

Meeting The Bereavement Needs Of Older Adults With Cognitive Challenges

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### Abstract

Approximately 5.5 million people in the United States are living with cognitive challenges such as Alzheimer's and other dementias. People with cognitive challenges, following the death of a loved one, often experience unacknowledged grief. This paper first describes grief as it occurs in older adults who are not cognitively challenged. This is followed by a review of literature focusing on the grief of older adults with cognitive challenges. The project looks at methods for accommodating the cognitive and communication needs of this population as they work through their grief process.

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### Meeting the Bereavement Needs of Older Adults with Cognitive Challenges

Today, over 15% of people in the United States are over 65 years of age (United States Census, 2015). By the year 2030, 70 million adults in the United States will be age 65 and older (Bradley, Whiting, Hendricks, & Wheat, 2010). Approximately 5.5 million people in the United States and 40 million worldwide are living with Alzheimer's and other dementias (Alzheimer's Association, 2017). By the year 2030 these numbers are expected to almost double. As one ages the risk for Alzheimer's disease increases; current research from the National Institute on Aging indicates that the prevalence of Alzheimer's disease doubles every 5 years past the age of 65 (Rentz, Krikorian, & Keys, 2005).

Considering the pervasiveness of Alzheimer's and dementia in the United States, one can assume that many people have a friend or relative currently impacted by this disease (Metzler, 2014). Blackman (2008) noted that cognitively challenged individuals, such as those suffering from Alzheimer's or dementia, have an increased likelihood of experiencing prolonged and unresolved grief. The reasons for this can include impaired communication and short-term memory skills, cognitive deficits, attachment difficulties or a dependency on the deceased (Blackman, 2008).

Counselors and caregivers often encounter barriers when providing services to older clients with cognitive challenges who are experiencing grief following the death of a spouse or loved one (Handley & Hutchinson 2013; Ober, Granello, & Wheaton, 2012). Barriers include (a) a common belief that cognitively challenged individuals may not experience grief (Blackman, 2008); (b) family members who often feel protective and do not want to add to the challenged person's sadness and burdens (Yale, 2013); and (c) the bereaved person's deficits in the areas of cognition, short-term memory and language skills that often coincide with Alzheimer's and

dementia challenge a counselor trained in traditional ways of supporting a grieving client (Lewis & Trzinski, 2006). Researchers have indicated that less than 50% of professional counselors have been trained in the area of bereavement for any population (Ober et al., 2012).

Grief is a universal experience yet during most of the 20th century, it was assumed that individuals with cognitive challenges were unaffected by the loss of a loved one, even the death of a partner (Handley & Hutchinson, 2013). It was generally accepted that people with dementia did not understand the finality of death and therefore did not grieve or mourn the passing of a loved one. The cognitively challenged person's inability to adequately communicate personal thoughts or feelings about death may have contributed to the erroneous notion that these individuals were unaffected by the loss of a loved one (Parkes & Prigerson, 2010). Many considered assisting the bereaved person through the process of adapting to changes in their day-to-day lives to be sufficient (Young, 2010). Though the external adjustment is important, it is one's internal adjustment and acceptance of the loved one's death that will give the bereaved a sense of peace.

The cognitively challenged person's loss of cognition "should not be seen also to mean loss of ability to experience emotions" (Doka, 2010, p. 16). This person will still feel grief (Doka, 2010; Lewis & Trzinski, 2006; Rentz et al., 2005). There is a need for accessible, easy to understand interventions for meeting the bereavement needs of older adults with dementia (Lewis & Trzinski, 2006). This project looks at methods for accommodating the cognitive and communication needs of older client's who are experiencing difficulty working through the grief process. Guidelines for developing client centered/culturally appropriate bereavement interventions that meet the needs of cognitively challenged older individuals are identified. These guidelines include interventions and are presented in an informational pamphlet.

### Terminology

Who are the cognitively challenged older adults? Throughout this paper the term cognitively challenged will be used to refer to individuals diagnosed with dementia and early to mid stage Alzheimer's disease. The latest edition of *the Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) (American Psychiatric Association [APA], 2013) contains the new category of neurocognitive disorders which include both major and mild neurocognitive disorders such as Alzheimer's disease. Neurocognitive disorders are acquired whereas neurological disorders are present from birth or early childhood (APA, 2013). Neurocognitive disorders represent a decline from an individual's previous level of neurocognitive functioning (APA, 2013). The term *dementia* is no longer included in the *DSM* but is a common term and is used by both the National Institute on Aging and the Alzheimer's Association (Sorrell, 2013).

Due to the similarities in cognitive and communication deficits found in persons diagnosed with neurocognitive disorders and some neurodevelopmental conditions, such as intellectual developmental disorders and communication disorders (APA, 2013), the information contained here may be helpful to caregivers and family members of all these groups. Regardless of the precipitator or etiology, if the disability manifests as a loss of memory or as a communication or cognitive impairment, the information contained in the project may be helpful in meeting bereavement needs.

The terms *bereavement* and *grief* may be thought of as two sides of the same coin. According to Wolfelt (2006), grief is not any particular emotion and can take many different forms ranging from anger to sorrow. Grief is highly individualized; it affects different people in different ways and is expressed emotionally, cognitively, physically, behaviorally and spiritually (Rentz et al., 2005). *Bereavement* is the process that people experience as they encounter a range

of emotions involved in coming to terms with the loss of a loved one and accepting that their life has been forever changed (Shear, 2012). *Mourning* is the individual expression of one's grief (Wolfelt, 2006). The term mourning is used to describe culture-based practices or the external demonstration of grief that might include wearing black, shading windows or flying a flag at half-mast (Schoulte, 2011).

Individuals who are diagnosed with neurocognitive disorders such as Alzheimer's disease or dementia often experience added difficulties in their grief process when working through the loss of a loved one. What follows is a review of the literature that considers the many elements contributing to decisions regarding why and how to assist people with cognitive challenges through the bereavement process.

### **Literature Review**

Bereavement may affect a person's social, emotional, cognitive, spiritual and physical well-being. Fatigue, loss of appetite, sleep disturbance, and agitation are examples of some of the physiological symptoms/manifestations of bereavement (Waller et al., 2016). Other symptoms or emotional responses may include suicide ideation, anxiety, depression, guilt, anger and panic disorder (Waller et al., 2016). Often times, bereaved individuals find themselves unable to focus and concentrate, sleep through the night, or eat a full meal. One of the most common fears of the bereaved person is that "they are going mad" (Parkes & Prigerson, 2010).

Until recently, grief and its temporary but potentially debilitating effect on one's ability to function, had been ignored by many mental health professionals. Though grief is acknowledged in Western society, it is assumed that the funeral services or the memorial marks the end of one's bereavement (Parkes & Prigerson, 2010). Thus after the funeral, bereaved



spouses often experience a departure of the support provided by family and friends, leaving them by themselves to work through their grief.

Grief and bereavement following the loss of a loved one is characterized by the experience of intense suffering that may last months or years (Shear, 2012; Waller et al., 2016). The individual's response to loss can be complex and varies according to circumstances of the death and the cultural, social and economic context (Richardson, 2007). The survivor's attachment style and the quality of the relationship between the survivor and the deceased influence one's grief (Richardson, 2007). For example, in the case of a deceased spouse who was the bereaved person's primary caregiver, the survivor is more likely to experience complicated grief. Their grief will be on multiple levels due to the absence of a lifelong partner, a person whom they loved, trusted, and depended on. Depending on the survivor's disability, change following the death may include the loss of their home and relocation to an assisted living facility. Thus the loss of their spouse precipitates multiple losses (Richardson, 2007). The survivor of a close and loving relationship is likely to have fewer complications than the survivor of a conflicted relationship.

### **Theoretical Framework for Counseling**

Companioning is a person-centered grief counseling intervention developed by Alan Wolfelt (Wolfelt, 2006; Wolfelt, 2016). Aligned with the Person Centered theory (Corey, 2013) emphasis is placed on building a strong therapeutic relationship with a foundation of empathy, congruence, and unconditional positive regard. Person-centered and companioning theories provide a platform for paying attention to the “ ‘person’ in persons with dementia” (Whitlatch, 2001, p. S20). R.T. Woods (2001), Professor of Clinical Psychology of Older People at the University of Wales, speaks to the Alzheimer's clients' unheeded emotional responses as

potentially being the underlying cause for displays of agitation and challenging behaviors.

Person-centered companioning recognizes the need to understand the cognitively challenged person's perspective as it relates to their journey through grieving. Companioning tenets include:

- being present to another person's pain, not trying to take it away;
- listening with the heart, not analyzing with the head;
- walking alongside, not leading or being led;
- respecting disorder and confusion, not imposing order and logic; and
- expressing compassionate curiosity; not expertise (Wolfelt, 2006).

Developing a therapeutic relationship built on principles of person-centered companioning (Wolfelt, 2016) helps create an atmosphere that minimizes the client's anxiety. Clients are supported in their effort to take in and remember information about the deceased person (Knight, 2004; Von Humboldt & Leal, 2015; Yale, 2013). In a 2014 study on the effect of memory training with 112 subjects who were referred by their physicians and geriatric fellows at the Memory Clinic at the Medical Center of central Georgia, all of the subjects were over the age of 65 with a spectrum of memory impairments ranging from age associated memory complaints to mild dementia. The study found that working with this population while employing a holistic person-centered approach that included stress reduction exercises had a positive effect on clients' attention and working memory (Hyer, Scott, Lyles, Dhabliwala, & McKenzie, 2014). At the same time, Knight (2004) cautioned that individuals with mild to moderate cognitive impairments will respond to changes, even subtle changes, in their immediate environment. Therefore, it is important that counselors and others monitor their own emotional state; a calm and accepting environment is most conducive to meeting the needs of the

cognitively challenged bereaved person. For clients suffering from dementia, the primary goal is for them, to the degree possible, is to maintain their relationships and interests; this is a key ingredient to a better quality of life for this population. In some instances, it is the relationship (with the counselor or caregiver) itself that provides the client with the reassurance of his/her capacity to relate to others and maintain relationships (Knight, 2004). Person-centered companioning interventions in this project include multimodality activities that are meant to meet the bereavement needs of the cognitively challenged older adult experiencing difficulties in the areas of cognition and communication

### **The History of Bereavement and the DSM-5**

The majority of those who experience bereavement are never diagnosed with a mental disorder. Much professional attention has been given to the consideration of the *bereavement exclusion* that was contained in the *DSM-IV* diagnosis criteria for major depressive disorder (MDD). Essentially, the bereavement exclusion proposed that clinicians should refrain from diagnosing someone with MDD if they had lost a loved one within a 2- month time frame of presenting for therapy (Shear, 2012). The *DSM-5* is the most recent update in this series of diagnostic manuals and with its development came much debate regarding whether to include or delete the bereavement exclusion (Zachar, 2015). Opponents of deleting the exclusionary clause reasoned that by doing so the *DSM-5* was *medicalizing* grief. Consequently, there is the fear that normal grief would be diagnosed as MDD, creating a level of unnecessary anxiety in the client (Sorrell, 2013) that might pathologize normal, healthy grieving patterns (Zachar, 2015). In the end, the bereavement exclusion was eliminated from the *DSM-5* with a notation that when bereavement and depression do co-occur the prognosis is serious (Sorrell, 2013).

Parkes (2014) noted that the *DSM-5* includes several conditions relevant to bereavement. Besides the diagnosis of MDD, these include the death of a loved one as a potential cause of an *adjustment disorder* (AD) (Parkes, 2014), caused by difficulties a person experiences due to a new source of stress. To be considered in future revisions of the *DSM* is the new diagnostic category of *persistent complex bereavement disorder* (PCBD) now contained in the *DSM-5* section entitled, “Conditions for Further Study”.

### **Grief Counseling and Older Adults**

Dr. Kubler Ross (1969) described the act of grieving as “moving from the dead back into life.” Loss of a significant loved one leads to a transition toward a new way of being in the world only after one has encountered the components of grief (Parkes & Prigerson, 2010). This may include feelings of anger, guilt, confusion, loneliness, numbness, detachment, longing, etc. (Parkes & Prigerson, 2010). Author and bereavement specialist, Alan Wolfelt (2006), described the process of grief as a way to heal and to become whole again. In the following sections of this paper, grief as it occurs in older adults who are not cognitively challenged will be described. This will be followed by a review of literature focusing on older adults with cognitive challenges and their experience of grief.

Grief was once thought of as a primarily private experience (Steiner, 2006). Today, however, the importance of social and community connections in supporting the bereaved is acknowledged. Steiner (2006) found that a high rate of bereaved individuals experienced a lack of support for their grief process. Elderly individuals are more likely to experience a loss of social connectedness and emotional isolation (Patterson, 2010). This may be coupled with age related physical, emotional and socio-economic changes (Ward, Mathias, & Hitchings, 2007).

Steiner (2006) in her study investigating the reasons for a low rate of involvement in bereavement support groups found that both the bereaved that participated in these groups and those who did not had similar responses to a survey. They reported that more caring overtures of concern, listening, and kindness from those in their family and community for a longer period of time would be comforting. Numerous individuals in this study noted, “People who really listen, understand and are non-judgmental, are definitely the most helpful” (Steiner, 2006, p. 39). This exploratory study drew its subjects from a bereavement cooperative based in a large metropolitan area. Participants were primarily spouses/partners, some adult children and a few adult siblings. Subjects were asked whether their bereavement needs were met and if so whether it was through formal or informal contacts.

Both informal and formal support systems can provide the bereaved with important social support (Kim, Kjervik, Belyea, & Choi, 2011; Steiner 2006). Informal systems include family, friends, coworkers and neighbors. They can be thought of as natural support systems. These are the people who are most likely to notice changes in the bereaved person’s behavior and are often the first to console and offer assistance to the bereaved (Steiner, 2006). Formal support systems include those provided by social workers, clergy members, counselors, nurses, and psychiatrists and therapists (Steiner, 2006). Results of this study showed that the bereaved found that the good listener who is non-judgmental and accepting is the most helpful bereavement intervention. The study’s participants indicated that whether the person doing the listening represented a formal or informal support system was unimportant (Steiner, 2006).

Difficulties within grieving families are common, as family members often have different ways of coping with their loss. Individuals have different timetables and may find another’s brevity or extended grief process is at odds with their own (Steiner, 2006). With the

disruption of natural support systems, formal support systems, such as individual counseling and bereavement groups may better meet the grieving person's needs. Counselor's advice is often sought and accepted by family members. Whereas the same advice from family members might be perceived as a criticism, the counselor's input is seen as an outcome of concern (Steiner, 2006).

Many older adults experience significant challenges adjusting to new environments in which the deceased is absent (Patterson, 2010; Rosnick, Small, & Burton, 2010). Ward (2007) noted that grief associated with the death of a spouse might affect cognitive abilities due to depression, anxiety and stress. This can lead to a misdiagnosis of bereaved elderly clients who present with somatic or cognitive problems (Horacek, 1988; Ward et al., 2007). The availability of support systems, both formal and informal, following the death of a loved one is critical.

### **Theories of the Process of Grief**

Traditionally, bereavement counseling has focused on what is called the *stage theory* as developed by Kubler-Ross (1969). The stage theory proposes that the process of grief unfolds through a series of reactions that begin with denial and step-by-step lead to acceptance of the loss of a loved one. Critics of this sequential process of grief noted that as older adults often experience multiple losses over a brief period of time (the death of a spouse, relatives, friends, health, income), their process might be lengthier and not follow any particular sequence (Horacek, 1988). In fact, it is not unusual for older adults never to finish their grief process.

Contemporary models of bereavement based on the theory that grief is a nonlinear process seem to more accurately reflect the grief experience of the elderly. These models hold that one's grief is shaped by the circumstances of the loss, the relationship with the deceased, and the bereaved person's feelings about their loss (Richardson, 2007; Stroebe & Schut, 2016). The

dual process model, as an example, is organized around three basic ideas: (a) loss orientation, which focuses one's thoughts and energy on the deceased person; (b) restoration-oriented coping, during which the bereaved focuses on attending to life changes, establishing new goals, identities and relationships; and (c) oscillation, which is the fluctuation between a focus on one's loss and being more oriented toward restoration and moving on (Richardson, 2007).

A study on the effectiveness of the dual model of bereavement counseling for older adults drew its data from a Changing Lives of Older Couples (CLOC) study, made up of over 1,500 English speaking, widows and widowers over the age of 65, who were living independently in the Detroit, Michigan area (Richardson, 2007). Interviews included the use of a scale that measured the participant's positive (sense of well being) and negative affect, focused on the participant's current activities, and evaluated their orientation toward loss or restoration (Richardson, 2007). A comparison of the control group (subjects who had not experienced a loss) and the study group indicated that the largest difference in well-being occurred at the 6 month mark (Richardson, 2007). Outcomes from the 18 month and 48 month interviews showed a decrease in differences in a sense of well being between the control group (of non-bereaved people) and study (bereaved) group (Richardson, 2007). These results validated the hypothesis that oscillation between loss and restoration activities through the course of bereavement does occur and enables the person to work through their grief (Richardson, 2007). A non-linear progression is the natural progression through grief.

Other findings in Richardson's (2007) study affirmed that the first year of bereavement is the most difficult. The author also proposed that a necessary role for counselors is to assist the bereaved in differentiating between constructive and destructive grief activities, noting that individuals who ruminated over the circumstances of the death of a loved one had significantly

lower levels of well-being. Excessively dwelling on the circumstances of a spouse's death is an example of rumination. The ability to spontaneously generate positive memories of the deceased is an example of a constructive activity.

### **Multicultural Considerations**

Today grief counseling recognizes the highly individualistic nature of the process of bereavement (Doughty & Hoskins, 2011; Schoulte, 2011). Factors that must be considered include one's culture, life experience, and personality. Based on the notion of bereavement as an individualistic process, there are many possible healthy responses to loss (Doughty & Hoskins, 2011). A model for considering grieving styles not specific to Western thought was developed by Martin and Doka (Doughty, 2007; Doughty & Hoskins, 2011). This model may be used with people around the world as it attempts to work with the natural and unique experience of the bereaved within their cultural context (Doughty & Hoskins, 2011). Three styles of grieving are considered in this model: intuitive, instrumental and blended. The *intuitive* style is most likely to be experienced in cultures that encourage heightened experience and expression following the death of a loved one (Doughty & Hoskins, 2011). *Instrumental* style grief is more likely to be experienced by those who manage, rather than openly express their emotions; they are likely to work through their grief by problem solving and thinking about their loss (Doughty & Hoskins, 2011). The *blended* style of grieving is the most prevalent style wherein there is an element of both the intuitive and instrumental styles (Doughty & Hoskins, 2011). Difficulties may arise in the grieving process when the bereaved experience both internal and external, social, and cultural pressures to grieve differently than how they are naturally inclined (Doughty, 2007; Doughty & Hoskins, 2011). Thus individuals who grieve using the style they are most comfortable with are less likely to become stuck in their process of bereavement.



**Bereavement in the Older Adult Cognitively Challenged Population**

Depending on the context and circumstances of the death the grief experience of older adults who are cognitively challenged can take different forms. Blackman (2008) noted that cognitively challenged individuals, such as those suffering from Alzheimer's or dementia, have an increased likelihood of experiencing complex grief also referred to as persistent complex bereavement disorder (PCBD). The reasons for this tendency include impaired communication and memory skills, cognitive deficits, attachment difficulties, and a dependency on the deceased (Blackman, 2008). Complex grief develops when a person has trouble accepting the loss and going on with life. The experience of loss is debilitating and does not improve over time.

Unrecognized or unacknowledged grief can be thought of as a *disenfranchised grief* (McRitchie, McKenzie, Quayle, Harlin, & Neumann, 2012). A person who is identified with a group that is not expected to understand or experience the loss of a loved one, such as those with dementia, will often be over-looked or even excluded from the rituals that are part of the grieving process (Parkes & Prigerson, 2010). In their groundbreaking research, exploring cognitively challenged person's experience of bereavement and grief, McRitchie and colleagues (2012), concluded that the participants in their study had grief experiences similar to the general population and thus had the same need to mourn their loss. Cognitively challenged persons who have experienced disenfranchised grief are more likely to exhibit behavioral difficulties than those who have received support during their time of mourning (Handley & Hutchinson, 2013). Challenging behaviors such as irritability, lethargy and hyperactivity may be linked to the experience of disenfranchised grief and the experience of being thwarted in their attempt to mourn (MacHale & Carey, 2001; McRitchie et al., 2012). Parkes and Prigerson (2010) noted that it is not unusual for members of a disenfranchised group not be invited to funerals and other

rituals associated with a loved one's death. Doka (2010) cautioned that a lack of acknowledgement of a dementia client's grief might exacerbate the conditions symptoms.

### **The Benefits of Counseling Older Adults with Alzheimer's and Dementia**

Although the progressive cognitive difficulties that the Alzheimer's client experiences have no cure, it is possible to alleviate some of the client's emotional distress resulting from the illness (Flowers, 1998; Romano, 2004; Yale, 2013). For example, participation in counseling or support groups decrease feelings of isolation, promote one's progress through grief and provide a forum for the exchange of information and resources (Von Humbolt & Leal, 2013; Yale, 2013). Participation in counseling services, giving the client a chance to talk about their concerns and feelings, may contribute to an improved mood. With support, the Alzheimer's client may be better able to adjust and accept their condition (Romano, 2004; Yale, 2013).

A number of organizations, around the world, dedicated to the provision of services to individuals with neurocognitive disorders, have recently begun to seek input from those with dementia regarding the development of federal plans, policies and materials directed at providing services to them (Alzheimer's Association, 2016; Yale, 2013). Thus the professional care providers are affirming the value of understanding and supporting the client's expressed needs and wants. The *Charter of Principles* developed by Alzheimer Disease International (Yale, 2013) states that "all people with dementia have worth and dignity and should have access to support" (Yale, 2013, p. 9).

Behavioral interventions that create psychosocial supports that enable the cognitively impaired person to continue engagement in meaningful activities do make a difference (Drossel & Trahan, 2015; Kales, Gitlin, & Lyketsos, 2015). Finely tuned and structured behavioral interventions tailored to the individual client can contribute to the sense of well being of the

person and their family members. Interventions suggested by Kales and colleagues (2015) includes increasing their level of activity, simplifying tasks, enhancing communication, and optimizing the environment with neither too much nor too little stimulation. When speaking to a cognitively challenged person, face the client (provide an unobstructed view), speak clearly, use short simple sentences and cover one point at a time (Knight, 2004). Kales et al. suggest that when working with a person with neurocognitive disorders, to explore the function of the client's behavior in context. Thus the bereaved Alzheimer's client who exhibits increased agitation following the death of a loved one may benefit from participation in some form of bereavement counseling or ritual of mourning.

### **Clients Diagnosed with Dementia: Expressions of Grief**

How people with dementia or Alzheimer's express their grief will be determined by factors such as the stage of the disease, loss of awareness of the significance of the relationship, and loss of the ability to recognize their loss (Doka, 2010; Rentz et al., 2005). It is not unusual for cognitively challenged persons to be unable to name the significant person who has died or to confuse a current loss with an earlier loss in their life (Doka, 2010). Caregivers may become frustrated or feel incompetent as the bereaved client mourns the loss only to forget the death. Doka (2010) recommended that in such cases the caregiver experiment and observe what works best for the client. Rentz and colleagues (2005) question whether caregivers and other providers should avoid any intervention that will result in the client's discomfort. The venting of emotions by cognitively challenged individuals was positively correlated with distress (Rentz et al., 2005). Venting can also have a negative affect on the client's ability to cope with their loss (Rentz et al., 2005). However, on the other hand, unacknowledged or disenfranchised grief (McRitchie, McKenzie, Quayle, Harlin, & Neumann, 2012) may have the effect of denying the cognitively

challenged individual their sense of personhood (Rentz et al., 2005). *Personhood* is defined by more than a person's cognitive abilities, rather it consists of the relationships in one's life (Rentz et al., 2005).

Historically there has been considerable reluctance on the part of the professional and general population to accept that individuals with dementia grieve (Blackman, 2008). Loss of cognitive abilities due to dementia or Alzheimer's does not mean that the older adult has also lost the ability to feel and experience emotion (Doka, 2010). This population may lack the cognitive or language skills to express their grief in ways expected by family, friends and caregivers (Lewis & Trzinski, 2006). Individuals with dementia are more likely to exhibit their feelings of grief by acting restless or showing agitation than through crying or verbal expression (Doka, 2010).

Those in the early stages of dementia, experiencing difficulties remembering immediate events and short-term memory retrieval, may exhibit grief marked by a recycling process (Lewis & Trzinski, 2006). That is, the Alzheimer's client, upon being told of a spouse's death retains only some of the information. It is not unusual for these early stage individuals to retain the non-specifics while forgetting the most important information, such as the person's name that died. The need for the caregiver to recycle this information numerous times can become distressing for the caregiver (Lewis & Trzinski, 2006). The client's inability to remember specific information may in turn cause them some anxiety and confusion. On the other hand, the unmet need for the older adult to grieve may result in agitation, depression, or behavioral problems (Lewis & Trzinski, 2006). For this reason, researchers note that even as the individual's cognitive abilities decline, their feelings and emotional stress remain (Doka, 2010). Caregivers of cognitively impaired individuals are encouraged to look for a change in the client's behaviors following the

death of a loved one. Close observation will provide some insight into the cognitively impaired person's emotional needs.

The concept of the finality of death may be a difficult, if not impossible to construct for those in the more advanced stages of dementia (Lewis & Trzinski, 2006). As dementia progresses the older adult may lose the ability to experience a specific sense of loss and grief. Rather they may have a generalized feeling that something is wrong or missing. Researchers and leaders in the field of bereavement advise that each person's need to grieve and how they grieve will be different (Doka, 2010). Caregivers are advised to observe the client's response to interventions that validate their grief. Interventions that cause the least distress and agitation are then deemed appropriate (Doka, 2010).

Family members of Alzheimer's clients often feel protective and believe that it is their responsibility to shelter the impaired relative from sad or difficult situations (Yale, 2013). However, it has been found that as dementia has become less stigmatized, individuals with neurocognitive disorders are being included in decisions regarding what is in their best interest (Yale, 2013). The results of testimony by persons with early stage dementia (PWESD) during the 2008 town hall meetings held throughout the United States sponsored by the Alzheimer's Association (Yale, 2013, p. 9), indicated the following:

- PWESD's want to learn what to expect and how best to cope with the disease.
- They want to be included in decisions and activities as much as possible.
- They wish to be heard, seen, and respected as viable, contributing members of society (Yale, 2013).

As witnessed by this testimony, individuals with dementia are most interested in participating to the greatest extent possible in a full life. Certainly, this includes their right to grieve the death of their spouse or others in their lives.

### **Family and Friends of Alzheimer's Clients: Their Experience of Grief**

Everyone touched by Alzheimer's or other dementias in family members or friends, experience some form of loss. This experience of grief and loss may affect relations and friends in a variety of ways. There may be the presence of anticipatory grief as they cope with the initial diagnosis (Doka, 2010). As they observe the loss of the person's persona and the intensification of symptoms, their own grief may intensify. Unfortunately, family members and caregivers anticipatory mourning is seldom recognized (Doka, 2010).

Providing care to someone with dementia carries with it, its own risk of precipitating the on-going experience of loss and the resulting grief (Doka, 2010). Caregivers may have secondary losses. They may experience the loss of their social and recreational life as well as the loss of their role as a worker (Doka, 2010). As the caregiver slowly loses the person they once knew, they may experience an anticipatory or early grief response (Worden, 2009).

For the caregiver (family member or friend), the death of the Alzheimer's client may elicit a number of different responses. The caregiver may feel a sense of relief from the responsibilities involved in this role. Some caregivers experience a loss of focus and a sense of meaninglessness (Doka, 2010). Others may assume that as the Alzheimer's client's illness progressed, that the caregiver already said good-bye and therefore no longer has the need to grieve. Thus caregivers often experience a disenfranchised grief, one in which the depth and impact of their loss is neither supported nor validated (Doka, 2010).

### **Counseling and Supporting Alzheimer's Clients: Training**

Those who provide care for cognitively challenged persons often find themselves questioning their ability to meet their clients' bereavement needs because they lack confidence and experience in talking about death (Blackman, 2008). Caregivers may conclude that the client would be best served by ignoring the loved one's death, believing that the topic is too confusing or painful to pursue. Caregivers who do attempt to broach the topic may find that the finality and/or universality of death are difficult concepts to convey.

Training in the areas of death education and grief counseling seems to be lacking in today's counselor preparation programs (Doughty & Hoskins, 2011; Harrawood, Doughty, & Wilde, 2011; Ober et al., 2012). A recent study by Ober and colleagues (2012) evaluated the effectiveness of counselor training in grief work and found a positive relationship between the level of training, the personal/professional experience in the area of grief/bereavement, and the level of perceived self-confidence of those involved in providing bereavement counseling (Ober et al., 2012). This study's 370 participants were drawn from a mid-western state board listing of licensed professional counselors. Three surveys measuring levels of grief competency, personal experience with grief, and professional training in the area of grief were administered to each participant (Ober et al., 2012). Results indicated that approximately half of all the study's counselors had completed one university course on grief. However, the researchers noted that the two grief theories (task and stages) to which the study's subjects were most exposed had not been empirically validated (Ober et al., 2012).

These findings (Doughty & Hoskins, 2011; Harrawood et al., 2011) seem to indicate both the benefit of student counselor training in this field and a need for exposure to evidenced-based grief counseling interventions. Unfortunately, counseling skills in the areas of bereavement are currently not included in the Council for Accreditation of Counseling and

Related Educational Programs (CACREP) requirements (Doughty & Hoskins, 2011).

Advocating for the right of all people to grieve in their own way, in spite of societal stigma or other barriers, is the responsibility of those in the helping professions (Doughty & Hoskins, 2011). On a positive note, Tomko and Munley (2013) found that counselor training and an emphasis on multicultural competence is a predictor of decreased bias when working with older adults.

### **Multimodality Bereavement Interventions**

The expression of emotion is a necessary part of a person's grief process (Knight, 2004). For a cognitively challenged person, the usual forms of grief counseling that primarily rely on formats of talk therapy may be insufficient. Multimodality interventions that support the grief process of the cognitively challenged person may be used in addition to traditional talk therapy or as a stand-alone approach. In particular, visual modalities are more concrete and often provide a reference that may be readily accessed at any time. An example of this is a wallet-sized picture of the deceased with the death date inscribed. The bereaved person can retrieve this from a wallet or purse as needed. This visual reminder may be the only prompt needed by a cognitively challenged person to remember his/her loved one's death. The auditory modality is another channel for stimulating memory. Specifically, music may be better remembered than verbal/spoken information (Knight, 2004). The tactile experience involved in the creation of a memory box that contains reminders of the loved one can be another effective expression. At the beginning stages of dementia, narrative (storytelling) strategies may be efficacious in assisting the bereaved in making meaning of their loss (Neimeyer, 1999). Finally, whenever possible, involving the cognitively challenged bereaved in community and/or religious functions and rituals will provide another avenue for them to mourn their loss in a supportive environment.



Any one or all of these strategies may be useful in bridging the cognitive, communication, or memory deficits of the cognitively challenged person experiencing grief.

### **Interventions**

#### **Narrative and Multimodality Strategies**

Narrative strategies associated with grief therapy most often reject the conventional approaches to moving through grief that involve employing the concept of stages. Instead narrative therapy addresses grieving as a complex process of adaptation (Neimeyer, 1999). It involves accepting a changed life, one that will never be the same. Narrative therapy maintains that each person is an active storyteller (Alves et al., 2014); people naturally organize their life experiences into a sequenced story that may be shared with others. Stories shaped by narrow interpretations with an emphasis on the client's life problems can have a detrimental effect. On the other hand, stories based on a larger view of one's life may be transformed with an emphasis on the client's strengths and abilities (Young, 2010). This approach serves the dual purpose of meaning making while simultaneously creating a more positive narrative.

The conventional imperative that narrative necessitates a reliance on chronology to make sense of one's story may be counterproductive when working with cognitively challenged clients (Young, 2010). Rather, an open and accepting approach that honors the bereaved person's interpretation of chronology and other specifics sets a productive tone. Placing an emphasis on the collaborative nature of the counselor-client relationship is more likely to promote the kind of reflection to help the bereaved person, accept and integrate his/her loss. Counselors and others should follow the rule of thumb that narrative strategies are most effective when presented as a collaborative activity that respects clients' boundaries and their emotional needs (Neimeyer, 1999). The work of grieving has no particular timetable. Neimeyer (1999) contended that

although this narrative model for grieving requires participation in one or more of the following activities, constant activity is not always beneficial; the client should be allowed to set the pace.

The multimodality, hands on component may be integrated into any one of the following narrative approaches or may be used as a stand-alone project. Originally presented by Neimeyer (1999), Steiner (2006) and Young and Garrard (2015), these interventions can be adapted for use with individuals with limited cognitive or language abilities. The narratives, along with the multimodality components, are meant to encourage clients' personal reflections about their loved ones. Their personalized creation of artifacts that memorialize their loved ones may be kept modified and retrieved as desired.

**Epitaphs.** This activity gives the client an opportunity to create a brief but heartfelt and meaningful way to memorialize the deceased. The epitaph may or may not be chiseled onto a tombstone; there are many other creative ways of displaying the epitaph, such as framed calligraphy.

**Journals.** Journaling about one's loss is best done when the bereaved has achieved a sense of equilibrium. The writing is most powerful when the client writes descriptively about the loss followed by a description of how he/she felt about it. The client's privacy must be respected: the decision of whether to share a journal entry is the client's.

**Linking Objects.** These are objects that are closely associated with the deceased. Such objects include special mementos that the deceased prized or certain items that simply remind the bereaved of his/her loved one. The objects may be displayed in the bereaved person's home or may be integrated into everyday life. An example of such an object would be including the deceased person's favorite hammer in the home toolbox.

**Metaphoric Images.** When literal words do not meet the grieving person's need for expression, turning to the use of metaphor may help. For instance, a counselor or caregiver might ask the client "How would you describe your grief if it were an object?" An example of a metaphorical response would be, "It's like a huge weight, a large rock, that I must carry."

In addition, a product called, "Flying Wish Paper," is available on Amazon. The bereaved writes a message (to their loved one) on the paper, which is then rolled into a tube. When the tube is lit on fire, the paper flies up several feet in the air and dissolves. For some this is a simple but powerful ritual.

### **Memory Boxes**

This bereavement strategy developed by Young and Garrard (2015) utilizes a multimodality approach to providing counseling for profoundly learning disabled persons whom experience cognitive, communication, and memory deficits. This approach may also be appropriate for working with individuals diagnosed with Alzheimer's and dementia. The purpose of memory box construction is similar to narrative therapy as both strategies enable people to reconnect with loved ones through mediated materials such as pictures, stories and other items that belonged to the deceased. Research on this strategy has highlighted benefits on two levels (Young & Garrard, 2015). First, the bereaved person is able to remember and grieve for their loved one without being solely dependent on their verbal communication skills. Second, the collaborative nature of the activity enhances the relationship between the caregiver and client.

**Memory box construction.** This is a multi-sensory, person-centered activity that entails the use of mementos that belonged to the deceased person. These may include any object that

the client associates with his/her loved one (Young & Garrard, 2015) including photographs, clothing items, artwork, writings, recipes, music and household items.

Selected items are then placed in a box, preferably one with a lid, and the client is asked to tell the story associated with each item. Bringing together an assortment of mementos serves to stimulate the client's memories about the deceased without heavy reliance on verbal communication (Young, 2010). In a case study of one client's creation of a memory box, Young (2010) found that the memory box could represent an enduring connection with the deceased. Another benefit is that the memory box can serve as a focal point and help to facilitate communication between the client and caregiver regarding the client's feelings about their loss. Finally, the process of creating the memory box and talking about its contents may give the client reassurance that his/her grief and sorrow are not unrecognized.

**Collage.** Images and words cut from magazines can be used to create a collage that represents some aspect of the loved one's life. Earl Rogers (Balk, 2010) hypothesized that using images from various sources reduces the performance anxiety of creating art. It is also possible that by using pictures cut from magazines the bereaved can express a greater range of emotions than they could verbalize. For instance, a bereaved person may find it easier to express feelings of abandonment and fear now that his/her loved one is gone.

### **Application**

The basic application or product of this project is an informational pamphlet directed at professionals, paraprofessionals and caregivers who provide services to cognitively challenged adults who are experiencing grief. The following is the outline for the pamphlet's contents, which is focused on providing meaningful support and interventions described under the "Approaches" subtitle of this project:

- Description of the intended audience,
- Symptoms of bereavement (in cognitively challenged persons),
- Steps to establish a person-centered therapeutic alliance with the bereaved,
- Timelines to consider when working through the grieving process,
- Modality considerations for selecting interventions,
- Identification of materials (e.g., books, pictures, keepsakes), rituals and interventions that are culturally appropriate and that meet the individual needs of the bereaved.

### **Conclusion**

This project focused on the need to support bereaved older adults who are cognitively challenged. The multiple effects of grief on fully functioning adults and cognitively challenged adults were examined (Waller et al., 2016). Though grief is a normal and natural process, it can be debilitating. For those older adults with neurocognitive disorders, the expression of grief may be inhibited. This is often due to the loss of cognitive abilities or limited language skills (Lewis & Trzinski, 2006).

Historically, the recognition by professionals and the general population that individuals with dementia grieve the loss of a loved one has been absent (Blackman, 2008). However, Doka (2010) confirmed that impairment due to Alzheimer's or dementia does not mean that the person has lost the ability to feel. Still, the experience of disenfranchised grief or unacknowledged grief for the cognitively challenged individual is a not uncommon experience (McRitchie, McKenzie, Quayle, Harlin, & Neumann, 2012; Parkes & Prigerson, 2010).

Without the emotional supports needed during their time of grief, cognitively challenged individuals may experience irritability, lethargy or restlessness (Doka, 2010; MacHale & Carey,

2001). In the beginning stages of Alzheimer's disease, both individual and group counseling have been found to decrease the client's feelings of isolation and promote an acceptance of their neurocognitive disorder (Yale, 2013). Specifically, a cognitively challenged individual may benefit from counseling interventions that are tailored to meet their communication style and modality preferences (Read, 2001; Yale, 2013).

The person-centered theory of companioning the bereaved developed by Wolfelt (2006) was presented as a foundational philosophy/methodology for counseling cognitively challenged individuals through their grief. Behavioral interventions that explore the function of the client's behavior may also be effective when working with individuals with neurocognitive disorders (Kales et al., 2015). While exploring ways to support a cognitively challenged person experiencing grief, it is important to consider the following parameters.

Consideration should be given to the communication style and modality preferences of the cognitively challenged individual (Read, 2001; Yale, 2013). Personalized, multi-sensory aids such as the construction of a memory box and other activities that can enhance the bereavement experience have been identified (Read, 2001). Other narrative interventions as suggested by Neimeyer (1999), such as creation of an epitaph, a journal or the use of keepsakes and mementos as linking objects, can enhance the cognitively challenged person's ability to memorialize the deceased person. Morgan and McEvoy (2014) suggested activities such as creating photo albums, life storybooks, and art therapy. These interventions when used in conjunction with a person-centered companioning approach can provide meaningful bereavement support to cognitively challenged older adults.

Counselors and others who work with cognitively challenged adults are the intended audience for this project. This audience can include community counselors, bereavement

counselors, paraprofessionals and family members. Anyone assisting cognitively challenged persons who are experiencing grief following the death of a loved one might benefit from the psychoeducational information contained in this project.

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## Appendix

## Key Concepts

Key concepts about the effects of grief and those diagnosed with Alzheimer's disease, dementia and other conditions that impair memory and cognition:

- Loss of cognitive abilities due to dementia or Alzheimer's does not mean that the older adult has lost the ability to feel and experience emotion.  
Doka, 2010
- Persons with dementia may lack the cognitive or language skills to express their grief.  
Lewis & Trzinski, 2006
- Individuals with dementia are more likely to exhibit their feelings of grief by acting restless or showing agitation than through crying or verbal expression.  
Doka, 2010



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*The information in this publication is not intended to provide or substitute for professional mental health services.*

## Meeting the Bereavement Needs of Older Adults with Cognitive Challenges



A Graduate Research Project  
By Terry Glendinning  
UAF Counseling Department

For family, caregivers and counselors supporting the bereaved.

## Narrative and Multimodality Bereavement Strategies

### Basic Guidelines:

- Grief work has no particular timeline.
- The client should be allowed to set the pace.
- Visual reminders of the deceased can be powerful.

### Narrative Activities:

- Stories should place an emphasis on the client's strengths and abilities.
- The story need not be chronologically accurate.
- Creating the story is a collaborative activity.

**Epitaphs:** Create a brief but heartfelt meaningful way to memorialize the deceased. Display it on a tombstone or use other creative presentations.

**Linking Objects:** Items that remind one of the deceased may be displayed in the bereaved person's home or may be integrated into everyday life. For example, including the deceased person's favorite hammer in a home toolbox.

**Metaphoric Images:** Ask, "How would you describe your grief if it were an object?" A response might be, "It's like a huge weight, a large rock that I must carry."

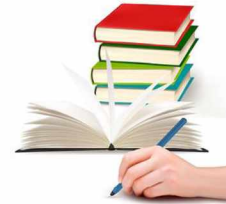
**Collage:** Images and words cut from magazines can be used to create a collage that represents some aspect of the loved one's life. Using pictures cut from magazines may allow expression of a greater range of emotion.

### Memory Boxes

The **purpose** of the memory box is to remember loved ones through mediated materials such as pictures, stories and items that belonged to the deceased.

Items may **include** photos, clothing, artwork, writings, recipes, music and other household objects.

Items are **placed in a box** with a lid. The bereaved is encouraged to **tell a story** associated with each object.



*References for these strategies are provided on the back page.*



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