

AN ASSESSMENT OF ANTICIPATORY GRIEF AS EXPERIENCED BY  
FAMILY CAREGIVERS OF INDIVIDUALS WITH DEMENTIA

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AN ASSESSMENT OF ANTICIPATORY GRIEF AS EXPERIENCED BY  
FAMILY CAREGIVERS OF INDIVIDUALS WITH DEMENTIA

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DISSERTATION ABSTRACT

AN ASSESSMENT OF ANTICIPATORY GRIEF AS EXPERIENCED BY  
FAMILY CAREGIVERS OF INDIVIDUALS WITH DEMENTIA

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The growing number of patients with a diagnosis of dementia represents a significant physical and mental health challenge not only for the health professions, but also, and even more dramatically, for the primary and secondary caregivers of dementia patients. Those affected include not only the persons with dementia, but also their spouses, siblings, children, friends, and caregivers. This study was designed to contribute to a deeper understanding of dementia caregivers' anxiety, stress, and depression by adding an examination of the presence and extent of grief that may be a part of the experience. Further, this study was designed to identify and examine the particular part of grief that is referred to as anticipatory grief. Anticipatory grief is a real phenomenon that affects many family caregivers of dementia patients. This study reinforces not only that grief is present for dementia caregivers; it also provides additional evidence for the few studies completed aligning anticipatory grief to the dementia caregiving experience. This

study shows that dementia caregivers are not experiencing “typical” grief; in fact, it demonstrates that their grief is much more complicated.

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Craig and I have lived by the doctrine that nothing truly worthwhile in life is free or easy and with faith and hard work, dreams can be realized.

What an amazing and worthwhile journey.....

I now know who I am, where I came from, and what I am made of.

I have truly begun to realize what I am capable of.

I have no question about the character, quality, and exceptionalness of my husband.

I have demonstrated perseverance, courage, and determination to my children.

I respect, appreciate and love my parents.

As a result, I now have the outstanding opportunity and responsibility to share what I have learned, to pour hard work, faith, and dedication into the lives I touch as a psychologist.

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## CHAPTER ONE

### STATEMENT OF THE PROBLEM

The current numbers of individuals affected by dementia is staggering. Nearly five million individuals in the United States alone suffer from Alzheimer's disease, the leading cause of dementia, resulting in 1 in 10 individuals over the age of 65 and nearly half of persons age 85 years and older directly affected by this disease (Blackwell, 2002; Butterfield & Pocerlich, 2003). More importantly, the continued growth of our population in the next few decades assures that the number of persons affected by this disease will grow even more exponentially to approximately 14 million Americans and 22 million individuals worldwide (Butterfield & Pocerlich, 2003). This number of patients represents a significant physical and mental health challenge not only for the health professions, but also, and even more dramatically, for the primary and secondary caregivers of dementia patients. Those affected include not only the persons with dementia, but also their spouses, siblings, children, friends, and caregivers. Multiple investigations have demonstrated the physical, emotional and psychological strain experienced by primary caregivers of dementia patients (Gaugler, Davey, Pearlin, & Zarit, 2000; Gaugler, Zarit, & Pearlin, 2003; Roth, Haley, Owen, Clay, & Goode, 2001; Vitaliano, Russo, Young, Teri, & Maiuro, 1991; Waelde, Thompson, & Gallagher-Thompson, 2004).

Dementia affects society as a whole on multiple dimensions. These effects include increased use of formal healthcare services by both the individual with dementia and their caregivers, increased institutionalization of dementia patients, lost time or productivity at work or even loss of participation in the workforce, all followed by a generalized increase in monetary cost to taxpayers (Banerjee, Foley, Atkins, Schneider, & Mann, 2003; Biegel & Blum, 1990; Harrow, Mahoney, Mendelsohn, Ory, Coon, Belle, & Nichols, 2004; Riggs, 2001; Stephens, Franks, & Atienza, 1997).

Researchers have examined at length the needs of families and caregivers who are involved with an individual who suffers from dementia. Much of the research literature has been restricted to looking at the nature and extent of the stress and burden faced by primary caregivers. Unfortunately, few researchers (Doka, 2000; Kuhn, 2001; Meuser & Marwit, 2001; Rando, 1997; Robinson, Clare, & Evans, 2005; Williams & Moretta, 1997) have gone beyond a focus on stress to examine the role of grief in caring for an individual with dementia who is dying slowly on the interior while looking completely normal on the exterior. Until relatively recently, if grief was addressed, it was seen as an issue for professionals to address after the death of the individual with dementia (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Farran & Keane-Hagarty, 1994; Kindig & Carnes, 1993; Lawton, 1994; Mittelman, Ferris, Shulman, Steinberg, Mackell, & Ambinder, 1994; Rabins, 1994). Even then, in some cases, the grief of primary caregivers was addressed only if such grief was determined to be complicated in nature; otherwise, it was seen as a “normal” grief response to the death of a loved one. The most recent research in this important area (Kuhn, 2001; Meuser & Marwit, 2001; Rando, 1997; Robinson, Clare, & Evans, 2005; Williams & Moretta, 1997) addresses grief in

terms of its potential impact on caregivers. Even in this research there seems to be little credence given to the importance of actually changing traditional services offered to caregivers (Paun, Farran, Perraud, & Loukissa, 2004; Roth, Mittelmann, Clay, Madan, & Haley, 2005).

*Anticipatory Grief.* A close look at the lives of dementia patients and the related experiences of primary caregivers suggests that grief plays a significant role long before the actual death of the patient. Meuser and Marwit (2001) and Marwit and Meuser, (2002, 2005) argue that the construct of anticipatory grief adds an important and needed dimension in more fully conceptualizing the grief experience of dementia caregivers. Anticipatory grief is a term that has come to be used to describe the grief process of individuals who are losing someone slowly, expectedly, and many times, in stages (Doka, 2000; Garner, 1997; Mayer, 2001; Ponder & Pomeroy, 1996; Rando, 2000). Typically, this concept of anticipatory grief has been applied by researchers to the experience of parents losing a terminally ill child. Most recently, anticipatory grief has been used to describe feelings of caregivers who have a loved one of any age with terminal, end-stage cancer. Multiple studies (Kuhn, 2001; Meuser & Marwit, 2001; Rando, 1997; Robinson, Clare, & Evans, 2005; Williams & Moretta, 1997) have demonstrated that caregivers and families involved with a demented individual face a series of losses, or multiple mini-deaths of the one who they once knew and the life they once shared.

Services provided by psychologists, counselors, and other healthcare workers typically address basic care task-oriented skills: increasing competency, behavior management, education on disease process, stress management, and utilization of services in day care and home care facilities. Service providers and support groups

generally focus their efforts almost exclusively on stress, burden, and lack of competency. The problem is that too little emphasis is given to the grief associated with the multiple losses experienced by these caregivers over a period that can span from 5-25 years.

### Purpose of the Study

There needs to be a deeper understanding of the nature and extent of grief experienced by dementia caregivers. Moreover, there is a need to improve our understanding of the influence of grief on the quality of life, and the care provided to both the caregiver and the individual with dementia. Also, anticipatory grief needs to be more extensively researched and examined as it applies to dementia caregivers.

This study was designed to contribute to a deeper understanding of dementia caregivers' anxiety, stress, and depression by adding an examination of the presence and extent of grief that may be a part of the experience. Further, this study was designed to identify and examine the particular part of grief that is referred to as anticipatory grief.

Marwit and Meuser have completed a series of three studies (2002, 2005; Meuser & Marwit, 2001) that examine the concept of anticipatory grief as applied to dementia caregivers. They developed the Marwit-Meuser Caregiver Grief Inventory (MM-CGI) (2002) as a tool to use in research and intervention with caregivers. Specifically, the inventory was created to produce a measure of an individual's total grief level specific to caregivers of dementia patients. Although reliability indices were relatively high in the initial studies, the original norming sample lacked diversity in that 154 of the 166 respondents were Caucasian, 133 participants were either Protestant or Catholic, and the overwhelming majority (135) were female (Marwit & Meuser, 2002). The present study

has built on the work of Meuser and Marwit by using the inventory with a more culturally diverse population. A more representative norming sample has the potential for adding important psychometric data to the instrument's core utility.

### Significance of the Study

This examination of the role anticipatory grief plays in the experience of dementia patients' primary caregivers ultimately provides important new information that can shape future health care and support service. By demonstrating the significance of grief in the dementia caregiving experience, and describing that grief as an anticipatory process, helping professionals can offer more targeted service, as well as resources and support to assist caregivers in working through their experiences. Researchers and practitioners have identified grief counseling and grief outreach programs and support groups as important to and beneficial for the psychological care of individuals experiencing grief. It is possible that dementia caregivers are experiencing grief not only upon the death of the patient, but along the journey of the illness as they strive to overcome multiple, incremental deaths of a loved one who is increasingly physically dependent upon them. As the number of individuals who are affected by dementia climbs, there will be a growing need for more appropriate and targeted mental health services to assist both primary and secondary caregivers. This study has examined the need for implementing anticipatory grief assistance to caregivers.

### Research Questions

The design of this study was guided by a set of key research questions. First, do dementia patients' primary caregivers report more anxiety, stress, depression, and grief as a part of their experience than caregivers who have family members with a cardiac

diagnosis? Secondly, do dementia caregivers report anticipatory grief? Finally, will the Marwit-Meuser Caregiver Grief Inventory short form (Marwit & Meuser, 2005) serve as a reliable instrument for use with a multicultural sample?

Psychologists and healthcare workers need to improve the specificity and accuracy of their understanding of dementia caregivers' experiences in order to provide the best care possible. Previous research has possibly overemphasized caregivers' stress and underemphasized or missed entirely their grief. Unfortunately, to date, there are only two instruments available for assessing grief in dementia caregivers, and only one instrument for identifying and assessing the experience of anticipatory grief in dementia caregivers over the duration of the disease.

This study assumed that anticipatory grief not only plays a large role in the lives and experiences of dementia caregivers but is underrepresented in research and planning for interventions with these individuals in need of our assistance. In an attempt to provide a representative picture of the experience of dementia caregivers, this study has added a needed multicultural element to current literature by collecting a sample of primary dementia caregivers that includes cultural and gender diversity.

## CHAPTER TWO

### REVIEW OF RELATED LITERATURE

The challenge of caring for an individual with a diagnosis of dementia is steadily becoming a greater concern not only for families and long-term care facilities, but also for society as a whole. America is currently faced with a growing elderly population, largely due to increased knowledge concerning diet, exercise, and general physical and psychological health practices combined with a multiplicity of new medical interventions (Quadagno, 1999). With this increased life expectancy comes a visible growth of the diseases such as dementia that generally affect our aging population most directly. Individuals with dementia are medically complex due to the prospective multiple co-morbidities associated with dementia-causing disease processes. This equates to dementia patients' greater physical, emotional, and financial dependence on significant others, including not only families, but also communities, and both primary and secondary health care providers.

#### Dementia

Providing daily care for an individual with dementia who may not only be resistive to care, but also combative or verbally agitating, is no easy task. The behaviors associated with dementia have multiple effects on the individual's daily life. Memory deficit is the most prominent symptom of early dementia (DSMIV-TR). As dementia progresses, individuals lose the ability to register, retain, recognize and recall new and



previously learned information (Slone & Gleason, 1999). The result of this deterioration is that simple tasks of daily living such as bathing, toileting, eating and socializing become overwhelming and eventually incapacitating (Riekse & Holstege, 1996). The individual in late dementia has limited verbal abilities, and may not even recognize family members or caregivers. This makes it very difficult for individuals suffering from dementia to express their needs and desires about how they wish to be treated (Sloan, 1998). Agitation, paranoia, wandering, pacing, disrobing, confusion, verbally aggressive behavior, and disorientation gradually increase in prevalence as the disease progresses (Riekse & Holstege, 1996).

Dementia is a term utilized to describe a progressive, irreversible, cognitive disorder that can result from one, several, or multiple disease processes. Generally, dementia affects individuals aged 65 or older and infrequently has early-onset at ages 40-50 (Neugroschl & Davis, 2002). For a diagnosis of dementia, certain cognitive impairments must be present. According to the DSM-IV TR (APA, 2000), an individual must have at least one of the following symptoms: aphasia, apraxia, agnosia, or executive functioning disturbances, and must have memory deficits as qualifiers for a diagnosis. The general characteristics of dementia include cognitive decline or cognitive deterioration resulting in memory, communication, executive processing decline, and self-care problems (Jackson & Siegal, 2002). Each disease process results in the dementia presenting and progressing slightly differently toward the ultimate late stage of incapacity. Further, most individuals with dementia have a combination of disease processes making the experience of having dementia not only unique but a true challenge to manage (Hamdy, 2002; Kindig & Carnes, 1993).

*Stages and Behaviors.* Dementia has been divided into stages: early, middle and late. These step-like stages offer a broad description of functional levels and have been useful in the study of and care for these individuals and their caregivers (Kindig & Carnes, 1993; Meuser & Marwit, 2001). Early stage dementia is easily missed by family, close friends and associates. In this stage, the patient is generally capable of maintaining their own activities of daily living such as bathing, dressing and feeding themselves. In fact, many individuals are able to compensate for cognitive deficits by using cueing systems (notes, calendars, reminder systems) and other family members to maintain safety and independence. Many of these individuals live with a family member or reside in an assisted living situation.

In middle stage dementia, deficits become more obvious and begin to impede the individuals' independence and ability to live without 24-hour assistance. Socially-inappropriate behavior makes going out difficult and sometimes embarrassing to family members. The patient's deficits in thinking and remembering are evident during conversation and in many cases at this stage patients may be unable to recognize close family members, become disoriented to time and situation, demonstrate paranoia and become overly sensitive to environmental stimulation.

In the final stage of dementia, individuals lose completely the ability to care for themselves. Generally, those who suffer from late stage dementia cannot eat or drink, cannot bath or dress themselves, are completely incontinent, and may lose nearly all ability to communicate to others. These individuals are completely dependent on the caregiver to meet all of their needs.

*Alzheimer's disease and dementia.* The disease process that is most commonly associated with dementia is Alzheimer's disease. In fact, it is estimated that 14 million people will have a diagnosis of Alzheimer's disease by the year 2050 (Panke & Volicer, 2002). This disease has been described in three progressive stages, namely, early, middle and late. An individual who presents with early stage Alzheimer's disease will commonly have difficulty finding the "right" word in conversation, have difficulty remembering recent events such as what they had for breakfast, misplace things, ask questions repeatedly, have changes in their personality, forget appointments and birthdays, complain of losing items, and have difficulty driving due to visiospatial processing deficits (Brunton, 2001; Kindig & Carnes, 1993). Craig, Mirakhur, Hart, McIlroy and Passmore (2004) studied 435 individuals with AD and found that in 65% of the patients, memory difficulties were the initial symptom of the disease process. The researchers also found that the most common symptom as reported by 76% of caregivers was apathy. These early symptoms are sometimes subtle, are gradual, and an individual who had high intellectual functioning prior to the acquisition of disease will be more adept at "covering," or "masking" their new shortcomings, making this stage of AD difficult for family and friends to recognize (Brunton, 2001; Hamdy, 2002).

AD gradually creates widespread irreversible cerebral neural degeneration forming neurofibrillary tangles and amyloid plaques in areas of the cortex used for memory (Carlson, 2001). The disease affects acetylcholinergic neurons first, disrupting nerve function, creating progressive nerve death. Acetylcholinergic transmission has been implicated as being involved with memory (Carlson, 2001). In AD, the temporoparietal region of the cortex is most commonly affected, which accounts for

difficulty naming objects and constructional dyspraxia (Garand, Buckwalter, & Hall, 2000). For example, as AD progresses to middle stage, the individual will have difficulty naming commonly used objects such as “comb,” “toothbrush,” and “fork” and will have difficulty copying two-dimensional drawings or assemble block designs.

The final stage of dementia or late stage AD results in an individual being completely dependent upon others to care for all activities of daily living including communication, bathing, eating and toileting. Patients are most likely to be cared for by a nursing facility when they reach this level of care primarily because families find the physical demands placed on them by this level of dependence beyond their capabilities.

*Vascular dementia.* Vascular dementias are the result of cerebrovascular disease and comprise the second leading cause of dementia (Lafosse, Reed, Mungus, Sterling, Wahbeh, & Jagust, 1997). This non-degenerative presentation of dementia produces a stepwise development of symptoms. These individuals present with greater verbal difficulties but less challenges to recall and recognition memory. General symptoms of vascular dementia include general apathy, memory disturbance, executive dysfunction, and verbal fluency disturbances that coincide with a strike or multiple transient ischemic attacks (TIA’s) and aphasia (Lafosse, et al., 1997). Family members may report that their loved one was “fine” at Thanksgiving, but very different and incapable of living on their own at Christmas. Further, symptoms are stable in-between episodes of decline never to regain prior functioning.

Other disease processes which cause a dementia include: HIV infection (American Academy of Neurology, 1991; Hillman, 1998), Picks disease, Lewy Body disease (Hamdy, 2002), Huntington’s disease, Vitamin B<sub>12</sub> deficiency, liver or kidney

failure, endocrine disorders [hypocalcemia or hypothyroidism] and alcohol or drug abuse (Jackson & Siegal, 2002).

*Caregivers' experience.* Many researchers have explored the experiences of the family's caregiving for their ill or dying loved ones. Overall, caregiving in this capacity is seen as stressful, time-consuming, financially straining, and physically and emotionally exhaustive, affecting not only the caregivers themselves but also their interactions with others including families, friends, and employers (Knussen, Tolson, Swan, Stott, & Brogan, 2005; Stephens, Franks, & Atienza, 1997).

There is an abundant amount of research examining the effects of caregiving in general. Illnesses such as cancer in adults and children, end-stage cardiac problems, and general debility of aging have attracted researchers to investigate the effects of caregiving. The majority of family caregivers tend to be female, either daughters or wives of the patient (Stephens, Franks, & Atienza, 1997). Studies have also shown that the styles of caregiving are different for male patients vs. females, and can also be different depending on the family's culture, religion, or region. Further, the issue of depression and burden in caregiving create role strain and difficulties for the caregivers as they struggle to cope with the challenges of continuing to provide in home care.

*Stress and depression.* Caregiving can be a strain on the entire family system, not just for those providing the direct care. Knussen, Tolson, Swan, Scott, and Brogan (2005) point out that the strain of caregiving can and does proliferate into many aspects of a family's function and each individual's life. They explored the stress experienced by non-spouse family members caring for individuals 65 years old and older. They described primary stressors as objective and subjective. The objective stressors included

characteristics of the patient, whereas the subjective stressors included the negative reactions of the caregiver to the objective stressors. The secondary stressor was the development of a poor family relationship that contributed to the caregiver's overall distress. In their study, when a caregiver's objective and subjective stressors increased, there was an effect on their relationship with other family members (Knussen, Tolson, Swan, Stott, & Brogan, 2005).

Studies indicate not only that caregiving can affect the individual caregiver and family unit, but it also can affect a caregiver's employment. Stephens, Franks and Atienza (1997) reported that interferences of caregiving in their role as employee included a decreased ability to concentrate on tasks at work, depleted energy to expend on work, and general disruptions in work involving the provision of care. Further, this study showed that this "negative spillover" was related to depression seen in the caregiver.

*Impact on dementia caregivers.* The caregiving experience for individuals faced with dementia has all of the above components of caregiving but also is unique in several ways. These caregivers are faced with the need to be flexible to the constantly changing behaviors of their loved one and the need to adapt to new challenges due to lost physical and mental abilities of the patient with dementia. All this must be done while grieving the loss of companionship, intimate connection, and hopes for the future.

Published literature addresses caregivers' experiences with dementia in several ways. Some researchers undertake a segmented view of a caregiver's experience, yet others take a holistic approach. Multicultural issues are often missed or ignored; there is a paucity of research that takes culture into consideration. Further, grief has only recently

been taken into account as an important piece of a caregivers' experience, with an even briefer look at anticipatory grief.

### Burden, Depression and Stress

The most common segmented presentation of dementia caregivers uses stress, depression and burden to describe a caregiver's experience (Cox, 1995; Gaugler, Davey, Pearlin, & Zarit, 2000; Gaugler, Zarit, & Pearlin, 2003; Vitaliano, Russo, Young, Teri, & Maiuro, 1991; Waelde, Thompson, Gallagher-Thompson, 2004). Researchers tend to assume the burden, depression, and stress model when exploring dementia caregiving (Gaugler, Davey, Pearlin, & Zarit, 2000; Roth, Haley, Owen, Clay, & Goode, 2001; Vitaliano, Russo, Young, Teri, & Maiuro, 1991).

Caregiving for a family member with dementia is stressful and can have multiple negative effects on personal psychological and physical health (Gaugler, Kane, Kane, & Newcomer, 2005; Vitaliano et al., 1991). Authors of a recent longitudinal study (Gaugler et al., 2005) stated that the initial stress of caregiving heavily influences outcomes of the caregiver's emotional health. They state that how the role is initiated, and then how the disease accelerates mediates to some extent the likelihood of not only increased rates of caregiver depression and stress, but also serves to expedite the speed with which patients are institutionalized. It is no surprise that having to unexpectedly assume a caregiving role for an individual with dementia has been shown to be overwhelming and stressful (Gaugler, Zarit, & Pearlin, 2003). On the other hand, family caregivers who acquire the role gradually before official diagnosis are less likely to institutionalize their family member regardless of how long they had been in that role. Even though many caregivers who assume the role of caregiver gradually report less anxiety with caregiving, as the

care demands increase many families discover the need to place their family member with dementia in a full time nursing facility (Gruss, McCann, Edelman, & Farran, 2004). This is readily demonstrated by the fact that approximately 75% of the residents in long-term care settings have a diagnosis of dementia.

Dementia affects the individual, the caregiver, and the family unit. Alterations in the individual include change in long term and short-term goals, urgency to complete projects, and the urgency to create and maintain meaningful and deepened relationships. Craig, Mirakhur, Hart, McIlroy and Passmore (2004) concluded from interviews with over 400 caregivers that the symptoms causing the greatest distress included sleep disturbances, aggression, agitation and depression or dysphoria of the AD patient. Caregivers changed their short and long-term goals, put retirement plans off or initiated them prematurely, and reframed vacations and dreams. There becomes an urgency to maintain connectedness with the affected family member. Emotional responses include anger, depression, anxiety, fear, denial, and acceptance. Caregivers report higher use of psychotropic medicines, a decline in immune system function, and increased mortality rate. Nearly all caregivers are forced to make adjustments in daily living such as changing their work status, confining their own independence, and increasing strain on finances as a result of lost employment, paying for in-home care assistance, respite care, and possibly institutionalization of the dementia patient.

Further, dementia affects the family unit. Changes are seen in long term and short-term goals. Expectations for the future are adjusted. Reunions and gatherings may be planned; families are motivated to avoid putting off important discussions or dispute resolution. Emotionally, the family may respond with an increased focus on the



importance of attachment to the individual with dementia. Strain in already poor relationships challenges communications skills. Finally, families too must make adjustments to daily living. For example, they may change expectations in chores or duties and change time allocation and importance of tasks.

### Multicultural Components

Dementia affects individuals across the globe encompassing multiple cultures and ethnicities. Unfortunately, much of the research examining caregiver experiences with dementia has focused almost solely on female, Caucasian Americans with little data to reflect the many other cultures and countries affected by this disease (Gaugler et al., 2000; Gaugler et al., 2003; Marwit & Meuser, 2002; Meuser & Marwit, 2001; Paun, Farran, Perraud, & Loukissa, 2004; Walker & Pomeroy, 1996; Zarit, Anthony, & Boutselis, 1987). Some studies failed to address ethnicity at all (Roth, Mittelman, Clay, Madan, & Haley, 2005; Vitaliano et al., 1991).

The importance of understanding and addressing cultural and ethnic diversity in the formulation of programs designed to assess and assist dementia caregivers has been demonstrated by the research of Cox (1995), and Bowes and Wilkinson (2003). In their article “We didn’t know it would get that bad: South Asian experiences of dementia and the service response,” Bowes and Wilkinson (2003) describe dementia as something that strips the individual of dignity and respect. Although the description of such feelings as isolation and stress do not differ from those found in Caucasian research, the root of stress and attitudes towards dementia and social support seemed much different. One of the primary differences rested in the conceptualization of dementia affecting the willingness to seek outside support and assistance. This study found that those

interviewed were extremely unlikely to place a family member in an institution as disease progressed; they preferred to provide sole care in the home even when caring for family in the home sometimes meant giving up religious rituals and incurring increasing amounts of physical burden. Another explanation for the reluctance to seek public assistance included language barriers, religious needs that could or would not be met in an institution, lack of sensitivity to cultural gender norms, and at times beliefs that the disease was caused by supernatural forces or “evil eye” situations.

Cox (1995) compared the experiences of black and white caregivers of dementia patients, and noted that although both black and white caregivers experienced stress, burden, and depression, and similarly suffered relationship strains and activity limitations, the underlying cause of these feelings seemed to differ. In the study of 76 black caregivers and 88 white caregivers, Cox found that the black caregivers had a greater proportion of outside assistance but that they stated a much greater need for social support. The cultural expectations of competence and social support left them feeling troubled when they could not meet the demands of an ever increasingly debilitated family member and needed more help and understanding at home. The white caregivers on the other hand expressed that the patients increasing loss of physical and cognitive function coupled with an increasing number of hours spent providing care caused the most strain.

### Grief

Grief is an important issue at some point in nearly every individual’s life. Researchers have established that although there is some variation in an individual’s specific response to loss, generalizations can be made as to how we work through a grief experience and what factors influence that experience regardless of the specific cause or

stimulus (Henderson, Hayslip, & King, 2004; Servaty-Seib, 2004). Further, recognizing aspects, effects, and expressions of grief is important to families, caregivers, and helping professionals because working through grief can be so mentally and physically exhausting that it is capable of altering an individual's overall psychological functioning, mood, affect, decision making, employment, immune system functioning, physical well-being, and relationships with others (Boerner, Schulz, & Horowitz, 2004; Gilbar & Ben-Zur, 2002).

In much of the early work investigating dementia caregivers' experiences, grief was either omitted or left as a normative response at the death of the demented individual. For example, Aneshensel, Pearlin, Mullan, Zarit, and Whitlatch (1995) worked together over a period of approximately three years investigating caregivers' experiences with dementia. One of the models introduced in this study demonstrated their understanding of the progression of the role of caregiver. In this progression, bereavement was seen as the stage directly following patient's death, although they admitted that in some cases bereavement can occur just prior to death, leaving the caregiver relieved at the actual time of death.

Once often overlooked as a factor in the caregiver's experience, grief has been found to play an important role in adapting to stress and changes in loved ones who have dementia. The most recent research on dementia caregivers includes the legitimacy and necessity of the issue of grief as an aspect of caregiving. The grief experience of AD caregivers is unique in many ways. Research has demonstrated that relationship to the dying individual before death influences the caregivers' experience of grief (Gilbar & Ben-Zur, 2002; Robinson, Clare, & Evans, 2005). Because the interpersonal

relationships the change so dramatically in the years before the death of the family member with dementia, the overall grieving process becomes complicated. Further, when the patient appears physically normal with gradual changes in mental status that may extend over a long period of time as in AD, the caregiver's grief is vulnerable to being overlooked or minimized by social relationships, employers, and relatives who might otherwise provide much needed support (Williams & Moretta, 1997). In comparison to caregivers of patients with such diseases as cancer, dementia patients differ not only in the longevity of the disease, but the impact of pervasive and gradual changes in cognition, dramatic changes in personality and behaviors, and a gradual decrease in functioning that culminates in a complete inability to attend to tasks of daily living and personal care. Further, the occasional reappearance of the patient's "former-self" introduces another dynamic in the caregiver's grief response. A caregiver's grief response is greatly influenced by their generalized responses to change in their own life and their problem-solving skills (Robinson, Clare, & Evans, 2005).

#### Anticipatory Grief

The idea of anticipatory grief was established in the 1940's by Eric Lindemann who recognized that grief can be and is felt before and after the time of death by survivors of patients with terminal illnesses. Anticipatory grief was used to describe the grief experienced prior to or in anticipation of the actual death and as a time of rehearsal for the post death experience of survivors (Fulton, 2003; Schoenberg, Carr, Kutscher, Peretz, & Goldberg, 1974). This grief experience encompasses the complexity of losing a close individual who has had a large impact on one's daily life. During the time of anticipatory grief, an individual not only prepares for life after the death of their loved

one, but acknowledges the “mini-losses” along the way. These “mini-losses” include but are not limited to a loss of future goals and plans, a loss of lifestyle both socially and economically, loss of companionship and intimacy, loss of assistance in daily tasks, and a loss of independence and freedom during the caretaking phase of caregiving (Kuhn, 2001; Schoenberg, et al., 1974; Zilberfein, 1999). Further, research has demonstrated that the length of time to impending death dictates the effect or appearance of anticipatory grief. The time of anticipatory grief of a family member with a terminal illness has been compared to a paradox in that as the caregiver tries to grieve the pulling away or loss of an individual, the physical care of their loved one demands more and more interaction (Gilliland & Fleming, 1998).

Families caring for a loved one with dementia face a series of changes, adjustments, and losses. Anticipatory grief describes their losses. They are living with someone who is indeed dying slowly, but in most cases, has the external appearance of someone who is extremely healthy and able. Future plans are changed or cancelled. Present job and daily task allocation is reassigned. The companionship they once counted on for support is fading. Living space is modified. They are slowly losing the “soul” of the individual they loved and counted on, and are left with shadows of that person, and eventually only a shell of the person they once knew (Doka, 2000; Farran, & Keane-Hagarty, 1994; Kuhn, 2001; Marwit & Meuser, 2002; Mayer, 2001).

The importance of recognizing a caregiver’s total experience during the course of dementia has been demonstrated by the two-year longitudinal study of 197 dementia caregivers completed by Roth, et al.(2001). This research group demonstrated a significant increase in physical symptoms and a marked decrease in life satisfaction over

the course of dementia caregiving. Further, they found that depression was stable for baseline, one year and two-year follow-ups in both their experimental and their control groups. This suggests that the depression found in caregivers is no different from non-caregivers and gives credence to the possibility that decreased life satisfaction and personal health could be explained by the presence of anticipatory grief. Walker and Pomeroy (1996) differentiated between symptoms of depression and anticipatory grief in dementia caregivers. Using the *Beck Depression Inventory* (Beck, Ward, Mendelson, Mock & Erbaugh, 1961) to measure depression for caregivers, and the *Grief Experience Inventory* (Sanders, Mauger & Strong, 1985) to measure anticipatory grief, they reported data showing that 63 percent of the variance in the *Beck Depression Inventory* could be explained by scores from the participants' *Grief Experience Inventory*. They further state that the depression often reported by caregivers many times could be better described as not only grief, but rather, anticipatory grief (1996).

Meuser and Marwit (2001) introduced and described the applicability of anticipatory grief as a descriptor of the dementia caregiver's experience. "Anticipatory grief in dementia caregivers is real grief" (p. 658). Multiple studies have examined caregiver stress and burden, but few studies have been completed applying grief concepts, let alone anticipatory grief, to a caregiver's experience. Participants in this study were asked to complete several quantitative instruments and then were interviewed and placed into focus groups in order to investigate caregiver's experiences throughout the stages of dementia. The data collected from this study demonstrated the presence of and changing nature of the dementia caregiver's grief process over the length of the disease (Meuser & Marwit, 2001). These researchers ultimately utilized the data

collected from this study to develop an instrument designed to measure anticipatory grief in caregivers of Alzheimer's disease patients (Marwit & Meuser, 2002).

When anticipatory grief is acknowledged and expressed in a healthy manner, gradual adjustments to loss can be made. In addition, appropriate support and education can be utilized in assisting these individuals as they live the experience of the impending and incrementally present death of their loved one, possibly preventing complicated grief reactions and accessing the invaluable support and assistance needed.

#### Interventions for Caregivers

There is no easy answer for the loved ones who are caring for a demented family member. Researchers have been diligently working to assess and describe the experiences of dementia caregivers in order to develop and provide interventions that adequately assist and provide the best care for these caregivers. The most common approach to reducing the well-researched stress and burden of dementia patient's caregivers includes a basic educational model with a support component in the form of a support group or individual assistance (Paun, Farran, Perraud, & Loukissa, 2004; Roth, Mittelman, Clay, Madan, & Haley, 2005; Waelde, Thompson, & Gallagher-Thompson, 2004; Zarit, Anthony, & Boutselis, 1987). Education is directed at teaching caregivers about disease processes, treatments for symptoms, managing behavior problems, and utilizing resources. Support is geared toward recognizing and utilizing community services, improving caregivers' communication skills, encouraging caregivers to reach out to others to maintain informal support, improving self-efficacy, and working with caregivers on their ability to identify their own symptoms of the physical affects of stress

(Paun, et al., 2004; Roth, et al., 2005; Waelde, et al., 2004; Zarit, Anthony, & Boutselis, 1987). Few published interventions address the caregiver's grief.

Although some interventions focus on both the caregiver and the patient, many focus on one or the other. The assumption utilized when focusing solely on the patient is that by addressing the behaviors of the patient with dementia, the stress and burden on the caregiver will be inevitably relieved (Lawton, 1994). In a study completed by Shin, Carter, Masterman, Fairbanks and Cummings (2004), 64 dyads consisting of an AD patient and a family caregiver were evaluated for perceptions of overall quality of life of the caregiver. Their results were not surprising based on similar research. What they found was that as neuropsychological behaviors increased, such as agitation, aggression, anxiety, disinhibition, and irritability, the caregiver's perceived quality of their own life decreased. As a result of their study, they suggest that work towards decreasing or eliminating these difficult behaviors would increase the quality of life of the caregiver (Shin, Carter, Masterman, Fairbanks, & Cummings, 2004). One suggested intervention to relieve caregivers from the distressing behaviors is respite care and institutionalization of the patient (Lawton, 1994). Although this may be a necessary option for a caregiver, research has established that there are also many potential benefits to maintaining the patient at home as long as possible

Roth, Mittleman, Clay, Madan, and Haley (2005) studied 406 spouse caregivers with a particular interest in the caregiver's social support. In this experiment, they provided the usual care as a control group. This meant that they gave caregivers information about community resources and offered advice or a referral only when requested. The experimental group participants were encouraged to participate in support



groups, were offered ad hoc phone counseling, and were involved in two individual counseling sessions and four family sessions that focused on learning techniques for managing troubling behaviors, increasing communication within the family, and strengthening current social support systems. The outcome of their intervention was positive; the experimental group experienced greater social support, received more assistance, had a larger number of support persons available to them and rated their self-satisfaction higher (Roth, et al., 2005).

Interventions for caregivers must include grief support and education. Therefore, a comprehensive model that recognizes and integrates the medical model (diagnosis, medical treatment, education on disease, education on caregiving skills and physical needs of patient), with the counseling model (social support and resources, communication skills training, anticipatory grief process exploration, grief counseling, and depression screening) best serves the patient, the caregiver, and the community as a whole. The importance of both pieces is immeasurable. Research supports early diagnosis, the importance of medical treatment and the benefits of having a working understanding of the disease (Blackwell, 2002; Brunton, 2001; Jackson & Siegal, 2002). Research also supports the undeniable importance of social support, community resources, competency training aimed at learning to work with behaviors, self efficacy, and communication skills, screening for and counseling depression and psychological challenges, and the importance of grief counseling (McCallion, Toseland, Gerber, & Banks, 2004; Paun, Farran, Perraud, & Loukissa 2004; Roth et al., 2005; Waelde, Thompson, & Gallagher-Thompson, 2004; Zilberfein, 1999).

Recent literature points out the importance and need for building a body of research to investigate the voids and uncertainties of dementia related care. One area of recent specific interest in the field of gerontology involves investigating the concept of grief as it may apply to the population of caregivers involved with dementia patients. Grief as a construct applicable to family caregivers of dementia patients is just beginning to surface as an area for further research and literary concern. Further, there is also a push in the field to obtain quantitative data to support the new and existing qualitative research on the experience of Alzheimer's disease and other dementias. Much of the research on dementia is qualitative in nature, subsequently dealing with limited, small sample sizes with very little attention to multicultural issues. The present study worked towards providing quantitative evidence in support of the presence of not only a sense of grief and loss in caregivers, but also a unique type of grief, anticipatory grief. This study obtained a multicultural sample containing African American and Caucasian caregivers as a response to the call for research that investigates the idea that caregivers of patients with dementia suffer from a gradual loss of their loved one or anticipatory grief.

## CHAPTER THREE

### METHODOLOGY

#### Research Questions

The primary research question examined the degree to which primary caregivers report anxiety, stress, depression, and grief as a part of their experience. A second research question addressed the anticipatory grief process experienced by dementia caregivers as assessed by comparing the scores of dementia caregivers on the Marwit-Meuser Caregiver Grief Inventory (Marwit & Meuser, 2005), The Loss Inventory (Niemeirer, Kennedy, McKinley & Cifu, 2004), and the Depression Anxiety Stress Scale (Lovibond & Lovibond, 1995) to the scores of cardiac patient caregivers on the same instruments. A third research question assessed the psychometric properties of the Marwit-Meuser Caregiver Inventory (Marwit & Meuser, 2005) when administered to a culturally diverse sample of dementia caregivers.

#### Hypotheses

- Anticipatory grief is a multicultural phenomenon that caregivers of dementia patients experience and can be measured using the Marwit-Meuser Caregiver Grief Inventory.
- Family caregivers of dementia patients will report higher scores than family caregivers of cardiac patients on an anticipatory grief measure and on a grief measure that is not directly associated with post death emotions.

- Family caregivers of cardiac patients will report high Depression Anxiety Stress Scores, low Loss Inventory scores and low Anticipatory Grief scores.

### Sample

An attempt was made to seek volunteers for this study that would collectively represent a culturally diverse sample for both dementia and cardiac patient family member groups. To accomplish this, volunteers were recruited from Central Alabama, Central/Western Georgia, and North/Eastern Indiana, locations of present or past employment of the researcher. Fifty-seven institutions including hospitals, home care agencies, long-term care facilities, assisted living and senior communities, rehabilitation hospitals, and dementia support groups were contacted. This sample is reflective of the thirty-five venues that were actually recruited to distribute packets. A total of 580 packets were distributed. An attempt was made to include under-represented groups such as male caregivers and African American caregivers, with a goal of obtaining a more racially representative sample. Two sample groups were obtained for this study; caregivers of family members with a diagnosis of dementia and caregivers of family members with a cardiac diagnosis. Cardiac patients and their caregivers, like dementia patient caregivers, have been shown to demonstrate frustration, progressive losses, social isolation, and the stress of balancing medical care and treatment (Murray, Boyd, Kendall, Worth, Brenton, & Clausen, 2002). With this in mind, cardiac caregivers were chosen as a comparison group to enable a comparison of possible differences in the presence of grief between the two groups while able to approximate equivalent expectations on stress,

depression and anxiety within a sample that is expected to have not only similar demographics but also similarities in experiences.

Volunteers were the primary caregivers of family members with either dementia or a current cardiac diagnosis who have cared for the patient a minimum of 2 weeks to 10+ years. Volunteers were accepted regardless of stage of disease progression for dementia. Volunteers included both males and females, ranging in age from 20 years old to 91-100. Interestingly, there were three dementia caregivers who reported their age as 91-100+. Further, family caregivers were caring for their family member either in their home or in another health care setting such as an assisted living or long-term care facility.

#### Procedures

*Recruitment.* The goal of this study was to recruit family caregivers of dementia patients, and individuals who are caregivers of family members with a cardiac diagnosis from Central Alabama, Central/Western Georgia, and North/Eastern Indiana. The researcher contacted long-term care facilities, assisted living facilities, home nursing care agencies, and Alzheimer's support groups in an effort to obtain a diverse sample of subjects. The data packets were given to each participating facility; key staff members at each facility were asked to personally invite appropriate family caregivers to participate, and then distribute the packets. All participation was voluntary and an incentive was offered for participation to all who accepted the data collection materials. The incentive offered was an educational recording that offered basic information in regards to stress reduction and management including maintaining a healthy diet and exercise, breathing exercises and simple relaxation techniques. This recording was an original produced by the researcher for this study as an incentive for data completion.

*Contact.* The data collection sites were contacted by phone, letter, personal interview, and via e-mail. With permission, information flyers inviting participation in the study were distributed to each site or group. If a caregiver expressed interest in participation, the facility representative gave the family member the pre-addressed and stamped envelope containing the MMCGI, Loss Inventory, and the DASS along with a demographic questionnaire, confidentiality statement and consent form, a card with researcher contact information they could keep to address any questions, and a letter of appreciation and instruction on how to fill out and return the forms. No identifying information was attached to the materials handed to the participant. Each site was given identical data packets. They were also given the educational recording at this time.

The time obligation of each participant was approximately 45 minutes or less to read the consent form and answer the 69 items, plus the 9 demographic questions. Each participant was asked to complete a basic demographic questionnaire. Next, they were asked to complete the following paper-pencil instruments, previously placed in envelopes in random order: The Depression Anxiety Stress Scale-21 (Lovibond & Lovibond, 1995), and the Marwit-Meuser Caregiver Grief Inventory Short Form (Marwit & Meuser, 2005), and The Loss Inventory (Niemeirer, Kennedy, McKinley & Cifu, 2004).

Confidentiality of all participants was ensured by maintaining all data collected as anonymous. The researcher did not meet any participants; participants did not place their names or other form of personal identification on any of the data collected, and each site was given identical data packets.

## Measures

The *Depression Anxiety Stress Scale* (DASS-21) (Antony, Bieling, Cox, Enns, & Swinson, 1998; Lovibond & Lovibond, 1995) assesses for and distinguishes between depression, anxiety and stress. The Depression subscale was developed to distinctly measure such elements of depression as dysphoria, hopelessness, devaluation of life, self-deprecation, lack of interest or involvement, anhedonia, and inertia. The Anxiety subscale assesses anxiety as autonomic arousal, skeletal musculature affects, situational anxiety, and subjective experience of anxious affect. The Stress subscale assesses areas of stress that included difficulty relaxing, nervous arousal, being easily upset or agitated, irritable or over-reactive, and impatient (Lovibond, 1998). The DASS-21 is a 21 question, self-report instrument. The reliability for the DASS-21 has been demonstrated to be at a Cronbach's alpha of .88 for depression, .82 for anxiety, .90 for stress, and has been shown to be a valid instrument in comparison to the Beck Depression Inventory (correlation of .69 for stress scale, .79 for depression scale, and .62 for anxiety scale), the State-Trait Anxiety Inventory (correlation of .68 for stress scale, .71 for depression scale, and .55 for anxiety), and the Beck Anxiety Inventory (correlation of .70 for stress, .51 for depression, and .85 for anxiety) (Antony, Bieling, Cox, Enns, & Swinson, 1998; Henry & Crawford, 2005).

*Marwit-Meuser Caregiver Grief Inventory* (MM-CGI) Short-form (Marwit & Meuser, 2005). The MM-CGI is the only tool designed specifically to measure the anticipatory grief experienced by dementia caregivers that takes into account the specific stage of the patient's disease. This instrument is based on a qualitative interview process completed by Marwit and Meuser (2001). Interview data were

transformed into a full 50-question scale (2002) and subsequently shortened into its present form (2005) of 18 items. Both the initial instrument and its shortened form segment anticipatory grief into three factors: personal sacrifice burden (measuring individual losses experienced as a result of caregiving), heartfelt sadness and longing (measuring intrapersonal emotional reactions in response to caregiving), and worry and felt isolation (measuring the feelings of losing connections with and support from others) (Marwit & Meuser, 2005). The combined scores create a personal grief profile that is used to quantitatively express the extent of anticipatory grief an individual is experiencing (Marwit & Meuser, 2005). The reliability for the initial 50-item inventory ranged from a Cronbach's alpha score of .90 to .96 (Marwit & Meuser, 2002). Internal reliability for the shortened form has been demonstrated to be (Cronbach alphas of .83, .80. and .80) (Marwit & Meuser, 2005).

*The Loss Inventory* (Niemeirer, Kennedy, McKinley & Cifu, 2004). the LI was designed to measure the grief an individual experiences when they have lost personal functional abilities due to disablement. The utility of this 30-item self-report scale is that its focus isn't specifically death-related grief; instead, it was designed to distinguish between depression and grief in a population where grief was often overlooked. The reliability for the Loss inventory has been demonstrated to be at a Cronbach's alpha of .90 with a Spearman-Brown equal length reliability coefficient of .88, and it has been shown to be valid in comparison to the *Texas Revised Inventory of Grief* (Faschingbauer, 1981) and the *Grief Experience Inventory* (Niemeier et al., 2004). This inventory relies less on bereavement terms to explain the grief associated with disablement, thus providing a sound construct validity foundation for use in the present study. Hence, it is



more appropriate to use in the case of a dementia caregiver's grief experience. As previously demonstrated, a caregiver's family member was not physically deceased but instead experiencing incremental disablement of cognitive functioning for dementia patients followed by physical disabilities of both the cardiac and dementia patients.

### Data Analysis

Reliability analysis using Cronbach's alpha was completed for each scale within each instrument and each instrument was run separately to handle the small  $n$  in the cardiac family member group. This was done to address the reliabilities of instruments used, particularly the MMCGI-Short Form. This also begins to address the question of the MMCGI-Short Form's psychometric properties and continuity of use.

Multivariate analysis of variance (MANOVA) was performed for both the DASS-Short form and the MMCGI-Short Form data to address the hypothesis that family caregivers of dementia patients will report higher scores than family caregivers of cardiac patients on an anticipatory grief measure and the hypothesis that family caregivers of cardiac patients demonstrate high Depression Anxiety Stress Scores, and low Anticipatory Grief scores.

A one-way ANOVA was performed to analyze data from the *Loss Inventory* instrument in order to address the hypothesis that family caregivers of dementia patients will report higher scores on a grief measure that is not directly associated with post death emotions and the hypothesis that family caregivers of cardiac patients demonstrate low *Loss Inventory* scores.

Multivariate analysis of variance (MANOVA) was performed to investigate whether there was a difference between race and responses on both the MMCGI-Short Form and the DASS-Short Form for Dementia caregivers.

## CHAPTER FOUR

### RESULTS

The primary goal of this study was to investigate dementia patient's family caregivers' experience of anxiety, stress, depression and grief as a result of the decreased ability of individuals with dementia to interact with loved ones and care for themselves independently as they had prior to diagnosis. Specifically, this study examined whether family caregivers of dementia patients experienced these constructs and how their experiences may compare to those of a population of cardiac family caregivers in similar circumstances. Secondly, providing that dementia caregivers experience grief, this study looked at the application of anticipatory grief as a construct to more accurately describe and differentiate the experience of dementia caregivers in comparison to a cardiac caregiver's experience. Finally, this study hoped to provide data to support the psychometric properties of the *Marwit-Meuser Caregiver Grief Inventory Short-Form* when used with a multicultural sample.

*Sample.* A total of 580 surveys were distributed for this study to support groups, long-term care facilities, home care agencies, physicians' offices, and rehabilitation hospitals over a 3-month period of time. Two hundred, or 34% of the surveys, were distributed within Alabama, 190 or 32% were distributed in Georgia, and 200 or 34% were distributed in Indiana. Of the total number of surveys distributed, 176 or 30% were returned and used in this study.

Of the 176 respondents, 138 were primary caregivers of dementia patients and 38 were caregivers of cardiac patients. As noted on Table 1, the distribution of male to female participants was fairly close with a total of 96 men and 80 women. Males formed a slight majority of the participants in both the dementia and cardiac samples, with men equaled 54.3% in the dementia sample and 55.3% in the cardiac sample and females equaled 45.7% in the dementia sample and 44.7% in the cardiac sample. Although this study's sample has a majority Caucasian sample population with very few Latino/a respondents, it holds a strong representation of African Americans at 40.6% in the dementia sample and 50% in the cardiac sample. The majority of the respondents for this study were from Alabama (89) and Georgia (75) with few representing Indiana (10). Chi-square analysis of this distribution indicated a significant difference ( $\chi^2 [df = 2] = 118.54, p < .01$ ) with a greater frequency of dementia caregivers coming from Alabama. Also notable is that the largest percent of respondents from Georgia were caring for cardiac patients.

The three most prominent age categories for caregivers in both dementia and cardiac respondents were 51-60, 61-70, and 71-80 with the majority being a son, daughter, or spouse. Chi-square analysis of the distribution of caregiver age indicated a significant difference ( $\chi^2 [df = 2] = 120.75, p < .01$ ) with dementia caregivers being significantly older than cardiac caregivers. The modal age for dementia caregivers fell in the 61+ age grouping, with cardiac caregiver's modal age falling in the 41-60 age grouping. There was also a notable difference in the relationship the caregivers had with the patient depending on diagnosis. Chi-square analysis of this distribution indicated a significant difference ( $\chi^2 [df = 2] = 116.37, p < .01$ ) with children being more

likely to caregive for dementia family members and spouses as more likely to care for cardiac patients.

Duration of caregiving, as noted on Table 1, ranged from 2-3 weeks to 10+years, with 3-5 years being the most prevalent response for dementia family members and 1-2 years for cardiac family members. Chi-square analysis of this distribution indicated a significant difference ( $\chi^2 [df = 3] = 125.77, p < .01$ ) demonstrating that the dementia caregivers had spent a significantly longer duration caregiving with 29.6% reporting caregiving for 6 years or greater. The largest portion of cardiac caregivers (24%) reported the duration of caregiving to be less than one year.

Table 1

Characteristics of Sample	n (%)	n (%)
	Dementia 138	Cardiac 38
Duration of Caregiving		
2-4 weeks	3 (2.2%)	2 (5.3%)
2-4 months	2 (1.4%)	0 (0%)
5-11 months	9 (6.5%)	7 (18.4%)
1-2 years	22 (15.9%)	17 (44.7%)
3-5 years	61 (44.2%)	10 (26.3%)
6-10 years	25 (18.1%)	0 (0%)
10+ years	14 (10.1%)	2 (5.3%)
Blank	2 (1.4%)	0 (0%)
Gender		
Male	75 (54.3%)	21 (55.3%)
Female	63 (45.7%)	17 (44.7%)
Age		
20-30	0 (0%)	5 (13.2%)
31-40	8 (5.8%)	3 (7.9%)
41-50	20 (14.5%)	7 (18.4%)
51-60	42 (30.4%)	14 (36.8%)
61-70	37 (26.8%)	6 (15.8%)
71-80	28 (20.3%)	3 (7.9%)
81-90	0 (0%)	0 (0%)
91-100+	3 (2.2%)	0 (0%)
Relationship		
Daughter	39 (28.3%)	6 (15.8%)
Son	47 (34.1%)	9 (23.7%)
Spouse	42 (30.4%)	18 (47.4%)
Life Partner	1 (.7%)	0 (0%)
Niece	1 (.7%)	1 (2.6%)
Nephew	1 (.7%)	1 (2.6%)
Brother	2 (1.4%)	0 (0%)
Sister	2 (1.4%)	0 (0%)
Grandchild	3 (2.2%)	0 (0%)
Other		3 (7.9%)
Race		
Caucasian	80 (58%)	18 (47.4%)
African American	56 (40.6%)	19 (50%)
Latino/a	2 (1.5%)	1 (2.6%)
Geographic location		
Alabama	56 (40.6%)	33 (86.8%)
Georgia	73 (52.9%)	2 (5.3%)
Indiana	7 (5.1%)	3 (7.9%)
Other	2 (1.4%)	0 (0%)

*Instrument Reliabilities.* The instruments used in this study consisted of the *Marwit-Meuser Caregiver Grief Inventory Short-form* (Marwit & Meuser, 2005), the *Depression Anxiety Stress Scale-21* (Lovibond & Lovibond, 1995), and the *Loss Inventory* (Niemeirer, et al, 2004). Reliability analysis using Cronbach’s alpha was completed for each scale within each instrument and each instrument was run separately to handle the small *n* in the cardiac family member group.

Table 2

Instrument Reliabilities					
Summary of Scales		Dementia		Cardiac	
	# in Scale	Mean & SD	Coefficient alpha	Mean & SD	Coefficient alpha
<i>MMCGI-Short Form</i>					
Sacrifice Burden	6	20.6/4.2	0.87	12.1/3.6	0.83
Sadness & Longing	6	21.3/3.9	0.82	12.3/3.4	0.81
Worry & Felt Isolation	6	20.3/4.5	0.86	13.0/3.8	0.88
Total Score	18	62.2 /11.1	0.93	37.3/10.1	0.94
<i>DASS-Short Form</i>					
Depression	7	11.0/5.2	0.90	4.3/3.1	0.79
Anxiety	7	8.9/5.2	0.88	4.3/2.9	0.78
Stress	7	12.4/4.8	0.88	5.4/3.0	0.71
Total Score	21	32.3/14.0	0.95	13.9/7.9	0.89
<i>The Loss Inventory</i>					
Total Score	30	97.9/25.4	0.98	52.1/14.8	0.95

*Marwit-Meuser Caregiver Grief Inventory Short-form:* As seen in Table 2, reliability indicators in this study for the Marwit-Meuser Caregiver Grief Inventory Short-form (Marwit & Meuser, 2005) include an overall Cronbach’s alpha of .93 for dementia caregivers and .94 for cardiac caregivers, a finding somewhat stronger than the norming alpha of .80. Total individual item reliabilities for the three scales within this measure resulted in coefficient alpha’s of .64 for Sacrifice and Burden which fell below the

original alpha of .83, .90 for Sadness and Longing which was greater than the original .80 alpha, and .91 for Worry and Felt Isolation, also larger than the original alpha of .80.

Table 3

MMCGI-Short Form						
Reliability of Individual Items						
Subscale	Item #	Dementia		Cardiac		Mean Difference
		Mean	SD	Mean	SD	
Sacrifice/Burden	16	3.47	0.95	2.03	0.94	1.44
	18	3.44	1.02	1.92	0.97	1.52
	17	3.37	0.96	1.92	0.67	1.45
	1	3.36	0.71	2.05	0.77	1.31
	2	3.35	0.84	2.02	0.75	1.33
	10	3.59	0.91	2.11	0.69	1.48
Sadness/Longing	12	3.77	0.79	2.42	0.98	1.35
	8	3.64	0.91	2.16	0.86	1.48
	15	3.61	0.89	1.95	0.66	1.66
	11	3.46	0.94	2.03	0.85	1.43
	4	3.43	0.91	1.71	0.69	1.72
	9	3.34	0.92	2.03	0.72	1.31
Worry/Isolation	7	3.49	0.98	2.58	0.89	0.91
	14	3.44	1.01	2.03	0.82	1.41
	5	3.44	0.97	2.29	0.84	1.15
	13	3.41	0.86	2.16	0.86	1.25
	6	3.41	0.95	1.97	0.64	1.44
	3	3.13	1.07	2.00	0.66	1.13

As seen in Table 3, the means for individual items were consistently higher in dementia participants than for the cardiac participants. The individual item mean range for dementia caregivers was 3.13 to 3.77 on a 1-5 point scale, and the mean range for cardiac caregivers was 1.71 to 2.58. The largest mean difference for the Sacrifice/Burden subscale was from item 18 (I'm stuck in this caregiving world and there's nothing I can do about it) with a mean difference of 1.52 on a 1-5 point scale. The largest difference in means (1.72) for the entire instrument fell on item number 4 (I



have this empty, sick feeling knowing that my loved one is “gone”.) as part of the Sadness/Longing subscale. The largest mean difference on the Worry/Isolation subscale (1.44) was item number 6 (I’ve lost the closeness with my loved one and connectedness with my family.).

*The Depression Anxiety Stress Scale-21* (Lovibond & Lovibond, 1995) scores provided evidence of internal reliability, with coefficient alpha’s of .95 for dementia caregivers and .89 for cardiac caregivers as seen in Table 2. Total individual item reliabilities for the three scales within this measure resulted in alpha’s of .92 for Depression which was comparable to the alpha of .88 in the original reliabilities of the instrument, .76 for Anxiety compared to the original reliability of .82, and .79 for Stress compared to the original reliability of .90.

Table 4

DASS-Short Form  
Reliability of Individual Items

Subscale	Item #	Dementia		Cardiac		Mean Difference
		Mean	SD	Mean	SD	
Depression	13	1.88	0.90	0.90	0.76	0.98
	16	1.80	0.93	0.55	0.65	1.25
	10	1.71	0.99	0.58	0.64	1.13
	17	1.67	1.01	0.74	0.76	0.93
	5	1.56	0.88	0.84	0.72	0.72
	3	1.25	0.87	0.40	0.55	0.85
	21	1.14	0.95	0.29	0.52	0.85
Anxiety	9	1.62	1.02	0.89	0.65	0.73
	15	1.54	1	0.71	0.61	0.83
	7	1.45	0.99	0.76	0.63	0.69
	19	1.42	1.1	0.66	0.71	0.76
	4	1.11	0.97	0.61	0.64	0.50
	20	1.09	0.95	0.40	0.55	0.69
	2	0.66	0.89	0.24	0.54	0.42
Stress	12	1.93	0.85	0.82	0.80	1.11
	11	1.83	0.94	0.87	0.74	0.96
	18	1.78	0.9	0.71	0.65	1.07
	8	1.75	0.9	0.82	0.69	0.93
	14	1.72	1.04	0.97	0.72	0.75
	6	1.71	0.79	0.92	0.82	0.79
	1	1.7	0.8	0.29	0.56	1.41

Table 4 demonstrates that the means on all individual items are higher for dementia caregivers. The individual item mean range for dementia caregivers was .66 to 1.93 on a 0-3 point scale, and the mean range for cardiac caregivers was .24 to .97. The largest mean difference in the Depression subscale (1.13) was on item number 16, (I felt that I had nothing to look forward to). Item number 15, (I felt I was close to panic) on the Anxiety scale had a mean difference of .83. The largest mean difference on the instrument fell within the Stress subscale under item number 1, (I found it hard to wind down) with a mean difference of 1.41. Respondents from both Cardiac and Dementia

groups had means that ranked similarly on the Anxiety subscale. Both groups had highest means for item 9, (I was worried about situations in which I might panic and make a fool of myself), had fourth highest means for item 19, (I was aware of the action of my heart in the absence of physical exertion).

*The Loss Inventory* responses provided evidence of solid internal reliability, with resulting coefficient alphas of .98 in dementia caregivers and .95 in cardiac caregivers. The means on individual items for this instrument shown in Table 5 reflect higher scores for dementia caregivers with a mean range of 3.48 to 3.11 on a 1-5 point scale with cardiac caregiver's individual means ranging from 2.08 to 1.53. The largest difference in means fell on item number 18, (I feel the need to talk about my loss) with the mean of Dementia subjects (3.43) and Cardiac subjects (1.63) to equal a mean difference of 1.8. Item number 23, (It is hard for me to believe that what I lost is gone) had a mean difference of 1.76, and item number 25, (I can't help thinking about the 'good old days' before my loss) had a mean difference of 1.75.

Table 5  
 The Loss Inventory  
 Reliability of Individual Items

Item #	Dementia		Cardiac		Mean Difference
	Mean	SD	Mean	SD	
2	3.48	0.77	2.08	0.71	1.40
29	3.46	0.94	1.76	0.82	1.70
18	3.43	1.09	1.63	0.79	1.80
25	3.43	0.86	1.68	0.77	1.75
8	3.41	1.02	1.89	0.76	1.52
19	3.38	0.96	1.68	0.90	1.70
13	3.36	0.93	1.95	0.84	1.41
1	3.30	0.91	1.87	0.66	1.43
15	3.30	1.01	1.68	0.77	1.62
9	3.32	1.11	1.76	0.79	1.56
23	3.31	1.06	1.55	0.65	1.76
20	3.27	1.08	1.84	0.75	1.43
26	3.27	1.10	1.74	0.79	1.53
27	3.27	1.06	1.71	0.84	1.56
4	3.25	0.97	1.89	0.80	1.36
17	3.25	1.06	1.79	0.87	1.46
7	3.23	1.05	1.74	0.64	1.49
6	3.22	1.06	1.92	0.67	1.30
10	3.22	1.14	1.66	0.71	0.71
11	3.20	1.14	1.53	0.80	1.67
14	3.20	1.10	1.66	0.67	1.54
22	3.20	1.17	1.79	0.78	1.41
3	3.18	1.08	1.82	0.73	1.36
30	3.18	1.17	1.55	0.76	1.63
12	3.17	1.12	1.58	0.68	1.59
21	3.14	1.13	1.76	0.82	1.38
5	3.13	1.18	1.79	0.70	1.34
16	3.12	1.16	1.61	0.72	1.51
24	3.12	1.03	1.58	0.76	1.54
28	3.11	1.14	1.63	0.71	1.48

## Hypothesis Testing

*Hypothesis One.* The previously discussed reliability tests were run to address the hypothesis that the *Marwit-Meuser Caregiver Grief Inventory-Short Form* is a reliable instrument in the measurement of anticipatory grief for the dementia family caregiver population. This study has contributed to establishing its reliability as addressed previously.

*Hypothesis Two.* Multivariate analysis of variance (MANOVA) was performed for both the DASS-Short form and the MMCGI-Short Form data to address the hypothesis that family caregivers of dementia patients will report higher scores than family caregivers of cardiac patients on an anticipatory grief measure and the hypothesis that family caregivers of cardiac patients demonstrate high depression, anxiety, and stress scores, and low anticipatory grief scores. The results of this study support the hypothesis suggesting that caregivers of dementia patients experience significant between subject effects [ $F(1, 174) = 3.90, p < .05$ ] for stress ( $F = 22.3, p < .05$ ), anxiety ( $F = 57.7, p < .05$ ), depression ( $F = 55, p < .05$ ), overall anticipatory grief ( $F = 134.7, p < .05$ ), personal sacrifice ( $F = 69.5, p < .05$ ), heartfelt sadness ( $F = 168.6, p < .05$ ), and Worry and Felt Isolation ( $F = 78.5, p < .05$ ). The means for dementia respondents were significantly higher than those of the cardiac group as seen on Table 6 and  $H_0$  is rejected. Hotelling's T-square contrasts for group differences revealed that dementia caregivers differed from cardiac caregivers in their responses to the *MMCGI-Short Form* ( $H^2 = 178, p < .001$ ) and the DASS-Short Form ( $H^2 = 67, p < .001$ ). These results are reported on Table 6.

A one-way ANOVA was performed to analyze data from the *Loss Inventory* instrument in order to address the hypothesis that family caregivers of dementia patients

will report higher scores on a grief measure that is not directly associated with post death emotions and the hypothesis that family caregivers of cardiac patients demonstrate low *Loss Inventory* scores. There was a significant difference in the mean responses on all of the items of this instrument between the dementia group and the cardiac group.  $H_0$  is rejected with a .05 confidence interval because the resulting  $F$  value of 102.7 falls within the critical region of rejection when  $F(1, 174)=3.90$ .

Table 6  
Comparison of Scales Scores

	Dementia Mean & SD	Cardiac Mean & SD	$F^*$
MMCGI-Short Form <sup>a</sup>			
Personal Sacrifice Burden	20.9/6.3	12.1/3.6	69.5*
Heartfelt Sadness & Longing	21.3/3.9	12.3/3.4	168.6*
Worry & Felt Isolation	16.9/3.9	10.9/3.1	78.5*
Total Score	62.5/12.3	37.4/10.1	134.7*
DASS-Short Form <sup>b</sup>			
Depression	11/5.2	4.2/3.0	55.0*
Anxiety	9.1/6.1	4.2/2.8	57.7*
Stress	12.6/5.6	5.3/3.0	22.3*
Total Score	32.7/1.5	13.9/7.8	57.8*
The Loss Inventory			
Total Score	98.4/27	52.3/14.6	102.7*

a. Hotellings  $T=178$ ,  $p<.001$

b. Hotellings  $T=67$ ,  $p<.001$

\*  $p<.05$

*Hypotheses Three.* Multivariate analysis of variance (MANOVA) was performed to investigate whether there was a difference between race and responses on both the MMCGI-Short Form and the DASS-Short Form for dementia caregivers in order to support or reject the hypothesis that anticipatory grief is a multicultural phenomenon and that the MMCGI-Short Form is a reliable instrument for a multicultural sample. There were too few Latino/a subjects to include them in this

analysis and subsequently only Caucasians ( $n= 80$ ) and African Americans ( $n= 56$ ) were compared. Hotelling's T-square contrasts for group differences revealed that Caucasian dementia caregivers differed from African American caregivers in their responses to the MMCGI-Short Form ( $H^2= 10.72, p < .001$ ) and the DASS-Short Form ( $H^2= 797.3, p < .001$ ). These results are reported on Table 7. Significant effects were noted with an  $F$  critical of  $[(1.134)= 3.90, p < .05]$  for total score MMCGI-Short Form ( $F= 8.4, p < .05$ ), the MMCGI-Short Form Personal Sacrifice and Burden subscale ( $F= 5.1, p < .05$ ) and the MMCGI-Short Form subscale for Worry and Felt Isolation ( $F= 9, p < .05$ ). The African American subjects responded with consistently higher overall and subscale means for the MMCGI-Short Form as seen on Table 8. The MMCGI-Short Form subscale Heartfelt Sadness and Longing did not achieve statistical significance, with an  $F= 3.5, p < .05$ , indicating that there was no significant difference between African American and Caucasian respondents reports of Heartfelt Sadness and Longing.

Table 7  
Multicultural Comparison of Dementia Caregivers' Responses

	African American n=56 Mean & SD	Caucasian n=80 Mean & SD	F*
MMCGI-Short Form <sup>a</sup>			
Personal Sacrifice Burden	22.5/7.8	20/4.5	5.1*
Heartfelt Sadness & Longing	22.1/3.0	21/4.3	3.5
Worry & Felt Isolation	18.2/3.0	16.2/4.2	9.0*
Total Score	66.3/11.4	60.4/12	8.4*
DASS-Short Form <sup>b</sup>			
Depression	12.2/4.2	10.3/5.6	4.4*
Anxiety	10/4.4	8.7/7.0	1.7
Stress	14.3/5.6	11.6/5.4	7.9*
Total Score	36.6/11.4	30.7/16.6	5.3*

a. Hotellings T= .080,  $p < .001$

b. Hotellings T= 5.95,  $p < .001$

\*  $p < .05$

Significant effects were noted on the DASS-Short Form for total score ( $F= 5.3$ ,  $p<.05$ ), and DASS-Short Form subscales for Depression ( $F= 4.4$ ,  $p<.05$ ), and Stress ( $F= 7.9$ ,  $p<.05$ ). The African American subjects responded with consistently higher overall and subscale means for the DASS-Short Form as seen on Table 7. There was not a significant effect for the DASS-Short Form subscale that measured Anxiety ( $F= 1.7$ ,  $p<.05$ ), indicating no significant difference in the reported anxiety of the two groups.



## CHAPTER FIVE

### SUMMARY OF FINDINGS

The number of individuals who will suffer the effects of dementia is steadily climbing. As life expectancy elongates, the opportunity to experience the cognitive decline associated with dementia becomes overtly promising (Blackwell, 2002; Butterfield & Pocerlich, 2003). Healthcare professionals from multiple areas of specialty and expertise are being called to assist not only the client diagnosed with dementia, but the family caregivers as well. The present study is a response to the paucity of needed research aimed at aiding helping professionals as they provide care for dementia patients and their families. This study examined the specific type of grief associated with caring for a family member with dementia that has been coined *anticipatory grief* by Marwit and Meuser (2005).

#### Summary of Findings

This study provided evidence that caregivers of dementia patients do report a great amount of anxiety, stress, depression and grief. In fact, the quantitative difference reported by dementia caregivers compared to cardiac caregivers exceeded standard statistically significant criteria reflecting a greater amount of each one of these feelings in the dementia caregiver population. Further, this study provided evidence that grief is a large factor in the dementia caregiving experience. In this study, caregivers of a dementia family member stated not only more grief on the *Loss Inventory*, but more

importantly, reported high scores on anticipatory grief as measured by the *MMCGI-Short Form*. In fact, the largest differences between dementia caregivers and cardiac caregivers resided in the areas that specifically addressed grief. The responses provided by dementia caregivers were overwhelmingly larger than the cardiac caregiver sample on the *Loss Inventory* and stated feelings of heartfelt sadness and longing from the *MMCGI-Short Form*. This grief response could have an additive effect on caregivers' felt anxiety, stress, and depression and explain the difference in the two group's responses on the *DASS-Short Form*. Both groups expressed some degree of depression, anxiety, and stress. It was anticipated that both groups would have been much more similar in mean scores than what this study showed. One explanation would be that working with and through a grief response is in itself stressful and anxiety provoking, and as experienced grief increases so does one's anxiety, stress, and stated feelings of depression. In addition, the findings of this study suggest that the longer duration of caregiving, different relationship variables, and advanced age of dementia caregivers could be true factors in accentuating the felt burden of caregiving.

Examination of the results that point at caregiver's experienced grief provides a closer look at the concept of anticipatory grief. The data provided from this study support the concept of anticipatory grief for dementia caregivers as hypothesized by Marwit and Meuser, and as measured by the *MMCGI-Short Form*. This instrument addressed feelings of personal sacrifice, burden, heartfelt sadness, longing, worry and felt isolation. Although cardiac caregivers to some degree demonstrated these feelings of grief as a part of their caregiving experience, the individual scaled scores and total instrument scores for the *MMCGI-Short form* were significantly higher for dementia

caregivers. Item number four on the *MMCGI-Short Form* addresses the feeling of loss as if the individual is “gone”. The criterion for inclusion in this study was that the diagnosed family member be alive at the time of participation. The mean difference in responses between cardiac family caregivers and dementia caregivers demonstrates that the dementia family caregiver has not only lost the closeness to the individual who suffers from dementia, but that they feel at least in some way that their loved one is not available to be close to anymore and are indeed in a position to experience grief for a living individual.

The third question this study addressed looked at whether the *MMCGI-Short Form* is a reliable instrument for a multicultural sample. One of the true strengths of this study was its large African American representation, something few other studies have been able to accomplish. On the other hand, this study was unable to collect a significant number of subjects representing other ethnicities and so it is not possible to speculate beyond Caucasian and African American subgroups. The data collected here suggests that this instrument can be effectively used with both Caucasian and African American populations as both groups reported elevated overall mean scores and equivocal scores on the subscale of heartfelt sadness and longing. When compared, the African American and Caucasian dementia caregiver’s scores on the *MMGCI-Short Form* were considerably different. Interestingly, the African American dementia caregivers’ subgroup reflected a greater feeling of worry, felt isolation, burden, and personal sacrifice than the Caucasian dementia caregiver subgroup. Overall, the African American dementia caregivers responded with much higher subscale means with an exception of feelings of heartfelt sadness and longing that generally reflects a

“typical-grief” response. This correlates with these two groups’ differing responses on the DASS-Short Form. African American dementia caregivers reported considerably higher amounts of depression and stress with no real difference in reported anxiety.

### Discussion

For many individuals, caregiving regardless of the disease process places challenges on an individual’s physical and emotional resources (Gaugler, Davey, Pearlin, & Zarit, 2000; Gaugler, Zarit, & Pearlin, 2003; Roth, Haley, Owen, Clay, & Goode, 2001; Vitaliano, Russo, Young, Teri, & Maiuro, 1991; Waelde, Thompson, & Gallagher-Thompson, 2004). As seen in the results of this study, caregivers experience strain with a lengthy duration of caregiving and uncertainty for future outcomes as in both cardiac and dementia patient’s situations. Both cardiac family caregivers and dementia family caregivers responded that they do feel stress, anxiety, depression, and loss. This study reinforced what has been previously found in dementia research. Results clearly show that stress, anxiety, depression, and grief are all a part of the dementia caregiving experience. Moreover, results provide evidence that the experience of caring for a loved one with dementia is demonstrably different from caring for a family member with a cardiac diagnosis and that the larger presence of grief in some way may attribute to higher anxiety, stress and feelings of depression.

The results of this study suggest that the difference between being a cardiac patient caregiver and a dementia patient caregiver is significant and dramatic. Self-report responses of dementia caregivers in this study indicate that they experience nearly twice the amount of personal sacrifice and burden, and heartfelt sadness and longing as Cardiac caregivers report. Dementia caregivers demonstrated a significant

difference in their reported feelings of Sadness/Longing as exemplified by a large mean difference on the item, (I have this empty, sick feeling knowing that my loved one is “gone”). This item takes into account that the loved one is physically present but that an important and intricate part of their psyche is no longer present. This loss is further expressed in the Dementia caregivers’ mean response to the item, (I’ve lost the closeness with my loved one and connectedness with my family). Dementia caregivers’ responses were significantly higher than that of Cardiac caregivers. This type of felt loss has been described as anticipatory grief. Based on these results it is clear that primary caregivers and family members of an individual with dementia likely suffer from anticipatory grief.

It is important to note that the felt experience of depression by dementia caregivers was nearly three times that of cardiac caregivers and they also have twice as much felt anxiety and stress. Dementia caregivers demonstrated a significant difference in mean responses to the first item on the DASS-Short Form that asks how difficult it was for them to wind down. They also felt strongly that they had nothing to look forward to (item 10) and felt they were close to panic (item 15). The overall responses to questions aimed at measuring stress, anxiety, and depression suggest that although both groups shared these feelings to some degree, the responses for dementia family caregivers were overwhelmingly more pronounced

Another significant finding is that dementia caregivers reported nearly twice the amount of felt loss and grief as cardiac caregivers. Specifically, dementia caregivers reported a significantly higher desire to talk about their loss (item 18), had difficulty

believing that what they lost is gone (item 23), and couldn't help but think about better days before their loss (item 25).

Overall, the dementia caregivers' mean scores on all three instruments were significantly higher, reflecting the true challenges faced by family members, specifically in regards to the construct of anticipatory grief. Based on results from this study, it appears that although the cardiac group responded affirmatively to the anticipatory grief items, their response total was significantly lower than the dementia group suggesting that caregiving for a family member with dementia involves greater feelings of longing, worry, and isolation, and a greater sacrifice of their own needs.

#### Anticipatory Grief

Anticipatory grief is a real phenomenon that affects many family caregivers of dementia patients. This study reinforces not only that grief is present for dementia caregivers, but also that it provides additional evidence aligning anticipatory grief to the dementia caregiving experience. This study shows that dementia caregivers are not experiencing "typical" grief. In fact, it demonstrates that their grief is much more complicated. It becomes much more difficult to work through grief when the one you grieve for is still present in body but not in persona and becomes increasingly more physically and financially demanding as the disease progresses.

Dementia caregivers experience the many strains that other caregivers do. What is different is the additional loss of the "true-self" of their loved one and the emotional strain that personal loss involves. The results of this study provide evidence that anticipatory grief can be quantified, therefore expanding the qualitative view of the caregiving experience. Anticipatory grief is significant in the experience reported by

most dementia caregivers, and likely adds to the stress, anxiety, and depression responses that can be a result of caregiving in general. Anticipatory grief encompasses the dementia caregiver's unique experience of grieving incrementally for losses that are not always obvious to others. Traditional grief inventories and instruments assume the death of a loved one, do not normally take into consideration feelings of sacrifice or burden, and may only make vague references to feelings of worry and felt isolation. The *MMCGI-Short Form* has proven to be a reliable instrument for evaluating anticipatory grief responses in dementia caregivers. This instrument assumes that the family member is still living and addresses feelings of worry, isolation, sacrifice, and burden. In this study it also proved to be adequate for use in research as it was easily self-administered. The importance of recognizing and measuring anticipatory grief facilitates the use of appropriate support and education in assisting dementia family members as they experience the impending and incrementally present death of their loved one, possibly preventing complicated grief reactions.

*Multicultural grief experiences.* One of the primary goals of this study was to investigate whether anticipatory grief is a multicultural experience and to examine the ability of the *MMCGI-Short Form* to reliably measure this construct in a multicultural sample. It is difficult to find studies that include proportionately accurate representation of minority group, let alone studies designed for specific minority groups. One of the goals of this study was to provide multicultural diversity as well as regional diversity. As stated earlier, a fairly large population of African American individuals participated in this study. It is likely our high representation is the result of avoiding traditional medical/hospital settings. Instead, less traditional data gathering locations were

approached. As a result of the adequate numbers in subgroups, this study has a higher confidence level in the reports of its findings.

Anticipatory grief is a multicultural experience. This study provides evidence that both Caucasian and African Americans reported heartfelt sadness and longing at similar frequencies without significant difference. The study supports the use of *MMCGI-Short Form* as a reliable instrument for adequately measuring multicultural responses to dementia caregiving. In fact, it may be slightly more sensitive to the African American population's felt experience and thereby may help multicultural caregivers, and professional leaders of their support groups, tailor services to meet more specific needs of their clientele.

The results of this study suggest that there are significant differences in the expressed experiences of Caucasian and African American dementia caregivers. Specifically, the largest differences suggest that African American caregivers feel a stronger sense of Personal Sacrifice and Burden, and Worry and Felt Isolation than do Caucasian caregivers. These results raise some very important questions. Since the data reflect a difference in the felt experience of the two groups, how can researchers and helping professionals understand and respond to this difference? Should supportive services be evaluated and restructured to reach both populations, and even more importantly, how vast is the difference between these two groups and other minority ethnicities? This study indicates that diversity should not be overlooked when providing support and services for dementia family caregivers, in fact, it provides evidence that there is a distinct difference in the needs of the two largest racial groups in America.



Unfortunately, the sample size for this study ended up being limited to two racial/cultural groups - African Americans and Caucasians, and in addition, was limited by its relatively small size. Although one goal of this study was to maximize diversity within the sample, the end sample included only a very small number of Latino/a subjects. An attempt was made to diversify the regions by recruiting in different regions and states; unfortunately, responses from Indiana were inadequate, with the largest numbers coming from two states, Georgia and Alabama. Further research with a larger sample with greater diversity would render a more specific assessment of the psychometric properties of the MMCGI-Short form with multicultural populations.

#### Implications and Recommendations

Until recently, the role of grief in dementia caregiving has been greatly overlooked, and the role of anticipatory grief in this population has been virtually unexplored (Meuser & Marwit , 2001; Marwit & Meuser, 2002, 2005). As society strives to understand this growing health care concern, raising the issue of grief and anticipatory grief may enable healthcare providers, professional helpers, support groups, friends, associates, co-workers and family members to develop and use a greater sense of empathy in their efforts to help caregivers,.. With support and empathy from their communities, caregivers may be better able to maintain their social, familial, and employment obligations with a reduced feeling of guilt, anxiety, stress, and depression and a better understanding of their feelings of loss and grief. With an increased understanding of the experience of having a family member with dementia, the family caregiver can be offered counseling and support to guide them through their experience, possibly resulting in an improved personal outcome. The goal of improved personal

mental health should directly affect the caregiver's ability to communicate and engage with others such as family members, health care professionals, co-workers, and employers, thus better ensuring that they are able to continue to provide care for their loved one with dementia, and at the same time reduce the stress and depression they're experiencing.

The results from this study suggest that there is a great need for outreach services to assist the dementia population to address stress, anxiety, and depression, but anticipatory grief also. Anticipatory grief should be addressed with dementia caregivers, healthcare providers, and helping professionals. This information can be used to assist in the design of education offered to healthcare providers, families, and support groups that places an emphasis on the need to implement outreach services that address anticipatory grief for these caregivers.

Restructuring support groups is one specific way that the information gained from this study can be utilized. The typical components including education of disease process, medication uses and implications, communication with healthcare professionals, and basic caregiving and planning skills are important. The social component of community support and shared experiences is also invaluable. What is currently missing is the recognition of and support through a true and unique grief process that is present in varying forms for an extended period of time. What is missing is the true value of processing, understanding, and supporting the long journey of anticipatory grief. This study not only supports the validity of anticipatory grief as a part of dementia caregiving, but also suggests that this grief likely compounds and intensifies feelings of stress, anxiety and depression. A new model for working with

dementia patients family members would place great emphasis on working through and with feelings of anticipatory grief and educational components as listed above would take an important, but more secondary role.

#### *Limitations and Research Recommendations*

Several limitations of this study involve the sample itself. As with any study that employs survey data, research is limited to those who are physically able to complete the survey independently and to those who are willing to complete and return the instruments. Subsequently, the results of this study should be viewed with awareness of possible volunteer bias that may restrict how well the results generalize across groups and populations. Further, due to the small number of cardiac respondents, it would be difficult to state unequivocally that the control group was equivalent enough to avoid a number of possible confounding variables such as duration of caregiving, age of caregiver, and relationship to patient. Another constraint of this study involved the absence of data to reflect participants' education level, current and past occupations, financial status or hardships, and size of family support system available. These items might have shed more light onto the observed difference between race and reported experience of anticipatory grief.

Recommendations for further research include striving to gain a large sample that is regionally diverse, culturally diverse, and consists of a more experimental sample verses the convenience sample provided in this study. Obtaining a control group that is more congruent with the experimental group would also increase the power of the results. A national team of collaborative researchers who have contacts in several communities with varying cultural dynamics would be an ideal way to comprehensively

study the impact of anticipatory grief. A more varied demographic data collection would offer the ability to provide more specific information about the contributing factors that result in differences in experienced anticipatory grief. This information could then be used by healthcare providers and helping professionals in their outreach to dementia caregivers. Finally, continued research investigating multicultural reliability of anticipatory grief instruments and outreach services, and comparing ethnic and cultural groups and their responses to caregiving and dementia would further improve the ability of helping professionals to provide the support and assistance that caregivers need.

## REFERENCES

- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders (4<sup>th</sup> ed.)*. Text revised. Washington, DC: Author.
- Anderson, K., Towsley, G., & Gaugler, J. (2004). The genetic connections of Alzheimer's Disease: An emerging source of caregiver stress. *Journal of Aging Studies, 18*, 429-443.
- Aneshensel, C., Pearlin, L., Mullan, J., Zarit, S., & Whitlatch, C. (1995). *Profiles in Caregiving: The unexpected career*. San Diego, CA: Academic Press.
- Antony, M., Bieling, P., Cox, B., Enns, M., & Swinson, R. (1998). Psychometric properties of the 42- item and 21- item versions of the depression anxiety stress scale in clinical groups and a community sample. *Psychological Assessment, 10*, 176-181.
- Banerjee, S., Murray, J., Foley, B., Atkins, L., Schneider, J., & Mann, A. (2003). Predictors of institutionalization in people with dementia. *Journal of Neurological Neurosurgery Psychiatry, 74*, 1315-1316.
- Beck, T., Ward, H., Mendelson, M., Mock, J., & Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry, 12*, 63-70.
- Biegel, D., & Blum, A. (Eds.). (1990). *Aging and caregiving*. Newbury Park, CA: Sage.
- Blackwell, J. (2002). Alzheimer's disease management. *Journal of the American Academy of Nurse Practitioners, 14*, 338-340.

- Boerner, K., Schulz, R., & Horowitz, A. (2004). Positive aspects of caregiving and adaptation to bereavement. *Psychology and Aging, 4*, 668-675.
- Bowes, A., & Wilkinson, H. (2003). 'We didn't know it would get that bad': South Asian experiences of dementia and the service response. *Health and Social Care in the Community, 11*, 387-396.
- Brunton, S. (2001). Alzheimer's disease: The importance of early diagnosis. *Family Practice Recertification, 23*, 33-44.
- Butterfield, D., & Pocernich, C. (2003). The Glutamatergic system and Alzheimer's disease: Therapeutic implications. *CNS Drugs, 17*, 641-652.
- Carlson, N. (2001). *Psychology of behavior, 7<sup>th</sup> (ed.)*. Boston, MA: Allyn & Bacon.
- Corr, C., & Corr, D. (2000). Anticipatory mourning and coping with dying: Similarities, differences, and suggested guidelines for helpers. In T. Rando, (Ed.), *Clinical dimensions of anticipatory mourning: Theory and practice in working with the dying, their loved ones, and their caregivers* (pp.223-251). Champaign, IL: Research Press.
- Cox, C. (1995). Comparing the experiences of black and white caregivers of dementia patients. *Social Work, 40*, 343-349.
- Craig, D., Mirakhur, A., Hart, D., McIlroy, S., & Passmore, P. (2004). A cross-sectional study of neuropsychiatry symptoms in 435 patients with Alzheimer's disease. *American Association for Geriatric Psychiatry*.
- Daker-White, G., Beattie, A., Gilliard, J., & Means, R. (2002). Minority groups in dementia care: A review of service needs, service provision and models of good practice. *Aging and Mental Health, 6*, 101-108.

- Doka, K. (2000). Mourning psychological loss: Anticipatory mourning in Alzheimer's Disease, ALS, and irreversible coma. In T. Rando, (Ed.), *Clinical dimensions of anticipatory mourning: theory and practice in working with the dying, their loved ones, and their caregivers* (pp. 477-492). Champagne, IL: Research Press.
- Duke, S. (1998). An exploration of anticipatory grief: The lived experience of people during their spouses' terminal illness and in bereavement. *Journal of Advanced Nursing*, 28, 829-839.
- Dunn, V., & Sacco, W. (1989). Psychometric evaluation of the Geriatric Depression Scale and the Zung Self-Rating Depression Scale using an elderly community sample. *Psychology and Aging*, 4, 125-126.
- Farran, C., & Keane-Hagarty, E. (1994). Multi-modal intervention strategies for caregivers of persons with dementia. In E. Light, G. Neiderehe, & B. Lebowitz. (Eds.), *Stress effects on family caregivers of Alzheimer's patients* (pp. 242-259). New York: Springer.
- Faschingbauer, T. (1981). *Texas revised inventory of grief manual*. Houston, TX: Honeycomb.
- Fulton, G., Madden, C., & Minichiello, V. (1996). The social construct of anticipatory grief. *Social Science & Medicine*, 43, 1349-1358.
- Fulton, R. (2003). Anticipatory mourning: A critique of the concept. *Mortality*, 8, 342-351.
- Gallant, M., & Connell, C. (2003). Neuroticism and depressive symptoms among spouse caregivers: Do health behaviors mediate this relationship? *Psychology and Aging*, 18, 587-592.

- Garand, L., Buckwalter, K., & Hall, G. (2000). The biological basis of behavioral symptoms in dementia. *Issues in Mental Health Nursing, 21*, 91-107.
- Garner, J. (1997). Dementia: An intimate death. *British Journal of Medical Psychology, 70*, 177-184.
- Gaugler, J., Davey, A., Pearlin, L., & Zarit, S. (2000). Modeling caregiver adaptation over time: The longitudinal impact of behavior problems. *Psychology and Aging, 15*, 437-450.
- Gaugler, J., Kane, R., Kane, R.A., & Newcomer, R. (2005). The longitudinal effects of early behavior problems in the dementia caregiving career. *Psychology and Aging, 20*, 100-116.
- Gaugler, J., Zarit, S., & Pearlin, L. (2003). The onset of dementia caregiving and its longitudinal implications. *Psychology and Aging, 18*, 171-180.
- Gilbar, O., & Ben-Zur, H. (2002). Bereavement of spouse caregivers of cancer patients. *American Journal of Orthopsychiatry, 72*, 422-432.
- Gilliland, G., & Fleming, S. (1998). A comparison of spousal anticipatory grief and conventional grief. *Death Studies, 22*, 541-569.
- Gruss, V., McCann, J., Edelman, P., & Farran, C. (2004). Job stress among nursing home certified nursing assistants: Comparison of empowered and nonempowered work environments. *Alzheimer's Care Quarterly, 5*, 207-216.
- Hamdy, R. (2002). Highlights from the annual scientific assembly: Managing the stages of Alzheimer's Disease-new management options. *Southern Medical Journal, 95*, 102-106.
- Harrow, B., Mahoney, D., Mendelsohn, A., Ory, M., Coon, D., Belle, S., & Nichols, L.



- (2004). Variations in cost of informal caregiving and formal-service use for people with Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias*, *19*, 299-308.
- Henderson, J., Hayslip, B., & King, J. (2004). The relationship between adjustment and bereavement-related distress: A longitudinal study. *Journal of Mental Health Counseling*, *26*, 98-124.
- Henry, J., & Crawford, J. (2005). The short-form version of the depression anxiety stress scales (DASS-21): Construct validity and normative data in large non-clinical sample. *British Journal of Clinical Psychology*, *44*, 227-239.
- Hillman, J. (1998). Health care providers' knowledge about HIV induced dementia among older adults. *Sexuality and Disability*, *16*, 181-192.
- Hogan, N., Greenfield, D., & Schmidt, L. (2001). Development and validation of the Hogan Grief Reaction Checklist. *Death Studies*, *25*, 1-32.
- Jackson, J., & Siegal, A. (2002). *Improving care of dementia residents: The value of assessment in behavioral and pharmacologic solutions*. Champaign, IL: ABcomm.
- Jordan, J., Backer, J., Matteis, M., Rosenthal, S., & Ware, E. (2005). The grief evaluation measure (GEM): An initial validation study. *Death Studies*, *29*, 301-332.
- Kindig, M., & Carnes, M. (1993). *Coping with Alzheimer's disease and other dementing illnesses: Coping with aging series*. San Diego, CA: Singular Publishing Group.
- Knussen, C., Tolson, D., Swan, I., Stott, D., & Brogan, C. (2005). Stress proliferation in

- caregivers: The relationships between caregiving stressors and deterioration in family relationships. *Psychology and Health*, 20, 207-221.
- Kuhn, D. (2001). Living with loss in Alzheimer's disease. *Alzheimer's Care Quarterly*, 2, 12-22.
- Lafosse, J., Reed, B., Mungus, D., Sterling, S., Wahbeh, H., & Jagust, W. (1997). Fluency and memory differences between ischemic vascular dementia and Alzheimer's Disease. *Neuropsychology*, 11, 514-522.
- Lawton, M. (1994). Broad-Spectrum service program effects on caregivers. . In E. Light, G. Neiderhe, & B. Lebowitz (Eds.), *Stress effects on family caregivers of Alzheimer's patients* (pp. 138-155).
- Lovibond, P. (1998). Long-term stability of depression, anxiety, and stress syndromes. *Journal of Abnormal Psychology*, 107, 520-526.
- Lovibond, S., & Lovibond, P. (1995). *Manual for the depression anxiety stress scales*. Sydney, Australia: Psychological Foundation.
- Marwit, S., & Meuser, T. (2002). Development and initial validation of an inventory to assess grief in caregivers of persons with Alzheimer's disease. *Gerontologist*, 42, 751-765.
- Marwit, S., & Meuser, T. (2005). Development of a short form inventory to assess grief in caregivers of dementia patients. *Death Studies*, 29, 191-205.
- Mayer, M. (2001). Chronic sorrow in caregiving spouses of patients with Alzheimer's Disease. *Journal of Aging and Identity*, 6, 49-60.
- McCallion, P., Toseland, R., Gerber, T., & Banks, S. (2004). Increasing the use of formal services by caregivers of people with dementia. *Social Work*, 49, 441-450.

- Meuser, T., & Marwit, S. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. *Gerontologist, 41*, 658-670.
- Miller, B., & Kaufman, J. (1996). Beyond gender stereotypes: Spouse caregivers of persons with dementia. *Journal of Aging Studies, 10*, 181-204.
- Mittelman, M., Ferris, S., Shulman, E., Steinberg, G., Mackell, J., & Ambinder, A. (1994). Efficacy of multi-component individualized treatment to improve the well-being of Alzheimer's caregivers. In E. Light, G. Neiderehe, & B. Lebowitz. (Eds.), *Stress effects on family caregivers of Alzheimer's patients* (pp. 156-184).
- Murray, S., Boyd, K., Kendall, M., Worth, A., Brenton, F., & Clausen, H. (2002). Dying of lung cancer or cardiac failure: Prospective qualitative interview study of patients and their carers in the community. *British Medical Journal, 325*, 929-932.
- Niemeier, J., Kennedy, R., McKinley, W., & Cifu, D. (2004). The loss inventory: Preliminary reliability and validity data for a new measure of emotional and cognitive responses to disability. *Disability and Rehabilitation, 26*, 614-623.
- Neugroschl, J., & Davis, K. (2002). Biological markers on Alzheimer's disease. *American Journal of Geriatric Psychiatry, 10*, 660-677.
- Ortiz, A., Simmons, J., & Hinton, L., (1999). Locations of remorse and homelands of resilience: Notes on grief and sense of loss of place of Latino and Irish-American caregivers of demented elders. *Culture, Medicine and Psychiatry, 23*, 477-500.
- Panke, J., & Volicer, L. (2002). Caring for persons with dementia: A palliative approach. *Journal of Hospice and Palliative Nursing, 4*, 143-152.
- Paun, O., Farran, C., Perraud, S., & Loukissa, D. (2004). Successful caregiving of

- persons with Alzheimer's disease: Skill development over time. *Alzheimer's Care Quarterly*, 5, 241-251.
- Ponder, R., & Pomeroy, E. (1996). The grief of caregivers: How pervasive is it? *Journal of Gerontological Social Work*, 27, 3-21.
- Quadagno, J. (1999). *Aging and the life course: An introduction to social gerontology*. Burr Ridge, IL: McGraw-Hill.
- Rabins, P. (1994). Clinical interventions with Alzheimer's caregivers: A conceptual approach. In E. Light, G. Neiderehe, & B. Lebowitz (Eds.), *Stress effects on family caregivers of Alzheimer's patients* (pp. 242-259). New York: Springer.
- Rando, T. (1997). Living and learning the reality of a loved one's dying: Traumatic stress and cognitive processing in anticipatory grief. In K. Doka, & J. Davidson, (Eds.), *Living with grief when illness is prolonged* (pp. 33-50). Bristol, PA: Taylor & Francis.
- Rando, T. (2000). The six dimensions of anticipatory mourning. In T. Rando, (Ed.), *Clinical dimensions of anticipatory mourning: theory and practice in working with the dying, their loved ones, and their caregivers* (pp. 477-492). Champaign, IL: Research Press.
- Riekse, R., & Holstege, H. (1996). *Growing older in America*. New York: McGraw-Hill.
- Riggs, J. (2001). The health and long-term care policy challenges of Alzheimer's disease. *Aging and Mental Health*, 5, S138-S145.
- Robinson, L., Clare, L., & Evans, K. (2005). Making sense of dementia and adjusting to loss: Psychological reactions to a diagnosis of dementia in couples. *Aging and*

*Mental Health, 9, 337-347.*

- Roth, D., Haley, W., Owen, J., Clay, O., & Goode, K. (2001). Latent growth models of the longitudinal effects of dementia caregiving: A comparison of African American and white family caregivers. *Psychology and Aging, 16*, 427-436.
- Roth, D., Mittelman, M., Clay, O., Madan, A., & Haley, W. (2005). Changes in social support as mediators of the impact of a psychosocial intervention for spouse caregivers of persons with Alzheimer's disease. *Psychology and Aging, 20*, 634-644.
- Sajatovic, M., & Ramirez, L. (2003). *Rating scales in mental health. 2<sup>nd</sup> Ed.* Hudson, OH: Lexicomp's.
- Sanders, M., Mauger, A., & Strong, N. (1985). *A manual for the Grief Experience Inventory.* Charlotte, NC: Center for the Study of Separation and Loss.
- Schaefer, A., Brown, J., Watson, C., Plemel, D., DeMotts, J., Howard, M., Petrik, N., Balleweg, B., & Anderson, D. (1985). Comparison of the validities of the Beck, Zung, and MMPI depression scales. *Journal of Consulting and Clinical Psychology, 53*, 415-418.
- Schoenberg, B., Carr, A., Kutscher, A., Peretz, D., & Goldberg, I. (1974). *Anticipatory Grief.* New York, NY: Columbia University Press.
- Servaty-Seib, H. (2004). Connections between counseling theories and current theories of grief and mourning. *Journal of Mental Health Counseling, 26*, 125-145.
- Shaji, K., Smitha, K., Praveen Lal, K., & Price, M. (2003). Caregivers of people with Alzheimer's disease: A qualitative study from the Indian 10/66 dementia research network. *International Journal of Geriatric Psychiatry, 18*, 1-6.

- Shin, I., Carter, M., Masterman, D., Fairbanks, L., & Cummings, J. (2004). Neuropsychiatric symptoms and quality of life in Alzheimer's disease. *American Association for Geriatric Psychiatry*.
- Skaff, M., Pearlin, L., & Mullan, J. (1996). Transitions in the caregiving career: Effects on sense of mastery. *Psychology and Aging, 11*, 274-257.
- Sloan, P. (1998). Advances in the treatment of Alzheimer's disease. *American Family Physician, 58*, 1577-1587.
- Slone, G., & Gleason, C. (1999). Behavior management planning for problem behaviors in dementia: A practical model. *Professional Psychology: Research and Practice, 30*, 27-36.
- Stephens, M., Franks, M., & Atienza, A. (1997). Where two roles intersect: Spillover between parent care and employment. *Psychology and Aging, 12*, 30-37.
- Theut, S., Jordan, L., & Ross, L. (1991). Caregiver's anticipatory grief in dementia. *International Journal of Aging and Human Development, 33*, 113-118.
- Vitaliano, P., Russo, J., Young, H., Teri, L., & Maiuro, R. (1991). Predictors of burden in spouse caregivers of individuals with Alzheimer's Disease. *Psychology and Aging, 6*, 392-402.
- Waelde, L., Thompson, L., & Gallagher-Thompson, D. (2004). A pilot study of a Yoga and meditation intervention for dementia caregiver stress. *Journal of Clinical Psychology, 60*, 677-687.
- Walker, R., & Pomeroy, E. (1996). Depression or grief? The experience of caregivers of people with dementia. *Health and Social Work, 21*, 247-255.
- Williams, C., & Moretta, B. (1997). Systematic understandings of loss and grief related

- to Alzheimer's Disease. In K. Doka, & J. Davidson (Eds.), *Living with grief when illness is prolonged* (pp. 119-132). Bristol, PA: Taylor & Francis.
- Yang, C., Hwang, J., Tsa, S., & Liu, K. (1996). Types and phenomenologic subtypes of dementia in Taiwan: a psychiatric inpatient study. *International Journal of Geriatric Psychiatry, 11*, 705-709.
- Yeo, G. (2001). Ethnicity and dementia. *Journal of American Geriatric Society, 49*, 1393-1394.
- Zarit, S., Anthony, C., & Boutselis, M. (1987). Interventions with care givers of dementia patients: Comparison of two approaches. *Psychology and Aging, 2*, 225-232.
- Zilberfein, F. (1999). Coping with death: Anticipatory grief and bereavement. *Generations, 23*, 69-74.

## APPENDICES



## APPENDIX 1

### INFORMATION SHEET

#### For a Research Study Entitled An Assessment of Anticipatory Grief as Experienced by Family Caregivers of Individuals with Dementia

You are invited to participate in a research study that will assist health care providers better meet the emotional needs of family members who provide care for their loved ones diagnosed with dementia. This study is being conducted by Angela Ross, RN, MS under the supervision of John Dagley, Ph.D. I hope to learn to what extent anticipatory grief is a measurable and identifiable experience that family members of dementia patients experience. You were selected as a possible participant because you are a family member of an individual with a diagnosis of either dementia or cardiac difficulties.

If you decide to participate, I ask that you complete the demographic questionnaire plus the three included self administered instruments; the Loss Inventory, the Depression, Anxiety, Stress Scale, and the Marwit and Meuser Caregiver Grief Inventory. Once you have completed these items, you will place them in the postage paid, addressed envelope provided and deposit the envelope in the US postal service mail. This process should take approximately 30 to 45 minutes of your time; this is a one time commitment. No other information or time commitment will be requested of you for this particular study.

All the information obtained in connection with this study will remain completely anonymous. Information collected through your participation may be used to fulfill educational requirements of my program of study which includes an original research dissertation, presented at a professional meeting, or published in a professional journal. If so, no identifiable information will be included as all information that you have submitted will be anonymous at the beginning of data collection to project completion. You have the right to withdraw from participation at any time, without penalty, however, after you have mailed your responses, I will be unable to withdraw your data since there will be no way to identify individual information.

I do not believe that there will be any significant risks or benefits to participating in this study. However, if you should experience any anxiety in

completing the enclosed instruments and demographic data sheet, please contact your local mental health care provider. This is a research project and not intended to treat any mental health condition.

1 of 2

You have been given the educational CD as compensation for your time and efforts. Further, if you would like to receive the results of the study, you may contact me via e-mail at [rossang@auburn.edu](mailto:rossang@auburn.edu) or by mail:

Department of Counselor Education, Counseling Psychology,  
and School Psychology,  
Auburn University  
2084 Haley Center  
Auburn, AL 36849-5222  
Attn: Angela Ross

Your decision whether or not to participate in this study will not jeopardize your future relations with Auburn University or the Department of Counselor Education, Counseling Psychology, and School Psychology; or the Faculties and Agencies assisting in this study.

If you have any questions I invite you to contact me or Dr. John Dagley and we will be happy to answer them. In the packet that was provided to you was a card with our contact information for further reference. You will also be provided a copy of this form to keep.

For more information regarding your rights as a research participant you may contact the Auburn University Office of Human Subjects Research or the Institutional Review Board by phone (334)-844-5966 or e-mail at [hsubjec@auburn.edu](mailto:hsubjec@auburn.edu) or [IRBChair@auburn.edu](mailto:IRBChair@auburn.edu).

HAVING READ THE INFORMATION PROVIDED, YOU MUST DECIDE WHETHER OR NOT YOU WISH TO PARTICIPATE IN THIS RESEARCH STUDY. IF YOU DECIDE TO PARTICIPATE, THE DATA YOU PROVIDE WILL SERVE AS YOUR AGREEMENT TO DO SO. THIS LETTER IS YOURS TO KEEP.

---

Investigator's Signature      Date

---

Print Name

## APPENDIX 2

### PARTICIPANT DIRECTIONS SHEET

For a Research Study Entitled  
An Assessment of Anticipatory Grief as Experienced by Family Caregivers of  
Individuals with Dementia

Thank you for agreeing to participate in my study. Below you will find directions for participation. If you have any questions that are not addressed here, please consult the information sheet included in this package, or you may contact me using the enclosed e-mail or mailing address.

1. Fill out the 9 question demographic sheet.
2. There are three questionnaires: The Loss Inventory  
The Marwit-Meuser Caregiver Grief Inventory-Short Form  
The DASS21
3. Complete all three using the specific directions listed at the top of each questionnaire. You may use ink or pencil.
4. Place the completed demographic sheet, Loss Inventory, DASS21, and Marwit-Meuser Caregiver Grief Inventory together in the stamped and addressed envelope provided.
5. Mail in any US postal box.

**Please DO NOT place your name or your family member's name  
anywhere on surveys you return to me.**

APPENDIX 3

SAMPLE LETTER TO FACILITY

Angela Ross, RN, MS  
Counseling Psychology Doctoral Candidate  
Auburn University  
2084 Haley Center  
Auburn, AL 36849-5222

1/9/2007

Dr.

EAMC

2000 Peperell Parkway

Opelika, AL 36801

Dear Dr.,

Thank you for your assistance in proposing my research project to the facilities entrusted to EAMC. I have enclosed for your review the forms that were sent to me by Ms. ....and a copy of Auburn Universities IRB (Ethics committee) review form that includes a general overview of my project and specific information regarding participants. I have also enclosed one of the survey packets that I have been distributing to other facilities and home health agencies. All of the packets are identical and I will have absolutely no way of identifying from what institution a completed survey has come from.

I am hopeful that EAMC will allow me to collect data for my study from its facilities. As you will see in review of the proposal, the results of this study will hopefully have an impact on the type of assistance that is provided to families with loved ones who have dementia. This is a field that I am passionate about and I am very excited to have the opportunity to pursue this research project.

Please let me know if there is any further information that I can provide for you or if you have any questions, I would be very happy to accommodate you.

Thank you again.

Sincerely,

Angela Ross, RN, MS  
[rossang@auburn.edu](mailto:rossang@auburn.edu)

APPENDIX 4

DEMOGRAPHIC QUESTIONNAIRE

*Please circle the answer that **best** describes your current situation.*

***My Family member is a:***      ***Dementia Patient***                              ***Cardiac Patient***

- |    |   |             |            |
|----|---|-------------|------------|
| 1. | Approximate duration of caregiving up to this date: | 2-4 weeks   | 2-4 months |
|    |   | 5-11 months | 1-2 years  |
|    |   | 3-5 years   | 6-10 years |
|    |   | 10+ years   |            |

2. My Gender:          Female          Male

3. My Age Range:      20-30    31-40    41-50    51-60    61-70    71-80    81-90    91-100+

- |                             |            |             |         |              |
|-----------------------------|------------|-------------|---------|--------------|
| 4. Relationship to patient: | Daughter   | Son         | Spouse  | Life Partner |
|                             | Niece      | Nephew      | Brother | Sister       |
|                             | Grandchild | Other _____ |         |              |

5. My Race:      Caucasian      African American      Latino/a      Asian  
                          Other: *Please specify* \_\_\_\_\_

- |                                 |                  |                    |
|---------------------------------|------------------|--------------------|
| 6. Current Geographic Location: | Central AL       | Central/Western GA |
|                                 | North/Eastern IN | Other _____        |

***For Caregiver's of Dementia Patients only:***

7. What level of care is your family member currently requiring?  
 \_\_\_\_\_ Cueing for memory and slight help with daily living skills.  
 \_\_\_\_\_ Constant reminders and supervision for safety.  
 \_\_\_\_\_ Total reliance on caregivers to have most/all daily needs met.

APPENDIX 5

POSTED FLYER

**Research Study**  
***Learning More About Dementia Caregiving***

- WHO?** Family Caregivers of patients with a diagnosis of either cardiac or dementia problems.
- WHAT?** You are invited to participate in a voluntary and anonymous study.
- WHY?** The goal of this study is to learn more about the experiences of family caregivers.
- WHEN?** Fill out the information in the envelope provided to you today and simply drop it in the mail!



**By learning more about the family caregivers experience, nurses, counselors, social workers and doctors can work towards better meeting your needs as you care for your loved one.**

## APPENDIX 6

### SCRIPT FOR RELAXATION CD

Hello, my name is Angela Ross, the primary researcher in the study you have agreed to participate in. I would like to take this opportunity to thank you for being willing to share your time carefully reading and thoughtfully answering the questionnaires found in the attached envelope. The ultimate goal of this study is to gain a greater understanding of the true experiences of family caregivers. The information you provide will not only help researchers such as myself gain insight relevant to your caregiving experience, but will also assist healthcare providers, social workers, and psychologists as they tailor their services to meet the needs of both you and your loved one. Please accept the following relaxation and stress reduction exercises as a token of my appreciation.

In a world as busy as ours, caregiving for a family member can be an extremely stressful addition to an already pressured life. It can be surprising how harmful stress can be. For example, stress:

- Increases blood pressure and heart rate
- Results in weight gain or loss
- Headaches, muscle aches
- Immune system suppression resulting in increased susceptibility to infections, colds and flue's
- Anxiety and depression
- Skin problems such as hives, acne, psoriasis
- Fatigue, or insomnia

To make a long story short, stress can systematically disable you preventing you from continuing to provide care for your loved one. It is important to take care of yourself too.

This CD is an invitation to take a moment to relax: to de-stress.

You might ask, “Why bother?” There are many benefits to stopping yourself and relaxing even for a few minutes each day.

- Decrease heart rate and blood pressure
- Increase blood flow to muscles
- Decrease muscle tension
- Increase concentration and the ability to focus
- But basically, in many ways, this will Increase your energy

Let's begin.

First take into account your environment.

Is it quiet?

Are you free from most distraction?

Are you someplace that you feel comfortable?

Are you someplace that you will not be disturbed for a while?

Check and see that your cell phone silenced.

If the answer is yes, we can move on.

Next, are you comfortable?

Take a moment to adjust your clothing so that you are comfortable.

You may need to loosen a tie, loosen your shoelaces or a tight belt or smooth and adjust clothing.

Adjust the way you are sitting so that your feet can firmly touch the ground, so your back is supported, so your arms have something to rest on.

If you are all set, we will begin.

Breathing is an automatic thing. But when we are stressed, our breathing becomes shallow, quick, and less efficient.

If we focus, we can slow our breath, allowing oxygen to flow deeply through our arteries to reach all of our muscles, organs, and most importantly, our brain.



**\*\*\*\*\*Enter Gentle Wind Chimes in background\*\*\*\*\***

Gently close your eyes.

Take a moment now to deeply inhale. And exhale.  
And another full inhale.....and exhale.

Next time and from here on, try to breathe in through your nose, and then out again through your nose...controlling your breath.

If this is difficult, its o.k. Try to breathe in through your nose and slowly out through your mouth in a slow, steady, controlled way.

Continue to breathe deeply and fully but not forcefully as we begin to relax.

As you inhale, feel your chest fill with oxygen  
As you exhale, push out all of the stale and stagnant air from every corner of your lungs tightening your abdomen forcing your diaphragm against your lungs, massaging your liver, pancreas, and stomach.

As you inhale, count to three, and exhale.

Inhale..1..2..3..& exhale and inhale..1..2..3.. and exhale  
& Inhaling.1..2..3..& exhale inhaling..1..2..3.. and exhale

Nice slow, steady, controlled breaths as we....inhale, and exhale.....

Continue to rest your eyes and breathe at your own slow & steady pace.

This is your time, deserved, needed, and necessary.

Place your fingertips on your temples and massage in slow steady circles.  
Gradually massage from your temples to your forehead just above your eyebrows and gently back

Allow your forehead to smooth out, allow the muscles around your temples and forehead to relax.

Now rest your hands back to your lap or just beside you.

Continue our nice full breaths.....1...2...3...& exhale...

Your forehead is completely relaxed.

The worries and concerns of the day are at rest.

Allow your eyes to drift in their sockets, your eyelids are heavy; your cheek bones are resting.

Allow the muscles around your mouth to rest, feel your cheeks let go as the wave of relaxation flows down to your ears.

Let your tongue rest in on the floor of your mouth.

The tension from your face is completely washed away.

Picture yourself as pleasantly satisfied, pleased with yourself.

& We'll allow our neck muscles to release.

We are feeling our shoulders to our elbows then to our forearms relax.

Feel the wave of relaxation flow all the way from the palms of our hands then rippling to your fingertips. Your palms feel warm.

Your arms are heavy, and completely relaxed.

Breathing slowly and fully into our chest, as our chest expands feel the fresh breathe enter your lungs and flow to your heart.

We'll inhale releasing your diaphragm, relaxing allowing the wave of relaxation to ripple through your stomach, your abdomen.

Allow the soft, comfortable feeling flow from your abdomen down to your hamstrings and quadriceps in you legs.

Release these muscles.

Release the overworked joints of your knees and relax all the way down to your ankles.

Feel the relaxation in your ankles, your heel and now up the arch of your foot.

All the way to the ball of your foot and now to our toes.

Your body is completely relaxed as you allow the fresh, slow, steady breaths to circulate through all of our organs, tissues, joints, and muscles.

Take this time to appreciate all the hard work our bodies do for us, as we take a moment to replenish the energy it needs to carry us through the rest of our day.

And we're inhaling..1..2..3.....& exhale.

Inhaling again, start to wiggle your fingers and toes. Gently open your eyes and role your head from left to right.

Were going to gently shrug and circle your shoulders forward.....& and backward.

Inhale and stretch your arms out and legs out long...&.good.

And finally, take a nice full inhale opening your eyes wide and filling your lungs completely.... and enjoy the rest of your day.

\*\*\*\*\**End wind chimes*\*\*\*\*\*

Thank you for taking the time to relax today. And thank you for accepting one of my surveys and filling it out completely and putting it in the mailbox so that I can do the research necessary to help family members coping with dementia.

