

**INTRODUCING THE 3-A GRIEF INTERVENTION  
MODEL FOR DEMENTIA CAREGIVERS:  
ACKNOWLEDGE, ASSESS AND ASSIST**

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**ABSTRACT**

With our aging population, it is estimated that in the near future there will be an overwhelming increase in the number of individuals dealing with Alzheimer's disease or a related dementia (ADRD). From the time that symptoms begin to insidiously emerge, it can take well over ten years for the disease to run its course. In addition to the crippling effect for those inflicted, this lengthy duration can have an ongoing debilitating effect on the family members who are grieving while providing care. Researchers have claimed that the manner in which family members experience and manage their grief reactions to the pre-death losses can influence both caregiving outcomes and adjustment to bereavement once those with the disease have died. Given the relevance of grief management, this article provides answers to such questions as: How do family caregivers of individuals with ADRD manifest their grief? How can healthcare professionals intervene in assisting with grief management? The answers are provided introducing the 3-A grief intervention model for family caregivers of individuals with ADRD. The 3-A model enfranchises the caregiver grief experience through Acknowledging, Assessing, and Assisting in grief management. In doing so, different grieving styles are identified and the role that denial and respite plays in adapting to the family caregiver's grief experience is recognized. Clinical strategies to assist in grief management are also provided.

## INTRODUCTION

Dementia is a neurological disorder affecting cognitive functioning that can be either reversible or irreversible. Alzheimer's disease is irreversible, and accounts for 60% of dementias. With our aging population, it is estimated that there will be an overwhelming increase in the number of individuals dealing with Alzheimer's disease or a related dementia (ADRD) in the near future. The average length of time from diagnosis to death is four to eight years, although it can take twenty years or more to run its course (Alzheimer Society of Canada, 2006; Hart, 2001). In addition to the crippling effect for those inflicted, this lengthy duration can have a debilitating effect on the family members who are providing care. As individuals with ADRD are living through the disease process, the family members are simultaneously experiencing a multitude of losses and grieving while at the same time also providing care.

This article attempts to shed light on how grief is embedded in the family members' experience of providing care for individuals with ADRD. The objective is to unravel the embedded grief by introducing the 3-A grief intervention model for dementia caregivers. The grief is unraveled through Acknowledgment, Assessment and Assistance provided so that family caregivers can adapt to the losses brought on by the disease.

Grief is recognized as a natural expectable reaction to many kinds of significant losses including the losses families go through in the dementia caregiving experience (Dempsey & Baago, 1998; Dhooper, 1991; Mace & Rabins, 1999; Peterson, 2006; Ponder & Pomeroy, 1996; Walker, Pomeroy, McNeil, & Franklin, 1994a). Although the literature on caregiver grief and intervention strategies is growing (Adams & Sanders, 2004; Burns, Nichols, Martindale-Adams et al., 2003; Doka, 2004; Kasl-Godley, 2003; Meuser, Marwit, & Sanders, 2004; Sanders & Saltz Corley, 2003), I have observed firsthand as a clinical social worker in the field for over five years that grief interventions are not being used in practice with caregivers. There has been little to no change since 1993 when I became a family caregiver for my father, who was living with dementia until he passed away in 1997.

I was a family caregiver years prior to practicing clinically. It was painstaking witnessing the disease gradually rob my father of his cognitive abilities and his dignity. As the disease progressed, it became more challenging to maintain his dignity. He had always been an immaculate, well-groomed man with a cheerful disposition. Apathy set in due to the illness. As the disease progressed, it was upsetting when others had to maintain his hygiene for him, knowing that others could not ever meet his once high standard of grooming. Particularly gut wrenching was moving my father out of his "pride of ownership" home and into residential care where he spent the last three years of his life. In the last six months of his life, his once cheerful disposition turned into a totally flat affect.

There was social work assistance provided in making decisions about my father's care but no clinical recognition or assistance provided for the "grey cloud

hanging over my head” as the disease progressed. It was not until providing support to dementia caregivers professionally that I noticed so many caregivers echoing the same remorse that was personally experienced. They were also helplessly questioning why the remaining years of those inflicted had to be lived in such an undignified manner.

Sanders and Saltz Corley (2003) noted that social workers neglect grief but assess depression and stress. In practice, this neglect could be extended to other healthcare professionals as well. An explanation for grief not being adequately addressed in practice could be that just like those in the general population (Neimeyer, 1994; Questia, 2006), health care professionals may have a difficult time themselves dealing with issues of death and dying. Unfortunately, neglecting the grief experience can make it harder for family members who are providing care with a “cloud hanging over their heads.” It would have been so relieving and helpful to have had someone acknowledge and normalize my grief and provide assistance throughout the disease process.

Based on personal experience, I feel justified in applying the grief paradigm in social work practice with dementia caregivers and feel fortunate to work in an agency that supports this client-centered practice. Addressing the grief is beneficial for adaptation to the uncontrollable circumstances families have to endure due to the disease. The provision of psychosocial support consequently can serve as a means of prevention. It makes sense that family members receiving assistance so they may adequately cope with the caregiver role will ultimately not need to seek out medical treatment for conditions such as depression.

Kasl-Godley (2003) argued that the degree to which family caregivers are able to cope effectively and adapt to relationship and role changes and losses is largely determined by how caregivers manage their grief around these losses. She made reference to Bass and Bowman’s (1990) and Bass, Bowman and Noekler’s (1991) research, proclaiming that the manner in which family caregivers experience and manage their grief reactions to the pre-death losses can influence not only caregiving outcomes but also subsequent adjustment once those with ADRD have died. Linking pre-death grief and post-death adaptation suggests that caregiving and bereavement be treated as a continuous, chronic, stressful situation.

## METHODOLOGY

Since grief management is being addressed as relevant to caregiving and bereavement outcomes, knowledgeable intervention, including grief assessment, is germane. In this article, an interpretive approach is being taken utilizing grounded theory, obtaining theory from data, to present the 3-A grief intervention model for dementia caregivers, the “A’s” representing the psychosocial components of Acknowledging, Assessing and Assisting in grief management.

Different methods have been used in this article to establish trustworthiness in presenting this grief intervention model. Firstly, the literature was reviewed, substantiating grief as integral to the dementia caregiving experience, particularly by translating existing grief models into clinical directions of practice with family caregivers of individuals with ADRD. Further substantiation was provided through my personal caregiving experience and accounts taken from informal, open ended interviews with three spousal caregivers, one male and two female, and one male son providing care. These four caregivers spoke about their experience from the onset of symptoms to the present. At the time of the interview, each of the caregivers either had a family member in a nursing home or was arranging for nursing home placement. They had been receiving ongoing social work support for at least two years. Each of the participants reviewed and validated what was written about their experience. Caregiver accounts from the literature are also included. My observations from clinical practice are relayed, having provided ongoing support to over five hundred families through home visits, telephone contacts and family support group facilitation at the Alzheimer Society of York Region. Finally, peer reviews were carried out with the senior social worker and director of the Alzheimer Society of York Region and a social worker presently practicing in a long term care facility in York Region.

This model of intervention is based on substantiating data taken from clinical practice demonstrating how several existing grief models apply in the caregiver milieu. In other words, a grief model is being derived from practice, the practice which has been derived from the application of existing grief models. It may be best understood as the alignment of practice with existing grief models which validates the development of a caregiver grief intervention model. The best way to illustrate the alignment is to present the substantiating data of caregiver accounts and practice intertwined within the grief theories in the literature review. Although different from the conventional presentation format of sectioning off the literature review from the data, the intertwining format is more effective for illustrating the objective. The data obtained from practice or caregiver accounts is well identified in this intertwined format.

### **ACKNOWLEDGING LOSS**

Alzheimer Disease can be described in three stages: early, middle, and late. Each stage could span for years. In practice, many caregivers reflect that the disease started years prior to diagnosis. Early on, symptoms have an insidious onset with most apparent indications being mild forgetfulness, difficulty following conversations, and getting lost in familiar places. Everyday functioning abilities such as dressing, bathing, and toileting remain relatively intact. As the disease progresses into the middle stage, assistance is required with dressing, bathing and toileting. More impairment is evident in memory, orientation to time and place, and ability to recognize people. In the late stage, the deterioration is more severe

and 24-hour care is required, with the impaired individual eventually being bedridden, sleeping more, and losing the ability to speak (Alzheimer Society of Canada, 2006; Hart, 2001).

The onset of symptoms is a catalyst for a series of losses to follow throughout the disease process. Research has been done on loss based on stage of ADRD. Adams and Sanders' (2004) results from their study of caregiver losses experienced based on stage conflicted with Meuser and Marwit's (2001) results in defining a stage-sensitive model of grief in dementia caregiving. One of the discrepancies was that Adams and Sanders did not find a significant difference, whereas, Meuser and Marwit found a significant difference in losses and grief reactions between those caring for a spouse and a parent.

Although loss and relationship type are important determinants of grief, they are not the only variables affecting the grief reaction. In Meuser, Marwit, and Sanders' (2004) article on assessing grief in family caregivers, they identify in their causal model multiple determinants of grief expression. Individual personality, situational and cultural factors are other variables to consider. Therefore, although there may be similarities based on stage and relationship type, it appears that each caregiver's loss experience is individual.

Betsy Peterson (2006), having been a spousal caregiver, signified different losses by stage through specific landmarks. In the earlier stage, a landmark of loss identified was when the doctor informs the family that the inflicted should not drive, and at a later stage when the individual with the disease asks the spouse what their daughter's name is. She identified the most excruciating landmark as placement of the inflicted family member into residential care.

Dempsey and Baago (1998) identified three dimensions of loss that caregivers experience: loss of the person inflicted, loss of personal identity, and symbolic loss of the ideal. In practice, many express sadness as the disease progresses at "what has become" of their family member. They have lost the person that conversed with them or/and paid the bills or/and given them advice or/and cooked their meals. The list grows as the disease progresses. Following is an account by Marian Ritchie (2005) from her book *The Long Way Home, A Journey through Alzheimer's*, writing about the changes in her husband brought on by the disease,

Everything was different! Edwin had become someone else—a stranger to me—and I was now being forced to start down a new road, an uncertain road, and a treacherous road to an unknown and frightening future.

As a family caregiver, Ritchie (2005) described time to herself as "precious and rare" as the disease progressed. In Butcher, Holkup, and Buckwalter's (2001) article describing the experience of caring for a family member with ADRD, they captured the loss of freedom by quoting a caregiver who relayed "It makes you a prisoner . . .". They also reported that the caregivers realized that their dreams for retirement in the golden years were not accessible. In practice, spousal caregivers often proclaim that "the golden years are not so golden!"

### ACKNOWLEDGING GRIEF

Betsy Peterson (2006) wrote about her experience as a family caregiver for her spouse, Pete, who was diagnosed in 1987 and died in 2001. In her writings, she expressed that it took her years to recognize that while caregiving, she was grieving for her husband in similar ways that individuals grieve a death. She stated there was no guidance for family members in dealing with the grief. Consequently, she felt there was something wrong with her, but continued to believe that what she was experiencing was not unusual or unhealthy. She questioned why the grief had not been addressed. Her own experience inspired the writing of her book *Voices of Alzheimer's: Courage, Hope and Love in the Face of Dementia*.

Dan is a caring son who submitted an article to the Toronto Star newspaper about his father, who at the time was attending the Alzheimer Society day program. He wrote:

The family endures two separate losses and grieves twice, once as the personality they recognize and love gradually disappears and finally when the patient dies (Horowitz, 2005).

Some family members, like Dan Horowitz and Betsy Peterson, recognize on their own the grief which accompanies ADRD. For intervention purposes, health care professionals need to know that a substantial number of caregivers only recognize they are grieving after they are told this is what is happening to them. Family caregivers often will not acknowledge on their own that they are grieving (Adams & Sanders, 2004; Dempsey & Baago, 1998). They may not fully comprehend what the grief experience is. An example is Bill, a son who provides care to his mother who is in the latter stage of the disease and lives in a nursing home. In providing an account of his experience, he did not perceive caregiving as a burden. When he was asked if he was grieving his mother, he questioned: "What is grief?"

Grief, the reaction to a significant loss, seemed foreign to Bill and to explain it is not so simple since grief is individually expressed emotionally, cognitively, spiritually, physically, and/or behaviorally (Rentz, Krikorian, & Keys, 2005). Bill's father, Larry presents as grieving behaviorally. Larry stated in his account that he never identified with the term "caregiver," explained caring for his wife as "my duty as a husband. . . for better or for worse . . . she would do it for me." He agreed, only when it was suggested, that he was doing grief work. On his own, he did not mention grieving.

In addition to the terms "hidden grievers" and "ambiguous loss" being used to describe caregivers and their reaction to the losses brought on by infliction of the disease (Dempsey & Baago, 1998; Dupuis, 2002; Boss, 1999), another term that has been used is "disenfranchised grief" (Doka, 2004; Dempsey & Baago, 1998; Doka, 1989). Grief has been identified as disenfranchised by the shame, secrecy, and stigma associated with Alzheimer Disease. Based on observation in practice, fear could also be added to that list. Doka (2004) described disenfranchised grief

as a reaction to a loss that cannot be socially sanctioned, openly acknowledged or publicly mourned. He identified that not all losses are death-related. Some of the contexts of disenfranchised grief are when the relationship and/or the loss is not recognized. Doka (2005) included caregivers in his list of relationships that are not socially recognized. Psychosocial loss and illness were included on his list of losses that are not socially recognized.

According to Boss (1999), the grief of caregivers is compounded by not knowing whether a loved person is absent or present. This ambiguity creates confusion for caregivers about roles within relationships and creates guilt in caregivers about experiencing feelings of grief. Because of this ambiguity, it is often difficult for caregivers to accurately recognize feelings of grief before the family member actually dies. Consequently, grief symptoms may be treated medically, identified as different conditions, such as depression (Walker & Pomeroy, 1996; Adams & Sanders, 2004).

Ambiguous loss, death anxiety and the stigma associated with ADRD are explanations for why grief is overlooked. The stigma impedes caregivers normal anticipatory grief processes (Walker, Pomeroy, McNeil, & Franklin, 1994; Adams & Sanders, 2004). Rando (1986) defined “anticipatory grief” as a multi-process phenomenon which prepares individuals for the death of the terminally ill person and facilitates adaptation to bereavement. One of the functions identified for anticipatory grief is to decrease attachment (Kasl-Godley, 2003). Peterson (2006) expressed opposition to the term “anticipatory grief,” retorting “What the hell is ‘anticipatory’ if your husband can no longer carry on a conversation?” Meuser, Marwit, and Sanders (2004) and Lindren, Connelly, and Gaspar (1999) found that the family members providing care to individuals with ADRD are reacting to felt loss experienced in the present rather than in anticipation of future death. In practice, many caregivers seem to be grieving in the present while at the same time anticipating future loss.

During this grieving process, family members are involved in the integral aspect of caregiving. The grief experience is often overlooked in the caregiving literature despite the fact that dementia caregiving is well recognized in the grief literature. In Gottlieb and Wolfe’s (2002) critical review of coping with family caregiving, grief is not mentioned. In Aneshensel, Pearlin, Mullen, Zarit, and Wiltch’s (1995) book, *Profiles of Caregiving: The Unexpected Career*, they developed a model of the “caregiver career” that progresses through various phases, including role acquisition at the beginning of providing care, role enactment which entails providing care in the home to placement in a nursing home facility as the disease progresses and then role disengagement which includes the final loss of the care receiver through death which leads to the subsequent bereavement process. It was only at the time of death that caregiver grief was recognized in this reference book on caregiving.

Burns et al. (2003) acknowledged in their Resources for Enhancing Alzheimer’s Caregiver Health (REACH) project that ADRD caregivers experience grief. They

however used a depression rather than a grief measure of health in their study. Since Freud's (1924) monumental work, *Mourning and Melancholia*, there have been other articles about the similarities and distinction between grief and depression (Prigerson, Bierhals, & Kasl, 1996; Robinson & Fleming, 1989; Walker & Pomeroy, 1996).

With grief acknowledged in the study, one might question, why the Center for Epidemiological Studies Depression (CES-D) scale (Radloff, 1977) was used instead of the Marwit-Meuser (2001) Caregiver Grief Inventory or Sanders, Mager and Strong's (1985) Grief Experience Inventory (GEI). The GEI was used in Lindgren, Connelly, and Gaspar's (1999) study to measure grief reactions in spouses and adult children providing care to dementia patients. An explanation for a grief scale not being used could be, relating back to a point made earlier in this article, that grief is often neglected, and rather treated medically, identified as depression. Grief is also not identified as a medical condition so may not be associated as a measure of health and well-being.

In some caregiving articles, grief gets some acknowledgment but is not given enough credence. In the caregiver literature review provided by Dhooper (1991), grief was acknowledged similarly as it was in Burns, Nichols, Martindale-Adams et al.'s (2003) article. In providing Teusink and Mahler's (1984) stages families go through in reaction to the Alzheimer's disease process, Dhooper, though acknowledging grief, did not go further to mention that the stages parallel with Elizabeth Kübler Ross's (1969) stages that people go through in the dying process. Elizabeth Kübler Ross, a pioneer in the field of death and dying postulated that in the dying process, people go through stages of denial, anger, bargaining, depression and finally acceptance. Teusink and Mahler's stages paralleled by describing caregivers' reactions to the changes in inflicted family members as moving from denial to acceptance. Also, grief symptoms of anger and guilt (Shuchter & Zisook, 1993) were included in the caregiving stages.

In this present article, grief is being given ample credence through combining the grief and caregiving paradigms so that the embedded grief is unraveled, thus supporting the need to acknowledge and implement clinical strategies that address caregiver grief. As mentioned earlier, addressing, rather than neglecting grief could serve a vital purpose in preventing the need for medical treatment of conditions such as depression.

### **ASSESSING: CAREGIVER GRIEVING STYLE**

Since Kübler Ross's work, there have been other theorists that have made modifications to her model. Commonly used in counseling is Worden's (1991) model for resolving grief through the subsequent "grief work" tasks of accepting the reality of the loss, experiencing the pain of grief, adjusting to an environment in which the loss object is missing, emotionally relocating the deceased/loss and moving on with life.

Worden's task model is well-suited for an intuitive griever. Martin and Doka (2000) noted that everyone does not grieve the same way and identified two styles of grieving, intuitive and instrumental. In addition to acknowledging the different styles, assessing the styles is required to determine if the caregiver is managing the grief in an adaptive or maladaptive manner. While intuitive grievers are more likely to experience their grief as waves of affect, instrumental grievers are more likely to experience it in physical terms or cognitively. While intuitive grievers often need to express their feelings and seek support, instrumental grievers are more likely to be cognitively processing or immersing themselves in activity (Martin & Doka, 2000). In other words, it could be stated that intuitive grievers "feel" the grief while instrumental grievers "do" the grief.

Caregivers who are intuitive grievers manifest the grief symptoms overtly as feelings. These feelings are described as intense inner pain, helplessness, hopelessness and loneliness. It is not unusual for intuitive grievers to express themselves through tears. They can experience a myriad of symptoms including sadness, pining for the loss object, irritability, anxiety, inability to concentrate, anger, regrets, and guilt (Martin & Doka, 2000).

Guilt is frequently assessed in caregivers, and can be crippling, especially around obtaining caregiving relief and nursing home placement. A good example is Jane, who provided care for years to her husband who she described in her account as a "bully," domineering throughout their marriage. Although one might assume that Jane would be relieved to be free of this man when he was placed in a nursing home, this was not the case. Initially she felt very guilty and for months required support to stop her from bringing him back home because he was pushing for her to take him home. She described the first few months after placement "were very lonely in spite of everything else . . . not having an easy life with him." Over the months she has come to see that she has "the freedom that I had not had in the last 60 years" of marriage. She is slowly adapting, with ongoing support, to an environment without her husband.

Guilt, anger and anxiety are apparent intuitive grief symptoms. Less apparent in assessing would be caregivers with an instrumental style, which is the more covert manifestation of grief symptoms. People who are grieving do not all walk around as though there is "a grey cloud hanging over their heads." The key elements that function together for instrumental grievers are the focus on cognition with a moderated affect, the reluctance to talk about feelings, the desire to master feelings and problem solving activity. Solving problems created by or associated with the loss is effective in providing instrumental grievers with an outlet for action (Martin & Doka, 2000).

In death-related loss, instrumental grievers problem solve by joining an organization promoting a cause associated with the death. As in death-related loss, in dealing with "psychological loss" or/and "ambiguous loss" due to AD/DRD, family members may also grieve instrumentally through promoting a cause associated with the illness. In this context, the literary works of Betsy Peterson (2006) and

Marian Ritchie (2005) could be viewed as instrumental grieving. Peterson and Ritchie each wrote books based on their experience with the objective of helping other caregivers.

Family members may also instrumentally problem solve through entering and attempting to master the “caregiving career.” Sanders and Saltz Corley (2003) noted that for many “career caregivers,” their grief is related to their identity as a caregiver, which often supersedes other social roles (p. 52). Identifying with the caregiving role complements an instrumental grieving style. Based on observation, I claim that these family members unconsciously enter into the caregiving role to fulfill their “grief work” instrumentally. Marian Ritchie (2005) reiterated “for better or worse” in describing her commitment to providing care for her husband. This was in response to a geriatrician who questioned her investment in this situation given that it was a second marriage and they had only been together for a few years. Ritchie expressed shock at the doctor’s attitude realizing she could never walk out on her husband. In practice, many spouses have voiced that providing care is an “obligation” and/or “s/he would have done the same for me.” Larry is the caregiving spouse mentioned earlier who voiced those same words, acknowledging he was grieving when it was suggested to him while being interviewed. He now spends six hours a day excluding weekends in the nursing home with his wife. He relayed that he normally does not like to go to places exclusively for old people. His words about going to the nursing home daily were: “What would I do if I wasn’t doing this. . . . I would not be doing this if my wife was not there.”

Schulz, Boerner, Shear, Zhang, and Gitlin (2006) noted that benefiting from the caregiving role could be a predictor for having a complicated grief experience after the death of the inflicted family member. They referred to Prigerson et al.’s (1997) work, explaining that one of the reasons for having a complicated grief experience after death is that perceiving the caregiving role positively may be a reflection of high attachment or dependency to the person they cared for. According to Bowlby (1997), complications can occur in grief resolution due to attachment symptoms of separation distress, such as yearning, pining and searching for the loss object. He identified that the goal of attachment behaviour is to maintain a bond. Any situation that endangers the attachment bond will elicit action to preserve the bond. The actions and intensity elicited are dependent upon the degree of danger of loss. Due to attachment issues, one could also surmise that family caregivers who are highly attached to the care recipient may have a complicated grieving experience prior to the inflicted family members’ death. These would be the individuals who insist while providing care at home that the situation is under control even if it appears to the healthcare professional as though it is not under control and more appropriate provisions of care are required. There are different degrees of behavior to assess, the most extreme being caregivers who deny having problems and resist to obtaining any assistance with care. These caregivers are clinging to who the care recipients were prior to the disease rather

than who they have become. They are clinging to what these inflicted family members represent such as the roles they played in the family and/or companionship. Through clinical observation, many care recipients represent loss of financial security especially when considering the expense related to nursing home placement.

Deep emotion may be displayed, often in tears by caregivers who are assessed as highly attached. The deep emotional stress may not just be attributed to danger of losing the attachment figure. Simultaneous to the threat of loss, the emotion may also be in reaction to the heavy burden of providing care. This may be particularly evident in the advanced stage of the disease when symptoms such as mobility and/or toileting and/or aggression become too difficult to handle. In practice, some family caregivers verbalize stress and fear of being without the inflicted family member, of being alone. Some family caregivers may isolate themselves and/or even resort to alcohol drinking to cope with the grief and caregiver stress. Accepting help threatens the attachment bond, the status quo. These individuals more often than not lack insight of their situation, are not forthcoming, presenting as resistant and/or in denial. Doka (2004) makes reference to Quayhagen and Quayhagen (1988) who noted that accepting help from formal agencies does not allow the defense of denial.

### **ASSESSING: DENIAL**

Denial and shock have been identified as the first stage in the grief process by many grief theorists proposing stages of normal grieving (Bowlby, 1997; Kubler-Ross, 1969; Shuchter & Zisook, 1993). Shuchter and Zisook (1993) caution against taking the stages too literally, noting that grief is not a linear process but rather a composite of overlapping phases that are unique to the individual. This is particularly true pertaining to ADRD caregivers. A grief reaction of denial is not exclusive to the early stage of the disease but can be witnessed in the later stages, especially when facing nursing home placement.

Rita is a caregiver who is now struggling in the later stage of arranging permanent nursing home placement for her spouse. Rita is facing, as Jane did, the task of adjusting to a future environment without her spouse. The step toward "letting go," fulfilling Worden's (1991) task of adjusting to an environment without the inflicted family member or emotionally relocating the loss, may be fulfilled with nursing home placement. There are so many caregivers, like Rita and Jane, who have difficulty facing nursing home placement. Consequently, these caregivers experience fatigue and burnout and reach a point where they can no longer deny the inevitable.

Rita is facing reality and has recently taken a major step in accepting short term respite for her spouse in a nursing home. Short term stay in a nursing home is just one form of taking respite. Respite refers to the relief provided for caregivers to assist them in coping with the multitude of tasks involved in caregiving. Other forms of respite include receiving home support and day program attendance for

those inflicted with the disease. Respite can be provided formally by a paid caregiver or informally from a family member. Earlier in the disease process, Rita also struggled with the notion of having her spouse attend the Alzheimer's day program every day. She had to make several adjustments throughout the disease process. Following is her account of what she was dealing with years ago in the early stage of becoming a caregiver shortly after her spouse took early retirement:

I knew there was something amiss . . . I started making excuses. . . . I blamed myself . . . I then thought it was because he retired . . . I could not imagine being his caregiver . . . he was a brilliant man. . . . I became very concerned when he could not find his way to the place he regularly went to meet his friend . . . after much cajoling for over a year we went to see the doctor and we got a diagnosis. . . . I then changed my attitude. . . . I became his caregiver rather than his partner. . . . I stopped trying to reason with him. . . . I acknowledged and accepted that I had a loss here . . . it removed expectations . . . I reasoned it to myself with a broken heart . . . the more I took on acceptance the easier it was for me to take care of him because I answered his needs . . . if I took a blind eye and did not accept, I would not be able to take care of him. . . .

It took some time in the early stage of the disease for Rita to acknowledge the importance of accepting the reality of loss in order to provide care. In Aneshensel and colleagues' (1995) model of the "caregiver career" that progresses through various phases, the beginning phase of providing care is role acquisition. From a grief perspective, accepting the reality of loss is required for family members to acquire the caregiving role. Larry has also been through the disease process with his wife. He commented about another man who has a wife just starting to show symptoms of ADRD. He stated this man "knows there is something wrong but he can't admit it . . . it is frightening." It can be frightening early in the disease process. Due to fear, family members may deny that there is an illness especially when symptoms characteristic of the disease are not consistent.

In practice, a common report family members often make in the earlier stage is "there are good days and bad days." Family members may not see the necessity of taking on a caregiving role for individuals with ADRD who are physically healthy and still functional, carrying out activities of daily living, such as dressing, toileting, and eating without assistance. It is also easy in the beginning to doubt the diagnosis, contributing symptoms, such as forgetfulness, to aging rather than to the disease (Dhooper, 1991). By doubting the diagnosis, the family does not have to face the reality of the losses that go along with the diagnosis. Due to the disenfranchised nature of the circumstances, family members may easily react in denial, not only denying the loss, but also denying the caregiving role.

In practice, a major contributing factor observed for family members to be in denial of the loss and avoid acquiring the caregiving role is the family dynamics. For instance, in couple dynamics where the spouse with ADRD has been very controlling, the inflicted person maintains control even after a diagnosis of the disease and often well into the disease process. The family member has historically

been controlled by the inflicted spouse. Therefore, it is difficult to start taking over, making the decisions, especially when the controlling spouse with the disease is insistent of still being the decision maker and the controlled spouse is fearful, locked in a power imbalance. Jane, the caregiver mentioned earlier who has the domineering spouse, fits this profile of being on the receiving end of a power imbalance. Jane described herself as being “bullied” and further relayed:

He was not an easy man, it always had to be his way. . . . He did not like me going out and doing things on my own. . . . I have always been on edge with him, always wondering what he is going to say. . . . I didn't grow up able to fight back . . . he could have me in tears very easily.

Jane initially reached out for social work support from the Alzheimer Society five years ago. She made sporadic calls when she could, when her husband went out. After her first call she proclaimed “I now have a lifeline!” Intervention from the Alzheimer's Society had begun with her acknowledging she was receiving support for the disease. At that time, early in the disease process, she was very concerned about their upcoming trip to Florida and she did not want him driving. She was not able to stand up to him and they ended up to her dismay going to Florida. For years, the sporadic contacts continued between Jane and the Alzheimer Society, Jane eventually allowing a home visit. In the last year, as the disease progressed, there was increasingly more support provided. Her husband was moved to a nursing home just over six months ago. Jane reported regrettably that due to her resentful feelings towards him, she had less patience providing care for him than for her children.

Many adult children in practice have echoed my sentiments as a daughter who was caregiving her father. They assume the caregiving role to give back what they received. Social work assistance, though, is often required in dealing with the hardship of taking over roles such as financial decision making for their parents. Historical conflict in the relationship can contribute to the difficulty of acquiring the caregiving role. Also, personality plays a role. Becoming a caregiver is not a fit for everybody and some people fit into the role more comfortably than others. If it works in their favor, people could deny anything is wrong.

### **ASSISTING: TAKING RESPITE**

In death-related conventional grief models, denial is an initial phase to be overcome in order to proceed in the grieving process. In this context, denial is often perceived as detrimental to accepting the reality of loss, particularly if people have difficulty moving out of denial. In the caregiving context, Meuser, Marwit, and Sanders (2004) questioned if dementia caregivers should be prompted to accept the reality of a pending loss when that final loss may be several years away. Interpreted in other words, is it okay for caregivers to deny, especially in the early stage?

In Stroebe and Schut's (1999) dual process model of coping with loss, they take a contrary stance, arguing that denying or avoiding aspects of grieving is required for healthy coping. Stroebe and Schut (1999) moved away from the stage/phase model, proposing that adaptive coping with loss is composed of confrontation-avoidance of loss-oriented stressors and restoration-oriented stressors. Loss-orientation refers to the concentration on processing of some aspect of the loss experience itself. Restoration-orientation refers to secondary sources related to, and coping with, stress due to the loss. In other words, restoration is focusing on what needs to be dealt with, such as social loneliness, and how it is dealt with, or restoring well being and social reintegration.

In the dual process model, an integral part of adaptive coping is the need to take respite from dealing with either of the stressors through oscillation. Oscillation, a central component of the model, is a dynamic process, referring to the alternation between loss-oriented and restoration-oriented coping, the process of avoidance and confrontation of different stressors associated with the loss.

Caregivers can experience oscillation between loss stressors and restoration-oriented stressors by taking respite hours having their family members with ADRD attend a day program. As the disease progresses, the caregivers experience stress due to loss of personal freedom as the demands for care are higher. By taking time away from the loss-oriented stressor through respite, caregivers are provided with some freedom to attend to restoration-oriented stressors, such as individual well being and/or social reintegration.

### **ASSISTING: CLINICAL STRATEGIES**

Encouraging respite assists in allowing for the dynamic grieving process of oscillation to occur. Based on clinical practice, if a caregiver is experiencing stress because the care recipient is resistant about attending a day program or there is separation distress due to attachment, s/he is not obtaining respite. Respite means relief and the caregivers are not getting relief when they are dealing with these stressors. In clinical practice, it is important to note that intervention is frequently required for caregivers to get over the stressful hurdle of dealing with recipient resistance and/or attachment issues related to respite.

Having a health professional encourage respite helps to lessen the caregivers' guilt for taking the respite, allowing them to "let go." Marian Ritchie (2005) relays in her book *The Long Way Home, A Journey through Alzheimer's* that her husband made her feel guilty for wanting a break. With nursing home not considered as an alternative, she realized as she was becoming "a bundle of nerves" that she needed to take respite. She wrote that a concentrated effort had to be made to "fight against bearing that guilt."

Tackling guilt is not unusual in the process of "letting go." For "letting go" or emotionally relocating the loss, Kasl-Godley (2003) identified that Worden's (1991) task model approach could be used with dementia caregivers. The concept

of “letting go” has a specific meaning in this article, representing movement towards grief resolution by “letting go” of the past and adapting to a new relationship that accommodates the changes brought on by the disease. Accommodation occurs through negotiating and renegotiating the meaning of the loss over time (Silverman, 1996). For instance, in the latter stage of the disease, Ritchie (2005) came to terms with her husband’s illness and wrote that she promised herself that she would give him “quality of life” rather than “quantity of life,” “keeping him happy while he was still alive.”

In addition to respite allowing caregivers to “let go,” normalizing the grief process also assists caregivers in adapting to loss (Meuser, Marwit, & Sanders, 2004; Kasl-Godley, 2003). Kasl-Godley ran an 8-week pilot group with the objective of assisting caregivers in managing grief reactions. The feedback obtained from caregivers when the group ended was extremely positive. The group provided cognitive restructuring, art therapy, supportive discussion, resourcing and psychoeducation. It was noted that psychoeducation served to educate about grief and normalize the grieving experience.

In the literature, there are articles that provide grief assessment and intervention strategies specific for caregivers of ADRD (Burns et al., 2003; Kasl-Godley, 2003; Meuser et al., 2004; Thompson, Gallagher-Thompson, & Haley, 2003; Walker, Pomeroy, McNeil, & Franklin, 1994a; Williams & Moretta, 1997). Burns et al. (2003) relayed that physicians are often frustrated with family expectations. In addition, they referred to Boise, Camicioli, and Morgan (1999) and Miller, Glasser and Rubin (1992), who relayed the inadequacy of what the medical system has to offer the patients, lacking the ability to manage dementia patients. In their Resources for Enhancing Alzheimer’s Caregiver Health (REACH) project, Burns et al. (2003) found caregivers benefited from receiving psychosocial intervention addressing their anxiety, grief and coping abilities. Those who obtained the psychosocial intervention in addition to support in managing the dementia behaviors scored significantly less distress on the General Well-Being scale (GWB) than those who only obtained managing dementia behaviors support without intervention addressing the anxiety, coping, and grief.

This present article has emphasized psychosocial intervention, presenting the 3-A model which includes, Acknowledging loss/grief, Assessing and Assisting dementia caregivers in managing the grief. Assessment entails acknowledging the different grieving styles, intuitive or instrumental. Some caregivers may exhibit both styles. For instance, they may be intuitive by expressing painful emotions and stress while at the same time be instrumental by taking on caregiving as a “career.” Those who assess need to identify those with attachment issues, acting over-responsibly and resistant to accepting any respite and/or refusing nursing home placement when recommended.

Some grieving caregivers may not require a great deal of support or critical intervention. When caregivers are highly stressed though and/or resistant to outside supports, it could be theoretically assessed as a maladaptive expression of

grief. These caregivers could be struggling with attachment issues or an inability to accept the reality of loss. This could lead to the caregiving duties not being carried out appropriately, perhaps putting safety at risk. In situations when safety is at risk, addressing the safety concerns is an overriding necessity, and close monitoring required.

To address the resistance, developing a good rapport through ongoing support with the caregivers is helpful to assure involvement with the family. Timing is also important. They may be closely attached to their respective inflicted family members or what the family members represent. For some the family members may represent companionship while for others financial security. Regardless, these caregivers need to be emotionally ready to accepting respite or/and nursing home placement. Through experience, I have found that pushing respite too hard and/or too early has the adverse effect of alienating the caregivers and damaging the rapport. They may then refuse in accepting any supports.

Healthcare professionals who provide empathic care will more easily develop a good rapport and are more likely to be sensitive with regards to the timing of encouraging respite. Empathy is defined as the capacity of being aware of, being sensitive to and vicariously experiencing the feelings, thoughts and experience of another (Meridian-Webster, 2005-2006). Doka (2005) used the term “empathic failure” (Lattanzi-Licht, & Doka, 2003; Wilson, & Thomas, 2004) to describe treatment given to individuals by professionals without empathy. Given that dementia caregiving has been identified as a disenfranchised grief experience and caregivers as “hidden grievers,” empathic treatment could be a means of socially sanctioning and acknowledging what family members go through providing care for individuals with ADRD. Being empathic would provide caregivers with a feeling of being heard and thus safe to accept support as they are grieving. Empathic care can be achieved through passive and active listening (Hepworth, Rooney, & Larsen, 1997; Gordon, 1976).

## FUTURE DIRECTIONS

Meuser, Marwit, and Sanders (2004) recognized that further research is needed to understand the tasks and rituals that would assist in addressing caregiver grief. They also noted the importance of normalization, nonjudgemental listening and taking respite. The same strategies have been discussed in this present article. In this article, grounded theory has been applied to provide a grief model of treatment for family caregivers of individuals with Alzheimer’s disease and related disorders. It has been named the 3-A model for easy reference to its psychosocial components of Acknowledgment, Assessment and Assistance. Further research will be helpful in developing and validating the 3-A grief intervention model for dementia caregivers.

Although the intervention model could be applicable to caregivers of other illnesses, there is an element that distinguishes providing care to individuals with

an irreversible dementia from caregiving those with other illnesses such as cancer. Unlike with cancer, in dementia caregiving, the individuals with the illness come to lack insight and can not participate with the family caregivers in the grieving process. For instance, an aspect of anticipatory grief is taking care of unfinished business (Walker et al., 1994). Taking care of unfinished business would be challenging for dementia caregivers to do with inflicted family members who claim there are no health problems due to poor insight brought on by the disease.

Although there has been evidence provided in this paper for intervention from a grief perspective there are still unanswered questions. For instance, some might argue that not every caregiver grieves. Further research could be done exploring questions such as “Does every caregiver grieve?” and “Is there a natural grief reaction in the dementia family caregiving experience?”

In exploring these questions, subjective research methods have to be used cautiously because, as discussed earlier, many caregivers will not acknowledge grief on their own. Also, as Ponder and Pomeroy (1996) pointed out about personal interviews, social desirability could limit the expression of negative feelings. Although subjective, Marwit-Meuser’s (2002) Caregiver Grief Inventory is an assessment tool which accounts for these issues in the scoring. They recognize that low scores may indicate denial or downplay of distress. In addition to their comments, the low scores may also be due to an instrumental rather than intuitive style of grieving.

It could be difficult for those without a knowledge base about grief to refute the grief perspective presented in this article. How many family caregivers would be like Bill, who earlier in this article was reported to have asked the question, “What is grief?” Further exploration into the definition of grief was beyond the scope of this article. Nonetheless, this article provides rich content of grief information applicable to caregiving, such as describing types of grief, grieving styles, and theories, including Bowlby’s attachment, Worden’s (1991) task model, and Stroebe and Schut’s (1999) dual process model. The more knowledge researchers have about the topic of grief, the better equipped they will be to carry out further exploration on this topic. Carrying on further research will benefit the family caregivers and better inform the health care professionals so that the grief embedded in dementia family caregiving is acknowledged, assessed, and assistance provided in addressing the grief.

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The caregivers are the heroes who this article is all about.

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