RECOGNIZING POST-CAREGIVING AS PART OF THE CAREGIVING CAREER: IMPLICATIONS FOR PRACTICE

Pam Orzeck a & Marjorie Silverman b

a Caregiver Support Centre, CSSS Cavendish, 5800 Boul. Cavendish, 2nd Floor, Montreal, Quebec H4W 2T5, Canada E-mail:
b Caregiver Support Centre, CSSS Cavendish, 5800 Boul. Cavendish, 2nd Floor, Montreal, Quebec H4W 2T5, Canada E-mail:

Published online: 31 May 2008.


To link to this article: http://dx.doi.org/10.1080/02650530802099866

PLEASE SCROLL DOWN FOR ARTICLE

Taylor & Francis makes every effort to ensure the accuracy of all the information (the “Content”) contained in the publications on our platform. However, Taylor & Francis, our agents, and our licensors make no representations or warranties whatsoever as to the accuracy, completeness, or suitability for any purpose of the Content. Any opinions and views expressed in this publication are the opinions and views of the authors, and are not the views of or endorsed by Taylor & Francis. The accuracy of the Content should not be relied upon and should be independently verified with primary sources of information. Taylor and Francis shall not be liable for any losses, actions, claims, proceedings, demands, costs, expenses, damages, and other liabilities whatsoever or howsoever caused arising directly or indirectly in connection with, in relation to or arising out of the use of the Content.

This article may be used for research, teaching, and private study purposes. Any substantial or systematic reproduction, redistribution, reselling, loan, sub-licensing, systematic supply, or distribution in any form to anyone is expressly forbidden. Terms &
Caregiving research and practice has tended not to view the post-caregiving stage as part of the larger caregiving lifecourse. Research on post-caregiving has focused primarily on how the caregiver copes following the death of the care-receiver, and practice has shown that the trend is to close the caregiver’s file (if a file exists at all) post-death. Yet caregivers face ongoing transitions and losses following the death of the care-receiver, including coping with potentially complicated mourning, as well as identity rebuilding. The fact that caregivers have ongoing emotional needs post-care indicates that this stage should be considered as part of the caregiving lifecourse. Post-caregivers should thus be provided the appropriate services and support. Providing services during this stage means viewing caregivers as holistic human beings with individual needs, rather than simply as instruments for providing care.

**Keywords** caregivers; post-caregiving; loss; lifecourse; identity; caregiving career; intervention

In the last 20 years, professionals’ knowledge of caregivers’ needs and how to respond to those needs through practice has gained enormous ground. Research began by examining the basic needs of family caregivers and the toll that providing care exacted on their lives (Guberman et al., 1991; Brody, 1985; Lavoie, 2000; Aneshensel et al., 1995; Lawton et al., 1991; Pruchno & Resch, 1989; Zarit et al., 1986). This early research helped to expand the use and importance of the term caregiver and to direct our collective societal awareness towards the recognition that these family members and friends providing regular physical, practical, and emotional support to someone suffering from an illness or disability were indeed going beyond the call of duty. As the picture of the family caregiver began to take shape — that they numbered in the millions (Cranswick, 1997), that they were found in every socio-economic and ethnocultural group (Guberman & Maheu, 1993), and that they suffered from physical, emotional, social, and financial problems of their own (Fast et al., 2001) — attention to the specific aspects of the caregiving experience started to take hold.

The focus of most caregiving research and practice has been on active caregiving, that is, the care provided while the care-receiver is alive. Although there is literature on how caregivers cope with the death of the care-receiver, there is little focus on the...
emotional needs of caregivers when their role comes to an end. That is, when the caregiver moves into a role of ‘post-care’. When the care-receiver dies, the caregiver — who may have sacrificed many aspects of their life — is often left to grieve the loss with very little support. Practical interventions are rarely planned for these ‘post-caregivers’ and they are often left to access general bereavement services that do not take into account their particular needs, identities and situations.

This paper argues for the recognition of post-caregiving as an integral part of the caregiving lifecourse and that the needs of post-caregivers be included in practice. Lifecourse theories have provided a strategic context for studying life transitions and their personal and social consequences (George, 1993; Elder, 1992), a highly relevant framework for the study of caregiving, which involves continual changes. Although traditionally lifecourse ends with death, caregivers continue living and having ongoing needs long after the death of the care-receiver. A review of the post-caregiving literature reveals that the post-care stage is often not perceived as being part of what is considered the overall caregiving career (Pearlin, 1992). Yet as two case studies illustrate, caregivers face ongoing transitions and losses during this post-care stage, confirming that their emotional needs do not come to an end upon the death of the care-receiver. Identity issues and complicated mourning are hallmarks of this stage, differentiating post-caregivers from other mourners. Because the death of the care-receiver does not mark the end of the caregiving lifecourse, services for caregivers in this stage should be integrated into practice.

Throughout this paper, we are writing from the perspective of practitioners in the field who engage in clinical work with caregivers, both with individuals and groups, as well as practice-based research in caregiving issues. This work takes place within the context of a community based program that specializes in caregiving.

From active caregiving to a lifecourse perspective

There is currently very little literature on post-caregiving as part of the caregiving career. Rather, the literature tends to focus on the impact of the care-receiver’s death on the caregiver and the factors that contribute to his or her specific reactions to loss.

Impact of care-receiver’s death

While some literature has argued that the death of the care-receiver brings the caregiver relief (Schulz et al., 1997), others have argued that the caregiver feels depleted by the loss (Bass & Bowman, 1990). The first perspective argues that because the caregiving has exacted such an enormous physical, emotional, social, and financial toll on the caregiver, the caregiver experiences relief when their role comes to an end. They are thus better able to cope with the loss. The second perspective argues that caregivers are in fact hugely drained from all the care they have given, and are thus depleted and do not have the resources to cope with the loss. Further, while some studies have argued that mourners who have been caregivers adjust more easily to the loss (Schulz et al., 2003), others have shown the opposite (Bonanno et al., 2002; Robinson-Whelen et al., 2001). These studies focus only on how the caregiver copes post-death, but not on their ongoing needs and how practice might respond to those needs.
Impacts of active caregiving on post-caregiving

There are a number of factors that contribute to how a caregiver copes with loss; however, in the literature they are largely related to the experiences of the caregiver during the active caregiving. For example, McHorney and Mor (1988) found that caregivers who experienced bereavement difficulties reported feeling dissatisfaction with their prior caregiving. Strained relations, subjective burden, health status, length of time caregiving, type of care-receiver illness, and support received during caregiving are just some of the many variables that have an influence on caregivers’ reactions to loss in the post-care stage.

Much of the current literature compares post-caregivers with other mourners and places little focus on the fact that the post-caregiver has ongoing emotional needs, related to the loss but also to their prior caregiving role. In order to understand these particular needs, and to intervene appropriately, post-caregiving must be perceived as one stage in the caregiver lifecourse, and the caregiver placed within the context of their complete caregiving career. The literature does not reflect this, as evidenced by the lack of research examining post-caregiving within a lifecourse perspective.

Post-caregiving and the lifecourse

Consideration of what counts as the caregiving career has shaped practice in ways that do not recognize post-caregiving as a phase within the lifecourse. The caregiving career is traditionally perceived to begin when care is first given, and to continue until the death of the care-receiver. However, research has shown that the chronic stress of caregiving does not end when the caregiving ends (Bodnar & Kiecolt-Glaser, 1994); moreover, caregivers are left with a multitude of mixed emotions and an often complicated bereavement process. The transition faced by the caregiver following the death of the care-receiver is one of many complicated transitions, and the losses they have to confront represent a continuation of the losses faced during active caregiving.

Transitions faced during post-caregiving

Prior to transitioning into the post-care stage, active caregiving is replete with various transitions, some of which are defined by the stages of an illness (as is the case with Alzheimer’s disease or cancer) and/or significant events (such as placement in a long-term care facility, hospital visits, or death). Becoming a caregiver is often a new phase in the course of one’s life that conflicts with other societal roles, including family life, employment, or implication in the community. Our practice experience has shown that this transition of becoming a caregiver, and the juggling of roles and responsibilities that it entails, is often a source of chronic stress during the caregiving period. Within active caregiving there are often various crises, ups and downs and plateaus, which for some can span many years and involve a steady routine of hourly, daily or weekly care.

Post-caregiving also entails yet another reorganization of one’s entire lifestyle and purpose. Once the care-receiver has died, the caregiver has to adjust to a sudden stop in providing care, propelling them into a period of reflection, questioning, and
lifestyle adjustments. Just as transitioning through the stages of an illness creates uncertainty, post-caregiving means facing yet further unknowns. The caregiver’s future can feel uncertain and potentially frightening. This transition often involves a redefinition of the caregiver’s identity, adding further to their emotional needs during this stage.

**Losses faced during active and post-caregiving**

The caregiver faces multiple losses long before the death of the care-receiver. During active caregiving, the caregiver must confront numerous losses, beginning with the reality that the care-receiver will decline, combined with the uncertain trajectory and timeline of the illness. As the care-receiver deteriorates, each new incapacity can lead to new losses. Caregivers to those with dementia experience grief and loss that may differ from those who are caring for someone with a physical impairment, as they often encounter anticipatory loss. Bereavement begins long before the actual death, as the care-receiver slowly loses their memory, personality traits, and daily functioning capacities. This process has also been called ‘dual dying’ (Jones & Martinson, 1992). During active caregiving the ‘caregiver’ must also come to terms with symbolic or secondary losses, such as changes to their vision of the future, loss of freedom, and changes in the relationship with the care-receiver. In our practice we see many caregivers who have to radically and suddenly change their vision of their retirement, and the intimate and healthy old age they imagined sharing with their partner.

When the actual death of the care-receiver occurs, the caregiver transitions into yet another stage of loss. The bereavement of this final loss is compounded by all the losses confronted during active caregiving stages. While some of the losses experienced with the death of the care-receiver are new, others are the continuation of earlier losses. The bereavement faced during the post-caregiving stage lies on a continuum of loss that is characterized by the entire caregiving lifecourse. The death of the care-receiver is one stage in a journey of multiple transitions experienced throughout the caregiving career.

**Needs of post-caregivers**

As mentioned above, for many caregivers the death of the care-receiver marks the start of a new phase. As with any death, this new phase often entails intense grief and mourning, and possibly depression and anxiety. Yet it also entails a number of other components that are specific to people who have been caregivers, including dealing with actual loss after possibly many years of anticipatory loss, rebuilding one’s identity after being consumed by the caregiving role, and dealing with mourning that is potentially complicated due to all the mixed emotions that can arise throughout the caregiving years.

**Identity**

The post-caregiving stage is often a time of identity re-building. Due to the significant time and energy involved in caregiving, caregivers often let go of their own interests,
projects, work lives, social networks and relationships — all integral pieces of their identities. The identity of being a caregiver takes over and becomes central, not always out of choice, but rather necessity. When the care-receiver dies, the caregiver not only has the task of grieving, but also of simultaneously rebuilding or recreating their own identity.

For example, Brenda, a 37-year-old caregiver, decided to move in with her mother who recently had a stroke. Brenda had a job that allowed her to work from home, and she optimistically thought that she could do it all. Yet very quickly Brenda realized that it was impossible to continue working, even part time, as her mother’s needs were too demanding. Brenda therefore quit her job and started receiving social assistance. As she placed more of her energies into caring for her mother, her social life was put aside, as were her romantic relationships, her exercise routine, and her hobbies. Brenda’s identity became primarily that of her mother’s caregiver. Due to her mother’s incapacities, Brenda had to assume almost all her mother’s activities of daily living — bathing, meal preparation, and financial management. This situation went on for 10 years, with many ups and downs, until Brenda’s mother died. Not only was Brenda devastated that her mother was gone, but she had to completely rebuild her life. Although there was a strong sense of relief mixed in with her grief, Brenda also experienced tremendous fear. How was she going to rebuild her identity? She had been out of the workforce for 10 years, she had put all her own projects on hold, and she was no longer familiar with her own interests.

Brenda’s bereavement was complicated by the role engulfment (Skaff & Pearlin, 1992) inherent in her caregiving situation, and the fact that she had not only lost certain aspects of her identity, but that her identity had in fact become that of a ‘caregiver’. The difficulty, therefore, was not only in rebuilding her life, but in letting go of the identity of caregiver. For many caregivers, this simultaneous letting go (which entails even further loss) and rebuilding is a complex process that requires significant emotional support.

This loss of self, as seen in the case of Brenda, is found to be more common among spouses, women, and younger caregivers (Skaff & Pearlin, 1992), yet it can also be found among adult children. Limited social contact and lack of social roles are found to be related to greater loss of self, lower self-esteem, and greater depressive symptomatology (Skaff & Pearlin, 1992). The loss of the professional role is found to be particularly difficult for most caregivers, yet it is often one of the first roles to be put aside. As in the case with Brenda, many caregivers regretfully have to stop their careers or quit their jobs due to the significant responsibility of caregiving. This can create considerable anxiety when it comes time to re-enter the workforce, not to mention anxiety regarding many years of lost income and pension benefits.

Complicated mourning

In addition to rebuilding identity, a hallmark of the post-caregiving stage — and one that requires specific emotional intervention — is complicated mourning. Post-caregiving bereavement is complicated due to the fact that caregiving can involve many mixed emotions and instigate difficult family situations. For example, the caregiver can be both intensely attached to the care-receiver, while at the same time experience feelings of guilt, anger, and resentment. The stress of the caregiving
situation can also bring to light past conflictual relationships or family dynamics that then continue into the active caregiving, and eventually post-caregiving stages.

For example, Rhoda was in a difficult and ambivalent marriage for 53 years. When Rhoda’s husband was diagnosed with Alzheimer’s disease, she was devastated. Her sadness that her husband would have to suffer from this illness was mixed with anger and resentment that her final years with him would be spent caregiving. Rhoda already felt as though she had spent her entire life caring for her husband, and now it was about to get worse. Throughout the three years that her husband lived with Alzheimer’s disease, Rhoda dutifully cared for him, yet experienced intense guilt due to her feelings of resentment and anger. When her husband died, she felt increasing guilt, wondering if she gave him enough care or the right kind of care, and not trusting that she did her best. Despite her feelings of unhappiness with him during their marriage, she now found herself feeling intensely sad and lonely. Her emotions felt complicated and confusing, and she did not know how to handle the mix of sadness, guilt, relief, and anger. At the same time Rhoda, like Brenda, needed to rebuild her identity. She realized that her identity had been that of ‘wife’ and then of ‘caregiver’ (which contributed to her resentment), and she did not feel that she had a sense of herself. Rhoda was 75 years old, and trying to rebuild her life.

Situations such as Rhoda’s demonstrate the impact that the history of the relationship between the caregiver and care-receiver can have on the active caregiving situation, and later on the bereavement process. The caregiving situation can create or excavate family conflicts that carry over into the mourning process. Had Rhoda’s husband died suddenly of a heart attack, rather than suffering from Alzheimer’s for three years, Rhoda would have likely still felt conflicting emotion, yet not in the same way as she did as a result of those caregiving years. The caregiving highlighted her guilt, anger, and mixed emotions, making the bereavement process considerably more complicated. Many of Rhoda’s emotional needs during this post-caregiving stage stemmed directly from her career as a caregiver. Rhoda’s task was now to rebuild her life and identity while at the same time dealing with her mixed emotions and the loss of her husband.

Implications for practice

In light of the ongoing needs of caregivers in the post-caregiving stage, services to support caregivers throughout this stage must be developed. During the active stages of caregiving there are occasionally services available for caregivers, such as respite, or support groups. It is still rare within the health and social service system that files are opened for caregivers and that they are assigned their own workers. When services are provided, very often the case is considered closed upon the death of the care-receiver. This would seem to go against what we have learned about the needs of the post-caregiver.

Services that could assist caregivers during the post-caregiving stage include support groups, counselling, therapy, and ongoing information and resources. Support groups allow caregivers to connect with others who are going through similar transitions, and to feel that they are not alone. Counselling or therapy allows the
caregiver to examine all the conflicting emotions and potentially unresolved issues that are arising, and to help them in the process of rebuilding their identity. Family therapy can also assist in healing wounds or family conflicts that may have arisen during active caregiving. Ongoing information and resources, for example a connection to an advocacy group, telephone conferencing, chat lines, social networks, or employment information, help to reintegrate the former caregiver back into society.

Although Rhoda could have continued on in her life without seeking formal support, she realized that her grief and guilt were preventing her from moving ahead. During approximately 12 sessions of counselling, she was able to explore the ways in which her current emotional conflicts were in many ways linked to long-standing difficulties in her complicated marriage. Counselling allowed her to disentangle what guilt was stemming from the current situation, and what guilt was a by-product of historical anger towards her husband. This emotional disentanglement allowed her to move on and work towards slowly rebuilding her life and identity.

Similarly, counselling helped Brenda distinguish and grieve her multiple losses — loss of her mother, her career, her hobbies and her personal life. Realizing that her sadness was not only linked to the immediate loss of her mother, but the loss of many aspects of her identity, helped her slowly start to re-focus on herself. In addition to receiving support from family members, counselling gave Brenda practical tools for re-integrating into employment and leisure activities. Although there is no ‘one size fits all’ solution, from these examples we see how a mix of informal and formal support can begin to address the multiple needs of post-caregivers.

Providing services post-care means perceiving the caregiver holistically, as a human being and not only an instrument for providing care, as policy and program guidelines would have us believe. Education is needed for service providers to help them perceive, and respond to, post-caregivers in this manner. If intervention is provided not only during times of crisis, or during active caregiving, but throughout the caregiving career, it sends a message of recognition that the caregiver’s emotional needs continue beyond the death of the care-receiver, and that the caregiver has needs that are separate from those of the care-receiver. Providing ongoing support can also act as a means of prevention, helping to shorten the caregiver’s period of distress following the care-receiver’s death. For example, support for caregivers of palliative care clients or Alzheimer’s patients can address the impending losses and them help prepare for the post-care reality.

Conclusion

The importance of recognizing and addressing post-caregiving needs within the caregiver career cannot be overstated. Caregiving has been termed the ‘unwanted career’ (Aneshensel et al., 1995) as it often involves a significant commitment of time and emotion that imposes itself over time. Even after active caregiving comes to an end, the psychological impacts remain. Losses and transitions continue, and the caregiver must simultaneously rebuild their identity while confronting yet another stage of bereavement.
Research to date has not highlighted the importance of including the post-care stage into the conceptualization of the caregiving lifecourse. In doing so we fail to see the caregiver as having ongoing needs that require appropriate supportive interventions. Future research could be qualitative, evaluative, or practice-based, for example measuring the impact of interventions in the active caregiving stage to determine how they address post-caregivers’ needs and to what extent. Does caregiver counselling prior to the death of the care-receiver serve to prevent some of the negative outcomes in the post-care stage? How can we adapt current screening and assessment tools to respond to the needs of post-caregivers? Other areas of future research could link with feminist studies to explore, for example, why it is that women in particular become so invested in the identity of being a caregiver and the psychodynamics embedded in these choices.

In both research and practice, considering post-care as part of the caregiving career leads us to view the caregiver holistically, within the context of all the caregiving experiences that preceded the death of the care-receiver. This allows for a greater understanding of the lived experiences of caregivers throughout their challenging caregiving career, and a greater response to their ongoing needs.

Note

1 Both authors work in the Caregiver Support Centre of the CSSS Cavendish, a health and social service centre in Montreal, Canada.

References


**Pam Orzeck** has a Masters degree in Social Work and is currently working on her PhD in Social Work and works in the Caregiver Support Centre of the CSSS Cavendish. *Address*: Caregiver Support Centre, CSSS Cavendish, 5800 Boul. Cavendish, 2nd Floor, Montreal, Quebec H4W 2T5, Canada. [email: pam.orzeck.cvd@ssss.gouv.qc.ca]

**Marjorie Silverman** has a Masters degree in Religious Studies and is currently working on her PhD in Social Work and works in the Caregiver Support Centre of the CSSS Cavendish. *Address*: Caregiver Support Centre, CSSS Cavendish, 5800 Boul. Cavendish, 2nd Floor, Montreal, Quebec H4W 2T5, Canada. [email: marjorie.silverman.cvd@ssss.gouv.qc.ca]