Latent Grief: The unique and hidden Grief of carers of loved ones with dementia

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Abstract

This paper provides a preliminary model of latent grief, the very unique and hidden grief experience of family caregivers of individuals with dementia. This model is based on a critical review of both grief and dementia care literature, as well as our own clinical experience in working with these families. The model describes three dimensions of loss and a number of dynamics that contribute to the latency of the grief process. We see latent grief as a major factor in caregiver stress and burnout, and believe that an understanding of this process will help to validate the ongoing grief that is part of the caregivers' experience. This will allow caregivers to recognize that their emotional turmoil, which they perceive to be a result of the burden of care, is also in large part due to the losses they endure on a daily basis.

Introduction

The care of an individual with any chronic illness is an incredibly challenging task. When chronic illness is that of a progressive dementia, the caregiving role is even more taxing. Dementia is the loss of intellectual functions – such as the ability to think, remember, judge, comprehend, perceive – of sufficient severity to interfere with a person's basic activities of daily living. It encompasses a group of symptoms that accompany certain diseases including:

- Alzheimer's disease, 50 to 60 percent;
- Multi-infarct or vascular dementia,
- 20 percent;
- Parkinson's dementia, Pick's disease and other diseases of uncertain origin,
  20 percent;
- Secondary dementias, 10 percent.[1]

The person's cognitive decline is evident almost from the beginning of the dementing disorder, with the physical deterioration often seen in the early stages of most other chronic illnesses, occurring much later. While the physical being of an individual with a dementing illness remains intact, the very essence of a person – the psychosocial self – slowly disintegrates. This is the paradox of dementia: The 'person' fades, but the body lives on.

As the person's cognitive abilities decline, the caregiver must absorb more and more responsibility, not only for the care of his loved one, but also for the roles that she previously filled in the relationship. In these difficult circumstances, many extreme and conflicting emotions have been observed in and described by caregivers – primarily those of anger, guilt, depression, anxiety and helplessness.[2-7]

A significant aspect of our role as counselors with the Alzheimer Society of Niagara is to help caregivers deal effectively with the multiplicity of their emotions as they struggle to care for their loved ones. In counselling our caregivers, it has become apparent to us that their emotional reactions parallel the emotions attributed to grieving individuals, as documented in the literature on grief and bereavement.[8-21] Dementing illnesses result in continuous losses in cognition and function, and because grief has been described as "the emotional response to any loss,"[21] it is reasonable to assume that for the caregiver of a loved one with dementia, the grief response would begin very early in his caregiving role.

What has also become apparent to us, however, is that caregivers do not seem to be aware that they are grieving. It is difficult for them to see that emotional turmoil is in response to the tremendous impact of the continuous losses they face. Although caregivers' emotions are overt and are often expressed as intense feelings of anger, guilt, anxiety, depression and helplessness – the same emotions identified with grief – these emotions are identified as a response to care, rather than as a response to loss. The grief that underlies emotions is covert, remaining deeply buried from conscious awareness.

Our emerging understanding has led us to speculate that caregivers are engaged in an occult or latent grieving process – "occult" in the sense of being concealed or hidden from the caregiver and "latent" in the sense that it lies dormant, waiting to be developed.[22]

In the concept of latent grief is valid, it is essential that caregivers and those who provide support for them develop an early awareness of this hidden grieving process. This will enable caregivers to access appropriate support systems, including grief counseling, so that they may begin to cope with their ongoing losses.

On investigating the current literature in search of empirical data to support our clinical observations, we found that the subject of dementia, in relation to the grieving process in caregivers, has been largely overlooked. What information we have been able to find, gives minimal attention, to the hidden aspects of grief.[10,11,17-19,21,23] The literature focuses instead on unresolved grief [7,14,15,17] and/or anticipatory grief [11,14,15,21,24,25] and introduces some additional concepts such as ambiguous loss,[26] disenfranchised grief,[22] pathological grief [2,13,15,19,27,28] and quasi-widowhood, [29] among others. We have also been unable to find anything that brings together the various theories and concepts to provide a perspective of this issue.

In the hope of initiating future research, we attempt to analyze what we have found in the literature and incorporate what is applicable with our own clinical experience to create a preliminary model of latent or occult grief that will provide reasons for this phenomenon and an understanding of its impact on the caregiving role.

Three dimensions of loss

Understanding the concept of loss in dementia is crucial to the issue of latent grief. There are three dimensions of loss for the caregiver. First, there is the loss of the ‘person’ with dementia. With cognitive decline, the person’s ability to communicate and interact is impaired, and the caregiver loses a companion, partner, friend, lover, mother, grandmother. With functional decline, gone is the homemaker, gardener, organizer, seamstress, cook, family babysitter. The person is no longer able to fulfill the multiple roles previously held in the relationship. Second is the symbolic loss, which relates to the psychosocial death,[14,18,26,27] and the personal meaning the caregiver attaches to the ongoing losses as the ‘person’ disappears, such as the loss of hopes, 18 dreams and expectations.[14] For spouses, symbolic loss often manifests itself as a sense of “a loss of dreams of a golden age together,”[2] in which the couple’s plans for retirement and travel are short-circuited.[30] The third dimension of loss is the caregiver’s loss of self or person identity. Marris, as cited in Cole, states that “the fundamental crisis of bereavement arises, not from the loss of the other, but from the loss of self.”[20] Any one of these three dimensions of loss would make coping difficult for the caregiver; the need to deal with them all simultaneously is overwhelming, particularly when there are multiple losses within each dimension.

There are various dynamics created by these dimensions of loss that may contribute to the latency of the grief. The caregiver may be in denial, which, according to the grief literature, is the initial response in the grieving process.[2,10,11,13,16,20] In the literature on dementia care, most authors also observe that denial comes into play from the beginning,[3-5,25,30,31] and our clinical experience would certainly support this. Coughlan states that overcoming denial is the first stage of caregiving30 and, according to Gruetzner, denial reflects the initial response that “nothing is wrong.”[3] Cole offers an excellent description of denial, calling it “a way of knowing and not knowing at the same time.”[20] This suggests a sense of ambiguity in the caregiver about his situation.

Ambiguity

The sense of ambiguity in the caregiving role is alluded to by many authors,[2,6,12,21,25,27,30,32,33] but the term “ambiguous loss” was coined by Boss. She described ambiguous loss with regard to dementia as the individual being physically present, but psychologically absent.[26] For the caregiver, there is a lack of clarity as to where the person now fits, not only in the relationship, but also in the family system itself. Boundaries have become blurred. Boss sees this as a severe stressor for caregivers that may lead to denial of the illness.[26] What may complicate the situation further is the fact that there are intermittent episodes of lucidity and confusion that keep the caregiver in a state of uncertainty as to whether or not there really is something wrong.[3,4,6] This factor may increase the ambiguity for various other family members and friends as well, who will all see the individual and her cognitive abilities very differently. The primary caregiver is the family member most aware of the impact of the cognitive decline. Our caregivers often comment, “Nobody understands what I’m going through, not even my children.” It is very possible then that such circumstances would support the need for caregivers to bury their grief. There is a sense of disenfranchisement. If the losses are not acknowledged by those around them, caregivers are essentially being denied the permission to grieve, thus forcing the grief underground.

Disenfranchisement

The concept of disenfranchisement has been addressed in the literature using various terms to describe the caregiver's experience of loss, such as 'unacknowledged,'[27] 'socially negated,'[14,21] 'unvalidated,'[26] and 'unrecognized,'[4,17] among others, but on the whole, the issue has received shallow treatment. Doke has edited a text devoted to disenfranchised grief, with an entire chapter given to the issue of psychosocial loss. He defines disenfranchised grief as "the grief that people experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported."[22] With the social negation caregivers experience, their loss is not openly acknowledged, and the caregiver is disqualified from grieving publicly, but even more importantly, the loss cannot be openly acknowledged even by the caregiver himself, as he often engages in self-disenfranchisement, leaving him unable to grieve at all.

Initially, the losses that occur with cognitive decline are so subtle that the caregiver may attribute them to other factors, saying, for example, "It's just old age" or "She's getting hard of hearing." By the time the losses have become compounded enough so that they are difficult to ignore, the caregiver is so solidly entrenched in the caregiving role that he has no time to reflect on the source of his anger, guilt, or anxiety, and transfers his emotions to the burden of care.

With every negative loss in his loved one, the caregiver experiences a negative gain for himself. With each loss, there is a decline in his loved one's cognition and function, which requires the caregiver to adapt to a new role and added responsibilities. He may no sooner begin the adaptation process when he finds himself facing yet another loss with more new challenges that require further adaptation. These compound losses mean that on any given day, the carer may be dealing simultaneously with a multitude of problems – incontinence, night wandering, disruptive behavior, falls, and immobility.[5] The caregiver is overwhelmed and fully aware of the emotional impact of the responsibilities he has gained, and responds accordingly, often with angry outbursts and subsequent feelings of guilt. He is, however, being equally impacted by all that he has lost, yet is seemingly unable to recognize these losses; hence he cannot respond appropriately with grief.

To fully understand the enormity of the losses for the caregiver, one must first grasp the theory of attachment and loss developed by Bowlby. This theory provides a model to understand human bonding and the reactions that occur when bonds are threatened or broken. Attachment bonds come from a need for security and safety, and develop early in life. Bowlby believes that it is from the bonds of mother and child that all subsequent relationships develop.[34] Attachment is the basis of the grieving process in that, in order to come to resolution of the loss of an attachment figure, a psychological detachment must occur.[8] This is reinforced by Rando, who states that the most crucial task in grief is untying the ties that bind the griever to the deceased individual.[14] When the attachment figure is threatened, the response is one of intense anxiety and strong emotional protest,[8] and clearly these emotions are evident in caregivers, because their attachment bonds are severely threatened by the psychosocial death, attachment bonds are severed permanently, but in progressive dementia, they are severed slowly, incompletely and, considering the previous discussion, ambiguously.

Placement

Perhaps the closest to a permanent severing of attachment bonds occurs with placement. It is generally not until placement becomes a reality that the caregiver begins to realize the magnitude of his loss and is finally able to acknowledge his grief. The act of placing a loved one has been aptly described by one of our caregivers, who sadly remarked en route to the facility, “This feels like the day of the funeral.”

With placement, the caregiver is more socially disenfranchised that ever, because it feels to him as if the death has occurred, but there are no rituals, no public acknowledgments, no expressions of sympathy to support his feelings of loss. He may now feel like a widower. Many references to this concept of quasi-widowhood have been made in the literature[10,13,14,19,30] under various terms, but in their study of wives of institutionalized elderly men, Rosenthal and Dawson describe quasi-widowhood as a “term intended to capture the situation of living alone without one’s former mate yet still married.”[39] The spouse finds himself in another ambiguous and paradoxical situation – married, yet alone. In the symbolic sense, he is no longer a spouse, nor is he truly widowed.

Placement has a finality which should allow an opportunity for the grieving process to move from latency to awareness, and in our experience this seems to be the case. Primarily, with the loss of the physical presence of the loved one in the home, a major attachment bond is severed and the loss can no longer be ignored. The concept of ‘quasi-death’[21] may fit here. Second, with placement, the primary care is now in the hands of the facility, so it is no longer possible for the caregiver to identify his emotions with the burden of care.

In our clinical experience, however, we find that most caregivers do not consider placement for many years after the onset of the disease. During this long period of latent grief, caregivers generally continue to relate their emotional state to the demands of care and remain unable to actualize their grief in order to work through to a resolution.

Grief

As noted by Parkes, grief is not a state, but a process19 that, as described in the literature, is complex, with recognizable patterns that have been formalized under a number of different theoretical frameworks, including stages,[19,35] tasks,[13] phases,[24] and reactions.[14] Although most theorists use different terminology to describe the grieving process, they are all consistent with the premise of an initial period of denial, followed by a need for acknowledgment in order to come to an acceptance of the loss, before resolution can occur.[7,13-17,19,23,30] While they see grief as a process that must be worked through progressively, non claim that the process is a linear one. As Rando states, “You can’t fit people into defined stages and push them from one to another.”[14] There is a general consensus that grief, as a reaction to loss, is a normal, universal process that serves a purpose and has a healing function.[15] There is also agreement that if this process is prolonged or complicated, the grief remains unresolved.

There are many references in the literature to the concept of unresolved grief under numerous terms, including absent,[14] chronic,[14,24,31] inhibited,[13,24] delayed,[10,11,13,24,36] conflicted,[14] distorted,[14] and prolonged.[10,15] This concept is usually related to post-death bereavement, with the implication being that a lack of resolution of the loss is abnormal or pathological. The issue of unresolved grief in caregivers, however, is generally discussed in reference to pre-death bereavement, again in the context of being pathological or abnormal. But pre and post-death bereavement differ qualitatively, and we believe this difference is significant. As stated by Faiano, with death there is finality, freeing the person to get on with his life.[23] If the grief remains unresolved following death, the notion that the grief response is pathological or abnormal could apply. However, in the case of caregivers, there is no finality to their loss. They are bereaved time and time again as they confront the continuous losses, with no opportunity to resolve the first before they are faced with the second and third. It is not their grieving that is abnormal, but the pathological circumstances of their situation that make it impossible to properly work through the grief process.

The caregiver is faced with a situation of compound losses, each resulting in a new bereavement that needs to be grieved. The term “bereavement” refers to a separation or a loss through death marked by a specific point in time.[15] Bereavement fits as a descriptor of loss in dementia, as there are multiple, individual, time-specific losses, each loss equating to a “mini-death.”

Describing the mini-death experience, a caregiver says that caring for a loved one with dementia can be likened to a long train journey with the ultimate destination of death, no fixed route, and no estimated time of arrival. The caregiver and his loved one are on the journey together, but in every case, the journey is unpredictable and unique. Along the way there are many stations, where “mini-deaths” occur, and these can be conceptualized as “stations of bereavement.” At each station, the caregiver, faced once again with a new loss, is “shunted” backwards in the grieving process and experiences a resurgence of denial, anger, guilt, depression, and so on. Because each new loss is a grim portent of the end destination, there may also come a time along the way when the caregiver will begin to anticipate the ultimate loss yet to be faced – the death of his loved one.

Anticipatory grief

Since first introduced by Lindeman and further developed by Aldrich,[15,37] the concept of anticipatory grief has been widely discussed in the grief and bereavement literature in relation to caregivers of the terminally ill.[8,9,14,15,25,37] A seminal work by Kubler-Ross describes the stages of the dying process of the terminally ill – denial, anger, bargaining, depression, and acceptance as they anticipate their death.[35] In the current discussions of grief and dementia, anticipatory grief now receives considerable attention,[3,5,21,24,25,31,32,36] and is often adopted as a working model of the caregiver's grief experience, perhaps because it relates so well to the issue of pre-death bereavement. Anticipatory grief has been defined as "the grief process that takes place in anticipation of the actual loss."[15] Rando identifies anticipatory grief as a psychological response in a person who is becoming more and more aware, not only of his loved one's impending death, but of the associated losses of past, present and future.[14]

Although anticipatory grief has been widely used to explain the grieving process of caregivers of a demented loved one, our clinical experience would indicate several areas where this model does not adequately fit. First and perhaps foremost, as stated by Austrom and Hendrie, caregivers "suffer many real losses, rather than simply anticipating them."[21] Also, according to the literature, anticipatory grieving fulfills several functions,[14,15,27] including to:

- Provide an opportunity to accept the reality of the impending death and openly discuss it with the terminally ill person;
- Allow the caregiver and his loved one to resolve any unfinished business that may exist between them and/or other family members;
- Raise awareness of the dying process; and
- Provide an opportunity for the caregiver to begin to detach or emotionally withdraw from his loved one.

We have found that for our family caregivers, the first two functions – discussing the death and resolving the unfinished business – cannot be fulfilled in most instances, because it is no longer possible to interact and communicate effectively with their dementing loved ones. The third function also may not apply, because in a dementing illness, the person's physical being usually remains intact until late in the disease. This healthy looking body is not congruent with the dying process. These clinical findings are also supported by Austrom and Hendrie, who describe a qualitative difference between the grief response of family caregivers of Alzheimer individuals, and the grief response of family caregivers of those with other terminal illnesses.[21] In respect to the fourth function, we do not see our family caregivers engaging in an emotional withdrawal from their loved ones. There is, in a sense, a detachment and reattachment process. Caregivers detach as their changing roles become, in effect, role reversals. As the dementing illness reduces the loved one's capacity to that of a child, the caregiver's relationship with his loved one changes from that of a spouse or adult child to that of a parent. He may have withdrawn the emotions he attached to his previous role and redirected these emotions to his new role as parent. There is now a sense of reattachment, like a parent-child bonding.

One of our caregivers described the role change between herself and her mother as being an unconscious process that occurred gradually over a long period of time as her mother became more and more dependent and childlike. "The role reversal was so insidious that I didn't even realize it had happened, until one day when I took my mother to a new doctor and introduced her with the comment, “This is Christina, and I am her mother.” This slip stunned me, and at that moment I realized I had undergone a major transition, both psychologically and behaviorally, and had become my mother’s mother.”

It seems clear that none of these four functions of anticipatory grieving can be adequately fulfilled by our caregivers, and in fact the latter two support our theory of the latency of the grief. First, there can be no real awareness of the dying process when the caregiver and those around him are confronted daily with a healthy body. Again, the grief is disenfranchised. Second, as previously stated in our discussion of the attachment theory, it is necessary that the caregiver psychologically detach from the attachment figure in order to come to a resolution of the loss.[14] In these circumstances, although there has been a psychological detachment of the previous bond, there has been a subsequent reattachment and a new bond created. And if Bowlby is correct about the importance of the parent-child bond, then the caregivers have rebounded with their loved one in a very significant way, as seen in caregivers who exhibit very strong attachment and protective behaviours in the care of their loved one. They are often reluctant to leave them in the care of anyone else, even other family members. They make excuses such as “She’ll be frightened if I go,” “She won’t do anything for anyone but me,” “She won’t eat if I’m not there,” and “She doesn’t like strangers.”

We have seen little evidence of anticipatory grief in caregivers who are still maintaining their loved one in the home environment. If, as we believe, caregivers are too overwhelmed by tasks to recognize their need to grieve the real and ongoing losses they experience, how can they possibly take time or find the necessary energy to prepare themselves for losses yet to come? For most caregivers with whom we work, anticipatory loss does not present itself until placement occurs. The finality of placement brings with it the reality that they have now reached the ‘point of no return.’ This is acknowledged by Coughlan, who speaks of placement as precipitating a very real grief reaction in caregivers: “the brutal truth is that nursing homes are places where people with dementia go to wait for death.”[31] She further points out that the grief precipitated by placement is still not the kind that allows a clear straightforward process of grieving and reconciliation.

As previously stated, this notion of a non-linear grieving process in association with caring for someone with dementia is generally agreed upon in the literature.[3,4,6,11-13,15,23,25,32,33] Because the disease is not static or predictable, any period of stability can suddenly be disrupted by a change in the person’s condition. Each change means yet another loss in the loved one, with a corresponding gain in responsibility for the caregiver. There is little wonder that the experience has been equated to a “non-stop emotional roller-coaster ride.”[23] Episodes of stability often bring with them a sense that the ‘person’ is back again as “periods of lucidity break through the swirls of confusion.” It is this experience that is perhaps the most devastating for caregivers, for with the end of the lucid moment they are once again confronted with the ‘death of the person’ they love. Each ‘min-death’ represents a new bereavement that thrusts the caregiver back into shock and denial, further enhancing the latency of the grief.

These unpredictable fluctuations in personality and behaviour require continuous role adaptations in the caregiver. Barrett discusses two types of problems that arise from the emotional adjustment of role changes – task oriented and psychological problems. She suggests that when caregivers take on the tasks previously done by their spouse, such as meal preparation and housekeeping chores, they may experience anger and even disorientation, resulting in anxiety. From a task-oriented perspective, these emotions can be dealt with on a very practical or “fix-it” level, and caregivers can learn to cope with role changes.6 In the case of our caregivers, we do see them adapt to the multiple tasks they face in their caregiving role, most often coping surprisingly well with the day-to-day demands. In essence, they intellectualize their emotional turmoil and blame it on the tasks at hand, nonetheless rising to the occasion to do what must be done. In their head they realize that in spite of their feelings, they can and must cope with the ongoing demands of care. In their heart, however, it is another story, and we see them in great emotional distress, yet unable to direct their anger, guilt, depression, anxiety and helplessness to the real source of their pain, the multiple losses they continuously face, and their latent grief. Barrett agrees that the caregiver identifies his emotions with the tasks, rather than relating them to “the problem behind the problem,” which in her view, is the upheaval of the established patterns in the relationship. She states that the caregiver’s psychological crisis is not due to the additional tasks, but to the fact that his “status quo had been disrupted, and his systems had been turned upside down.”[6]

Barrett’s analysis is consistent with our clinical experience in which we observe that our caregivers perceive their emotions as a response to care and fail to see the “problem behind the problem.” Where we differ is that while we see the underlying problem as latent grief, she sees the unrecognized source of their anxieties as a lifetime of expectations and patterns of behaviour gone awry,[6] which may allude to a sense of symbolic loss in that there is a dramatic change in the established relationship. Her analysis is valid, but she has touched upon only the symbolic loss of the three previously described dimensions of loss experienced by our caregivers. She has overlooked the other two important dimensions – the loss of the person and, ultimately, the loss of self.

Loss of self

The loss of self has been raised consistently in the data we have examined.[10,14,17,20,30] Since, as Cole states, our identity is defined partly by the many roles we play,[20] the caregiver is constantly required to redefine his sense of self, as he relinquishes some of his old roles, usually those of a social nature, and assumes new ones. There is a continuous assault on the integrity of his personal identity, as he is forced to redefine himself on an ongoing basis. Not surprisingly, the caregiver often loses sight of who he really is, seeing himself only in the context of his caregiving role. Gone are the days when his daily life included social activities such as nights out with friends, golfing, bowling or church functions. Caregiving often complain that they cannot even sit down to enjoy their favorite TV programs or read a newspaper without being interrupted by their dementing spouse. This diminished world of constant caregiving adds to the fragmentation of the self, as the caregiver is cut off from his former social and personal roles.

The loved one is irretrievably lost, but the caregiver, in his fragmented state, must find himself and become whole again in order to live on. The caregiver is so enmeshed with his loved one, that he is generally unable to recognize his loss of self and his grief remains occult and latent until he is able to disengage.

Placement is the point where the caregiver is confronted with all three dimensions of loss. He is now physically detached from his partner and can no longer relate his emotions to the burden of care. It is no longer possible for him to ignore the fact that the ‘person’ is gone, as there would be no need for placement if the ‘person’ were intact. He has lost the only real sense of self he may have had, his role of caregiver, and now, for the first time, must face this loss of self as he has no way to define himself at this moment. Symbolically he has been a ‘widow’ for some time, but now his state of quasi-widowhood can no longer be denied. He has lost his partner in the symbolic sense as surely as if she had died.

Caregivers who are adult children can also experience the sense of loss of the parenting role when placement occurs. One of our caregivers very clearly expresses her experience of the three dimensions of loss in the following description of the day she took her mother to a nursing home for placement. She describes the ordeal as a “catastrophic emotional event” that left her with overwhelming feelings of guilt, anxiety, and remorse.

“I left my mother standing at the end of a long hall in the care of a staff member, and as I walked away, I looked back. My mother had a confused expression on her face as she watched me go. She looked so lost, frightened and forlorn that I felt as though I was abandoning my little girl who could not understand why ‘Mommy’ was leaving. The physical distance between us was nothing compared to the emotional distance I began to feel. I had to stop myself from running back down the hall, hugging her tightly and taking her back home with me. It was only when placement was imminent that I began to recognize that I had already lost my mother to this dreadful disease; now I was losing her once again, only this time as my child. The incredible sense of loss was overwhelming. So much of me was wrapped up in her care, I couldn’t even begin to comprehend who I would be without her.”

The above situation encapsulates perfectly the three dimensions of loss that we believe are at the heart of the latent grief experience. Our model includes various dynamics created by these dimensions of loss, which lead to the latency of the grief for the caregiver. First, the ambiguity of the loss results in a lack of clarity as to whether or not there really is something wrong, and also about where the person now fits, not only in the relationship, but also in the family system. Second, the disenfranchisement of the grief by others, and often by the caregiver himself, denies him either the right or the need to grieve. These first two dynamics are major contributors to the caregiver’s initial denial of his grief. Third, since each loss in the loved one results in new demands on the caregiver, he mistakenly directs his emotional response to the burden of care, rather than to the losses that precipitated it. Fourth, not only are the losses ongoing and unpredictable, but they are often simultaneous, leaving the caregiver in a perpetual state of emotional imbalance. Fifth, as the caregiver detaches and withdraws his emotions from his role as spouse or adult child, he subsequently reattaches and redirects his emotions to his new role as parent. Sixth, the paradoxical issues of quasi-death (physically present/psychologically dead), and quasi-widowhood (married, but alone) leave the caregiver in a state of ambivalence. Seventh, each new loss forces the caregiver to revert to a previous stage of the grieving process, often into a new denial. This nonlinear process results in the grief continually being buried, further enhancing its latency. Eighth, the unresolved grief is the result, not of pathological grieving, but of the pathological circumstances in which the caregiver finds himself. Finally, the constant role changes require that the caregiver must continually adapt and redefine his shattered sense of self.

Any one of these dynamics could contribute to the caregiver's need to bury his grief, and most caregivers are caught up in them all at any given time. The sense of chaos created by these circumstances is overpowering for the caregiver, but directing his emotional response to the care demands, rather than recognizing that the real source of his emotions is his latent grief, only adds to his emotional distress. His anger, depression and helplessness around the constant demands now placed on him contribute further to his feelings of guilt and anxiety. His guilt stems not only from his feelings toward the caregiving role, but also from a deep sense of personal failure, since from his perspective, he is unable to provide the care as efficiently, effectively, lovingly and patiently as he thinks he should. This thinking is evident in our caregivers and results in limiting their capacity to make effective decisions, not only on behalf of their loved one, but for themselves as well.

To relieve the caregiver's emotional turmoil, it is necessary that the family, friends and professionals who provide support to him and his loved one, validate the fact that he is engulfed in pathological circumstances not of his own making. Such validation will help to relieve his sense of disenfranchisement and free him to grieve openly. As Shakespeare so eloquently states in MacBeth, "Give sorrow words; the grief that does not speak knits up the o'er wrought heart and bids it break." If others recognize and acknowledge the dynamics of the losses, particularly the ambiguity of it all, the caregiver will feel more supported and less inclined to bury his grief. He needs to know that his emotions are both normal and legitimate. He has a right to feel angry, guilty, anxious, depressed and helpless about this dreadful disease that is stealing his loved one away in increments, robbing him of his hopes and dreams of a future and fragmenting his sense of personal identity.

Discussion

We have attempted to promote an understanding of the caregiver's unique grief experience by providing our preliminary model of latent grief. We believe this model clearly demonstrates that, in addition to accessing information on dementia and coping strategies for effective caregiving, there is also an urgent need for caregivers to have access to grief counseling from the outset. In so doing, not only will they be more effective in their caregiving role, but they will also come away from the caregiving experience with a greater sense of emotional and physical well-being and a more integrated sense of self.

Further research is required to find empirical data that will support or modify our model, taking into account variables not addresses in this paper including age, gender, length and type of relationship with the dementing individual, and/or cultural and ethnic background. There is no dispute that dementia caregivers do eventually engage in overt grieving, but the long period of latent grief has significant implications for the healthcare system, as long-term care moves from the institutional setting to the community. It is essential for all that we come to an understanding of this unique and hidden grief in caregivers.

References

1. Ganesan R, Standish T, Molloy D, et al: New treatments for dementia. Myth, Magic & Science. *Canadian Family Physician*. 1994;40: 1149-1157.
2. Oliver R, Bock FA: *Coping with Alzheimer's: A Caregiver's Emotional Survival Guide*. North Hollywood, California, Wilshire Books, 1987
3. Gruetzner H: *Alzheimer's: A Caregiver's Guide & Source Book*. New York: John Wiley & Sons Inc., 1992.
4. Mace NL, Rabins PV: *The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementing Illnesses, and Memory Loss in Life*. Baltimore: John Hopkins University Press, 1991.
5. Gallagher D. Wrabetz A, Lovett S, et al: Depression and other negative affects in family caregivers. In Light E, Lebowitz BD (eds). *Alzheimer Disease Treatment & Family Stress.* New York: Harper & Ros, 1990; 218 – 244.
6. Carroll D: *When Your Loved One Has Alzheimer's*. New York: Harper & Row, 1990.
7. Shadday-Haarhoff A: The effects of a bereavement support group on caregivers of Alzheimer victims. *The American Journal of Alzheimer's Care and Related Disorders & Research.* 1992; 3(7): 24 – 30.
8. Bowlby J: *Attachment and Loss Volume II, Separation, Anxiety and Anger.* New York: Basic Books, Inc., 1973.
9. Davidson G: The waiting vulture syndrome. In Schoenberg B, Gerber I, Wiener A, et al (eds.): *Bereavement & Its Psychosocial Aspects.* New York: Columbia University Press, 1975; 357 – 361.
10. Forsythe E: *Alzheimer's Disease, The Long Bereavement.* London: Faber & Faber, 1990.
11. Stearns A: *Living Through Personal Crisis*. New York, Ballantine Books, 1984.
12. Walsh F, McGoldreick M: Loss and the family: A systemic perspective. In Walsh F, McGoldrick M (eds.). *Living Beyond Loss, Death in the Family.* New York: W.W. Norton & Company, 1991; 1 – 29.
13. Worden JW: *Grief Counselling & Grief Therapy. A Handbook for the Mental Health Practitioner.* New York: Springer Publishing Company, 1991.
14. Rando TA: *Grief, Dying and Death. Clinical Interventions for Caregivers.* Champaign, Illinois: Research Press Company, 1984.
15. Burnell M, Burnell AB: Clinical Management of Bereavement. *A Handbook for Healthcare Professionals.* Human Sciences Press, Inc., 1989.
16. Ballard EL: *Managing Grief and Bereavement: A Guide for Families and Professionals Caring for Memory Impaired Adults and Other Chronically Ill Persons*. Durham, North Carolina: Duke University Medical Centre, 1994.

17. Eaton W: *Unresolved Grief in Family Members of Alzheimer Victims,* 1989.
18. Carr AC: Bereavement as a relative experience. In Schenberg B, Gerber I, Wiener A, et al (eds.). *Bereavement. Its Psychosocial Aspects.* New York: Columbia University Press, 1975; 1 – 8.
19. Parkes C: Bereavement*. Studies of Grief in Adult Life.* New York: International Universities Press, Inc., 1973.
20. Cole D: *After Great Pain A New Life Emerges*. New York: Summit Books, 1992.
21. Austrom M, Hendrie H: The grief response of the Alzheimer's disease family caregiver. *The American Journal of Alzheimer's Care and Related Disorders & Research.* 1990; 5(2): 16 – 27.
22. Doka KJ, Aber R: Psychosocial loss and grief. In Doka KJ (ed). *Disenfranchised Grief: Recognizing Hidden Sorrow.* New York: Maxwell Macmillan International, 1991: 187 – 198.
23. Fabiano L: *Mother, I'm Doing the Best I Can*. Seagrave, Ontario: FLS Publications, 1991.
24. Powell LS, Courtice K: *Alzheimer Disease a Guide for Families.* London: Addison-Wesley Publishing Company, 1983.
25. Collins C, Liken M, King S, Kokinalis C: Loss and Grief Among Family Caregivers of Relatives with Dementia. *Qualitative Health Research.* 1993; 3(2): 236 – 253.
26. Boss P: Ambiguous Loss. In Walsh F, McGoldrick M (eds*.). Living Beyond Loss & Death in the Family.* New York: W.W. Norton & Company, 1991: 164 – 175.
27. Cohen D, Eisdorfer C: *The Loss of Self. A Family Resource for the Care of Alzheimer's Disease and Related Disorders.* New York: Plume Books, 1987.
28. Nicholas P, Jackson L: Grieving Needs of Caregivers. Presented at the Alzheimer Association of Ontario Annual Conference, Toronto, Canada, 1994.
29. Rosenthal DJ, Dawson P: Wives of institutionalized elderly men. The first stage of the transition to quasi widowhood. *Journal of Aging and Health.* 1991; 3(3): 315 – 334.
30. Coughlan PB: *Facing Alzheimer's. Family Caregiver Speak.* New York: Ballantine Books, 1993.
31. Aronson M: Patients & Families: Impact and long-term management implications. In Aronson M (ed.). *Understanding Alzheimer's Disease. What It Is: How to Cope with It; Future Directions.* New York: Charles Scribner's Sons, 1988; 74 – 88.
32. Roberts DJ: *Taking Care of Caregiver. For Families & Others Who Care for People with Alzheimer's Disease and Other Forms of Dementia.* Palo Alto, California, Bull Publishing Company, 1991.
33. Zarit SH, Orr NK, Zarit JM: *The Hidden Victims of Alzheimer's Disease: Families Under Stress.* New York: New York University Press, 1988.
34. Bowlby J: *Attachment and Loss: Attachment, Vol. 1.* New York: Basic Books, 1978.
35. Kubler-Ross E: *On Death and Dying.* New York: McMillan Publishing, 1969.
36. Cohler BJ, Groves L, Borden W, Lazarus L: Caring for family members with Alzheimer's Disease. In Light E, Lebowitz BD (eds.). *Alzheimer Disease Treatment and Family Stress.* New York: Hemisphere Publishing Corp., 1990; 50 – 105.
37. Rolland JS: Helping families out with anticipatory loss. In Walsh F, McGoldrich M (eds.). *Living Beyond Loss*. New York: W.W. North & Company, 1991; 144 – 163.