions of caregiving that influence grief and bereavement. | Factors impacting upon bereavement and adjustment included: quality of pre-existing relationship; recurring images and quality of death; good social support and confidence in knowing they had done their best. |
| Grande and Ewing<br>2009<br><br>UK | 216 bereaved carers | Quantitative prospective study. | Explore if bereavement outcomes are related to carers' satisfaction with quality of support at end-of-life and place of death. | Bereaved carers perceived home to be 'right' place to die; importance placed on provision of support; place of death influenced by range of personal circumstances; no relationship between place of death and bereavement outcomes. |
| Haley et al<br>2008<br><br>USA | 254 bereaved carers | Longitudinal mixed methods study. | Examine effects of bereavement and interventions on spouse carers' depressive symptoms. | Death of care recipient led to differential levels of depression; spouse carers who kept care recipient at home experienced higher levels of depression; those who institutionalised care recipient experienced grief prior to death and depression levels remained stable after bereavement. |

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| Hash and Cramer 2003<br><br>USA | 19 gay and lesbian carers | Qualitative exploratory study. | Explore caregiving experiences of same-sex carers before/after death of partner. | Feelings of loneliness and depression post-caregiving; caution about seeking bereavement support and social interactions. Non-acceptance of gay relationship and discrimination from professionals. |
| Hasson et al 2010<br><br>UK | 15 former carers | Qualitative exploratory descriptive design. | Explore former carers' experiences of palliative care for Parkinson's Disease. | Formers carers struggled to cope before and after death; felt lonely, displaced, bereft; critical of lateness of referral to palliative care; felt abandoned by professionals through immediate withdrawal of services once patient died. |
| Hebert et al 2006<br><br>USA | 222 bereaved carers | Longitudinal mixed method prospective study. | Explore relationship between preparedness for death and mental health in dementia carers. | Despite providing high intensity care for many years, dementia carers not prepared for death of care recipient; experienced higher levels of depression, anxiety and complicated grief. |
| Hennings et al 2013<br><br>UK | 10 spouse carers | Longitudinal qualitative narrative study. | Explore experiences of spouse carers of people with advanced dementia living in care homes. | Carers 'living in two worlds' following care home placement; role ambiguity, liminal positon, enduring grief as result of transition; carers want to remain involved in caregiving within institutional setting; professionals fail to acknowledge this need. |
| Johansson et al 2014<br><br>Sweden | 10 former carers | Qualitative descriptive study | Illuminate carers' experiences of relinquishing care of person with dementia to a care home. | Carers had negative perceptions of institutional care; found adjusting to new support role stressful; attempted to remain connected to care recipient despite relinquishing of responsibility; recognition as a partner in provision of care was supportive and reassuring. |
| Keene and Procos 2008 | 189 bereaved spouses | A prospective longitudinal mixed methods study, *Changing Lives of Older* | Explore how spousal caregiving influences depressive symptoms six | Duration of caregiving is strongest predictor of spouse depression in post-caregiving period. Long term caregivers experience greater relief and fewer |

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| USA | | *People* | months after death. | depressive symptoms in bereavement than short term caregivers. Relief from chronically stressful care situation may ameliorate the negative effects of loss. |
| Larkin 2009<br><br>UK | 37 former carers | Qualitative exploratory study | Explore experiences of former carers aged over 60. | Post-caring life had identifiable trajectory with various levels of distress; following bereavement some former carers experienced higher levels of distress; for others these remained stable over the post-caregiving transition. |
| Masterton et al 2015<br><br>USA | 51 bereaved carers | Secondary analysis of data from longitudinal study. | Examine psychosocial outcomes after first year of bereavement following palliative caregiving. | Stress conceptualised as a continuum; carers report high levels of stress which continues beyond first year of bereavement; thereafter depression reduces but social function has not improved by this stage. |
| Penders et al 2015<br><br>Belgium | 98 carers | Retrospective cross-sectional study, *Dying Well with Dementia.* | Describe awareness of dementia by carers of nursing home residents dying with dementia. | Family carers of care residents were often unaware that relative had dementia; high awareness only in cases of advanced dementia just before death and when opportunities for disclosure and information were too late. |
| Philips et al 2014<br><br>Australia | 10 bereaved carers | Qualitative exploratory study | Understand experiences and needs of carers of people with COPD. | Bereaved carers were unprepared for role: nature and chronicity of COPD are different; this has implications for carer wellbeing; lack of professional support increased burden on carer. |
| Sanderson et al 2013<br><br>Australia | 32 bereaved carers | Mixed method *Australian Ovarian Cancer Quality of Life Study;* article reports on qualitative data only. | Identify evidence of post-traumatic stress disorder in carers of women with ovarian cancer. | ‘Shocked carers’ displayed symptoms of trauma and provide harrowing accounts of death; carers were not prepared for the end and had little warning of what it might entail; six months post-death carers still traumatised and few had ‘moved on’. |

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| Small et al, 2009<br><br>UK | 20 bereaved carers | Longitudinal mixed methods survey; article reports on qualitative data only. | Explore carers' views of dying, death and bereavement for persons who had died with heart failure. | People with heart failure are more likely to experience an unpredictable illness trajectory than people with cancer; deaths at home were considered 'good'; few bereaved carers accessed support services; identified need for continued support for bereaved carers. |
| Waldrop 2007<br><br>USA | 30 bereaved carers | Longitudinal mixed methods descriptive study. | Explore caregiver grief during terminal illness and after death of care recipients. | Post-caregiving, anxiety and hostility decreased significantly but loneliness, sadness, poor sleep and distress persisted; overwhelming emotional responses triggered by visual or auditory reminders of the care recipient. |
| Whitehead et al 2012<br><br>UK | 24 people with MND<br>18 continuing carers<br>10 former carers | Qualitative exploratory study. | Explore experiences of people with MND and their carers. | MND is characterised by rapid decline in final stages of illness: increased need for carer support; anxiety and distress is heightened; bereaved carers expressed relief at the death of loved one but expressed grief, anger, guilt; despite high levels of distress few received bereavement support and caregiving had a lasting negative impact. |
| Wong and Ussher 2009<br><br>Australia | 22 bereaved carers | Cross-sectional mixed methods study; article reports on qualitative data only | Explore bereaved carers experiences of providing palliative care at home. | Bereaved carers felt that being present at point of death was rewarding and facilitated the process of saying goodbye, provided closure and these aspects helped in reconciling loss and grief. |