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Experiences of bereaved former carers: issues from the literature

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Although unpaid carers provide the majority of care for older, ill and disabled people in the UK, they are members of a marginalised population (Hash and Cramer, 2003: 50). Whilst caregiving is a dynamic process that changes over time, it has some key components as outlined by Stetz and Brown's (1997) overarching term *taking care* and defined by them as the guiding, giving and doing for the ill person to meet his or her needs. This encompasses a very wide range of tasks and processes including what Brown and Stetz (1999: 191) call 'midwifing the death' of the person being cared for.

Conceptualised as a 'career' (Lindgren, 1993; Aneshensel et al, 1995), caregiving comprises various phases of which the post-caregiving period is only one of many that carers experience. Lindgren (1993: 214) defines the caregiver career as the "specific period within a spouse's life in which caregiving is the central focus". She outlines three distinct stages of caregiving as the: encounter stage; enduring stage; and exit stage (Lindgren 1993). Aneshensel et al (1995), who consider the caregiving career to be "unplanned and unexpected", also describe three phases comprising role acquisition, role enactment and role disengagement. Another simplistic framework developed by Ume and Evans (2011) identifies three phases as being pre-caregiving, active caregiving and post-caregiving.

Despite each author using a different term, common to the models outlined above is the identification of beginning, a discernible temporal direction and an end of caregiving. The 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). 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). While an established body of literature has documented the experiences and needs of unpaid carers, relatively little is known about the post-caregiving period and the increasingly large group of former carers. This situation is problematic given the current policy agenda.

Current policy

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

support for carers in the form of information, assessment and support services. However, the Carers Bill that was presented to the Scottish Parliament in May 2015 aims to increase take-up and improve support to carers by removing the eligibility criteria for an assessment so that all carers will be entitled to what will become known as a Carers' Support Plan.

In this context, carers are viewed as an important resource, which is essential to the success of current care policies. Thus, in theory if not in practice, some degree of support is currently available to the estimated 6.5 million unpaid carers in the UK (Carers UK, 2014). In an era of scarce resources, support is directed to those carers who are deemed to have the greatest support needs and who tend to be 'visible' or known to service providers. Increasingly, social workers and allied health professionals have an important role to play in identifying, assessing and supporting carers (Hussain & Manthorpe, 2012) through their caregiving career.

The carer population is not homogeneous or static. 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. It is estimated that each year almost 2 million individuals become a carer and for another 2 million people, caregiving comes to an end (Carers UK 2014). 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). Although former carers comprise a relatively large proportion of society, there is a paucity of literature exploring their experiences. Recent literature from the palliative care field talks about 'bereaved carers' and appears to have focused on former caregivers of people with specific conditions such as Parkinson's Disease (Hasson et al 2010), Motor Neurone Disease (O'Brien et al 2012) or cancer (Grande et al 2009). These literatures, however, mainly explore the experience of carers in an attempt to evaluate and improve service delivery. Rarely is the impact of caregiving on the bereaved unpaid carer considered. Similarly, the literature from the fields of gerontology, sociology and nursing tend to focus on various aspects of caregiving other than post-caring experiences. The limited literature that does focus on post-caregivers suggests that former carers have unmet needs, experience the post-caregiving period as stressful and would welcome some form of continued support. These issues are considered further below.

The issue of stress/distress

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; Orzeck and Silverman, 2008). Cumulative stress theory argues that the burden and emotional demands of caring precipitates significant distress post bereavement. This argument, however, is countered by the stress reduction theory that proposes that family carers experience a reduction in stress enabling them to adjust more readily (Breen, 2012). The literature thus discusses a range of stress reactions of former carers in response to the transition to post-caring that

Cronin et al (2015) characterise as being 'between worlds', particularly in the early post-caring phase.

Most carers become former carers through bereavement. A focus on the 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. As an example, some carers experience increasing levels of distress at some point following bereavement and might benefit from professional support (Larkin, 2009) while others show stable distress symptoms over time.

Burton et al (2006) discuss the post caregiving experience of older carers in relation to expected and unexpected death 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. Sanderson et al's (2013) research into the experiences of caregivers 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. Even six months after the death, participants' used the language of shock and trauma during interviews. In the period following the expected death, the lives of these bereaved caregivers were characterised by emotions of shock, numbness, pain and incredulity at what had happened (Sanderson et al, 2013). Similar to the experiences of bereaved 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's (2013) findings challenge the suggestion that carers who expect the death of the person they are caring for (and can be said to be prepared for the death) have less distress in bereavement, supporting Herbert et al's (2006) contention that the relationship between preparedness and bereavement mental health is inconclusive.

Keene and Prokos (2008) 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. Findings from their study 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.

Changing caring roles and identities

Andershed's (2006) literature review of the role of relatives in end-of-life care found that relatives place great importance on their loved one receiving the best possible care in the last stage of life. Sometimes this involves relocating the care of a relative from home to an institutional setting and this may also occur earlier in the illness trajectory. Where carers are not confident that they have secured the best care for their relative, feelings of guilt may result

(Cronin et al, 2015). It has been noted by Cronin et al (2015: 3) 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, 2007). The additional strain of travelling to and from the care setting may create a new burden for caregivers adding to feelings of exhaustion in the post-caregiving period (Andren and Elmstahl, 2002).

In the context of a relative moving into an institutional care setting such as a hospice, the caregiver’s identity as a carer may be challenged and this is a theme in some of the literature that debates active and post-caring perspectives. This move is characterised by Johannson et al (2014: 1033) as a relinquishing of care and suggests a transfer of assumed responsibility. Given the life-changing nature of the decision (for both the caregiver and the care receiver) to change the place 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.

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 caregivers to this modified role that may positively result in them being recognised as partners in care (Johansson et al, 2014: 1033) can be a stressful transition and this may not be readily acknowledged by care home staff (Hennings et al, 2013).

Conclusions

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. Caregivers are not uniform in their responses to the end of their caregiving. Whilst there is evidence that many former carers would benefit from more supportive interventions, particularly in bereavement, this is by no means universal illustrative of the multiple domains of bereavement outcomes. Grief is 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. What does emerge from the literature is that bereavement is not perceived by the former caregiver as an endpoint but as a transition within an ongoing care-related lifecourse 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.

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. It is argued that improving support for them should be a policy priority.

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