A TEST OF A MODEL OF
POSITIVE AND NEGATIVE DEATH ATTITUDES
AMONG FAMILY CAREGIVERS OF THE ELDERLY

DISSERTATION

Presented in Partial Fulfillment of the Requirements for
the Degree Doctor of Philosophy in
the Graduate School of The Ohio State University

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* * * * *

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ABSTRACT

Caregiving for an older relative is a rather common and potentially stressful experience. Tasks of caregiving include providing care during the dying process and adjusting to the death of a loved one. Interventions for family caregivers could be improved by understanding the nature of family caregivers’ death attitudes, the factors that influence caregivers’ death attitudes, and the effect that death attitudes have on the caregiving experience. The present study provided evidence of differences in the caregiving experience for men and women as well as for adult child and spousal caregivers. Evidence of the reliability and validity of two measures of death attitudes was evaluated, indicating support for their use with family caregivers. Additionally, predictors of coping with death and fear of death among family caregivers were identified. The findings of the regression analyses were consistent with hypotheses derived from a comprehensive model of death anxiety, suggesting that the model may be used to explain the death attitudes of family caregivers. Suggestions for future research and limitations of the present study also were discussed.
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“To love someone is to learn the song that is in their hearts
and sing it to them when they have forgotten.”
~ Anonymous

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One role of increasing importance to the lives of adults in the U.S. is that of caregiving for an elderly relative. For the present study, the term “caregiver” is used to refer to an individual, often a relative, who provides informal care to an elderly patient. Informal care typically includes assistance with instrumental activities of daily living (IADLs; e.g., shopping, cooking, light housekeeping) as well as more functional activities of daily living (ADLs; e.g., feeding, bathing, and assistance transferring from the bed to a chair, for example). Caregivers tend to be either the spouse or adult child of the care recipient, and are more likely to be women (National Alliance for Caregiving & AARP, April, 2004; Robert Wood Johnson Foundation, 2001).

Caregiving usually occurs over many years, and varies in intensity. The average length of time providing care was found to be 4.5 years in one national sample (National Alliance for Caregiving & AARP, April, 2004). Fifty percent of caregivers in one survey reported that caregiving was “frequently” or “sometimes” too much to handle. Partners (65%), siblings (50%), and caregivers of an individual with a traumatic injury (54%) reported the most emotional stress (Robert Wood Johnson Foundation, 2001).
Experts conceptualize caregiving as a career with various career “trajectories,” specific stressors, and points of entry and exit (e.g., exit due to institutionalization of care recipient, or due to death of care recipient or caregiver; Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Montgomery & Kosloski, n.d.). Montgomery and Kosloski (n.d.) identify seven “markers” of the caregiving experience, including “Termination of the Caregiving Role.” Similarly, Aneshensel, Pearlin, Mullan, Zarit, and Whitlatch (1995) observe that caregiving as a career can end for a number of reasons, including the death of the care recipient. Thus, one task of caregiving may be coping with the death of the care recipient (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Montgomery & Kosloski, n.d.).

To date, research on death attitudes have been conducted primarily with samples of college students and healthcare professionals, and studies of the caregiving experience have ignored the effect of death attitudes among family caregivers. The present study sought to link these two bodies of literature by exploring the positive and negative death attitudes of family caregivers as these attitudes relate to important caregiving-related variables such as subjective burden, health status, and caregiving self-efficacy.

The present study is based upon a comprehensive model of death anxiety (Figure 1; Tomer & Eliason, 1996, 2000a), which itself draws from the rich history of philosophical and psychological perspectives on death attitudes. Tomer and Eliason’s model postulates that death anxiety is directly influenced by death attitudes, past- and future-related regrets, and is indirectly influenced by coping processes, beliefs about one’s self and the world, and by the degree to which death is salient to an individual. Figures 2 and 3 show the specific elements of the comprehensive model that will be
Figure 1: A Comprehensive Model of Death Anxiety (Tomer & Eliason, 1996, 2000a).
Figure 2: Predictors of Coping With Death. Simplified version of Tomer & Eliason’s (1996, 2000a) model of death anxiety illustrating variables postulated to predict Coping with Death. Caregiver and care recipient health status indicate Death Salience.
Figure 3: Data Test Model. Simplified version of Tomer & Eliason's (1996, 2000a) model of death anxiety where caregiver and care recipient health status as indicate Death Salience, and hypothesizing a reciprocal relationship between Beliefs About Self and Death Attitudes.
examined in the present study. In particular, the present study proposes to examine the relationships among the following primary variables: caregiver health and perceived burden, caregiving self-efficacy and self-esteem, and coping with death and fear of death.

Death salience refers to factors that serve to heighten one’s awareness of eventual death (Tomer & Eliason, 2000a). For the present study, death salience will be operationally defined by indicators of the health status of the care recipient and caregiver as well as the caregiver’s perceived burden of care. Thus, death salience includes not only how likely the caregiver is to face his/her death, but also the likelihood that his or her loved one is close to death.

Many researchers have examined the health effects of caregiving on physical and mental health, such as depressive symptoms, anxiety, life satisfaction, social support, health promoting behaviors, and immune functioning (Martire & Schulz, 2001). Caregiving has both positive and negative effects. For instance, most caregivers report that they are in good health (83% reported health ranging from good to excellent; National Alliance for Caregiving & AARP, April, 2004). Roff, Burgio, Gitlin, Nichols, Chaplin, and Hardin (2004) found that religiosity influenced caregiving. They found that African American caregivers reported more positive aspects of caregiving than did Caucasian caregivers.

“Caregivers who report caregiving has made their health worse tend to be lower income, women, age 50 and over, provide higher levels of care, and live with the person they provide care for” (National Alliance for Caregiving & AARP, April, 2004, p. 18). Furthermore, caregivers who report physical strain due to caregiving (about 15%) were likely to report poorer health, to feel like they did not have a choice in taking on the
caregiver role, and to report a higher level of overall burden (National Alliance for Caregiving & AARP, April, 2004). Emotional stress also was related to perceived general burden and the perception of choice in taking on the caregiver role (Robert Wood Johnson Foundation, 2001). Additionally, caregivers’ health, residence with the care recipient and being female also were associated with higher reports of emotional stress. Most caregivers reported a decrease in the time available to visit other family members or friends (Robert Wood Johnson Foundation, 2001).

The present study focuses on two beliefs about self: self-esteem and self-efficacy for the caregiving role. Beliefs about self refer to the cognitive self-appraisals of the caregiver and can include self-concept and self-esteem (Tomer & Eliason, 1996, 2000a). Self-esteem has been shown to moderate the relationship between mortality salience and unconscious death anxiety (Greenberg, Solomon, & Pyszczynski, 1997). Individuals with experimentally-induced self-esteem or dispositionally high self-esteem appear to be protected from the anxiety induced by conditions of mortality threat in research settings. Cicirelli (2002) examined the relationship between self-esteem and conscious death anxiety among older adults. He found that while self-esteem correlated negatively with indicators of death anxiety, self-esteem was not a significant predictor of fear of death. The effect of self-esteem on death anxiety may, therefore, differ depending upon the level at which death anxiety is assessed (e.g., conscious versus unconscious). Direct measures of conscious death anxiety were used in the present study.

Self-esteem provides one indicator of self-beliefs that may influence a caregiver’s death attitudes. Another self-belief postulated to influence the caregiving experience is caregivers’ confidence, or self-efficacy, about providing care. Self-efficacy expectations
refer to an individual’s evaluations of her or his confidence to perform behaviors within a specific domain (Bandura, 1997). For example, individuals may form cake baking self-efficacy expectations by evaluating their confidence to perform the tasks required for successfully baking a cake (e.g., gather the correct ingredients, follow the recipe carefully, and remove the cake from the oven at the optimal time). Caregiving self-efficacy refers to a caregiver’s belief in her or his ability to successfully perform the duties of caregiving (Gottlieb & Rooney, 2003).

Self-efficacy theory postulates three outcomes of self-efficacy expectations: initiation of or avoidance of the desired behavior, degree of effort, and extent of persistence (Figure 4; Bandura, 1997). When applied to caregiving, self-efficacy theory provides a theoretical perspective to predict which family members will accept the caregiver role, which caregivers will persist in caregiving, and which caregivers will be more likely to avoid the disruptive emotional reactions in response to the stress of caregiving (Zeiss, Gallagher-Thompson, Lovett, Rose, & McKibbon, 1999).

Perceived self-efficacy for caregiving has been shown to correlate with caregivers’ levels of depression, anger, anxiety, and beliefs about how well they are coping with their caregiving responsibilities (Gottlieb & Rooney, 2003; Steffan, McKibbon, Zeiss, Gallagher-Thompson, & Bandura, 2002; Zeiss, Gallagher-Thompson, Lovett, Rose, & McKibbon, 1999). Self-efficacy theory “seems to hold promise for understanding why caregivers vary so greatly in their ability to cope with caregiving demands” (Zeiss, Gallagher-Thompson, Lovett, Rose, & McKibbon, 1999; p. 222).

Self-efficacy theory (Bandura, 1997) applied to caregiving postulates that individuals with greater caregiving self-efficacy will be more likely to become
Figure 4: A Model of Self-Efficacy Theory (Bandura, 1997).
caregivers, will be more likely to persist with caregiving in the face of obstacles, and will be less likely to experience adverse emotional responses as a caregiver. It stands to reason that family caregivers’ caregiving self-efficacy will correlate positively with coping with death and correlate negatively with death anxiety. The exact relationship between these constructs is unexamined.

Finally, death attitudes are defined herein as the cognitive, behavioral, and affective responses of an individual to the fact of death. Death attitudes may consist of “fear, threat, unease, discomfort and similar negative emotional reactions, as well as anxiety in the psychodynamic sense as a kind of diffuse fear that has no clear object,” and “can also include positive appraisals of death, such as death approach or readiness” (Neimeyer, Moser, & Wittkowski, 2003; p. 47). In particular, the present study considers death attitudes as positive or negative cognitive, behavioral, and affective responses to death. Negative death attitudes include fears about death and death avoidance, whereas positive death attitudes include beliefs about one’s ability to cope with and accept death.

Coping with death, or death competence, refers to an individual’s attitudes about death that facilitate management of an experience with either one’s own or another’s death (Robbins, 1990-91). Coping with death consists of cognitive (e.g., “Lately I find it O.K. to think about death”), affective (e.g., “I can tell people, before I or they die, how much I love them”), and behavioral (e.g., “I can talk about my death with family and friends”) responses to the anticipated death of oneself or another. Coping with death has been shown to be negatively correlated with indicators of death fears (Robbins, 1990-91).

Understanding the end-of-life care wishes of a care recipient is one aspect of coping with that individual’s death (Robbins, 1990-91). In one survey, 54% of caregivers
were unaware of their care recipient’s wishes about the types of medical treatments they desired as the illness progressed. Only one-third of respondents had this plan in writing (Robert Wood Johnson Foundation, 2001). Coping with death has been found to correlate with assertiveness, purpose in life, length of service among hospice volunteers, and death preparatory behaviors such as writing a will and organ donation (Robbins, 1990-91, 1992).

Coping with death appears to be related to length of experience with the dying and their families and possibly to age. Robbins (1992) reported that death competence correlated positively with length of service among hospice volunteers. Amenta (1984) reported that hospice volunteers who persisted twelve months after training scored lower on a measure of death anxiety than did volunteers who withdrew before their year commitment expired. Age was a possible confound in both studies. Volunteers who reported greater death competence (either as higher scores on a coping with death measure or lower scores on a death anxiety measure) were more likely to be older than were those volunteers who terminated service early.

Two lines of research related to the death anxiety of healthcare professionals have implications related to family caregivers. First, death anxiety among professional healthcare workers has been found to differ with respect to specialty (Bene & Foxall, 1991; Viswanathan, 1996). Findings suggest that a self-selection effect occurs with respect to specialization among physicians. For example, Viswanathan (1996) found that psychiatrists reported greater levels of death anxiety than did surgeons, who are more likely to be exposed to death more often than are psychiatrists. While physicians are able
to select specialties that best fit with their levels of death anxiety, family caregivers may not have the luxury of choosing to avoid caregiving for a frail relative.

Additionally, Viswanathan (1996) reported that physicians’ preferred method for notifying next of kin by telephone after a loved one’s unexpected death varied with respect to the physicians’ level of death anxiety. Physicians with greater death anxiety were more likely to inform next of kin that their relative was in “critical status” rather than to report the loved one as having died unexpectedly. Death anxiety also correlated with physicians’ personal preferences for being informed of their own loved one’s unexpected death. These results suggest that death anxiety can affect physicians’ styles of communicating about death with others. The way that death anxiety and other death attitudes affect family caregivers’ communications with their loved ones has been unexamined. The present study seeks to lay a foundation for exploring these issues.

The present study examined the relationship of caregiving-related factors to death attitudes among a sample of family caregivers. Differences among caregivers by gender and kin relationship were examined with respect to primary study variables, including health status, subjective and objective burden, self-esteem, caregiving self-efficacy, and death attitudes. Two measures of death attitudes were administered to participants. One instrument focused on the positive death attitude of coping with death and the other assessed five death attitudes: fear of death, death avoidance, approach acceptance, escape acceptance, and neutral acceptance. Evidence for the reliability and validity of the two death attitude scales were examined. Finally, based upon the comprehensive model of death anxiety (Tomer & Eliason, 1996, 2000a), predictors of coping with death and fear of death were examined using hierarchical regression analyses.
One of the unique features of the present study is the assessment of death attitudes among family caregivers of the elderly. Most research on death attitudes is conducted with samples of young adults or formal caregivers such as physicians or nurses (Neimeyer & Van Brunt, 1995). Participants were recruited through member organizations of the Ohio Association of Adult Day Services (OAADS). Furthermore, rather than strictly examining the anxiety caregivers experience about death, the present study included positive and facilitative attitudes about death (e.g., coping with death). The present study is intended to add to and expand the existing bodies of literature on caregiving and death attitudes.
CHAPTER 2

LITERATURE REVIEW

2.1 Death Salience & Health Status of Adult Day Program Consumers & Patients

Death salience refers to an individual’s awareness of or alertness to his or her potential death and is hypothesized to influence death attitudes directly and indirectly through beliefs about the self and the world (Tomer & Eliason, 2000b). Tomer and Eliason observe that death salience is likely to increase as one is “closer to death” (2000a; p. 3). Additionally, an illness or death in one’s family is likely to increase death salience (Tomer & Eliason, 2000a). Therefore, an individual’s or frail family member’s age and health status could serve as indicators of death salience. For the present study, health status of care recipients and caregivers serve as indicators of death salience.

Results of a study of the four-year mortality rate of caregivers versus non-caregivers provide support for a link between physical and mental health status and death salience. Schulz and Beach (1999) categorized participants into one of four groups according to caregiving status: (1) spouse not disabled (non-caregiver, control condition); (2) spouse disabled, not providing assistance; (3) spouse disabled, providing assistance, no self-reported caregiving strain; and (4) spouse disabled, providing assistance, self
reported caregiving strain. Participants’ health status was carefully reviewed and participants were classified as having (1) a prevalent disease, (2) a subclinical disease (no prevalent disease), and (3) neither a prevalent nor a subclinical disease.

After controlling for sociodemographic factors (e.g., age, sex, race, years of education, self-reported stressful life events) and physical health status, results of Cox regression models indicated that the mortality risk of caregivers reporting strain was 63% higher than for non-caregivers. The other two groups of caregivers, neither of which reported strain, did not differ from non-caregivers in their risk for mortality after a four-year period. Mortality risk also increased for participants who were older, male, African American, and with at least one prevalent disease. The results add to a large body of evidence of the health risks associated with caregiving (Kiecolt-Glaser & Glaser, 1999; Schulz, O’Brien, Bookwala, & Fleissner, 1995).

Commonly used indicators of care recipient- and caregiver-related health and well-being include the following: care recipients’ activities of daily living and instrumental activities of daily living, frequency of patients’ memory and behavior problems (i.e., objective burden), caregivers’ reactions to patients’ memory and behavior problems (i.e., subjective burden), caregivers’ physical health, anxiety and depressive symptomatology (Pinquart & Sorensen, 2003; Teri, Truax, Logsdon, Uomoto, Zarit, & Vitaliano, 1992; Zarit, Stephens, Townsend, Greene, & Leitsch, 1999). In the present study, care recipient health status is assessed using measures of activities of daily living and frequency of memory and behavioral problems, while caregiver health status is assessed by self-reported physical and mental health and subjective burden.
Participants for the present study were recruited through adult day programs; therefore, the following review focuses on studies conducted with caregivers whose care recipient uses an adult day program. Many studies reviewed below emerged from larger programs of research on outcomes of adult day program use (Gaugler, Jarrott, Zarit, Stephens, Townsend, & Greene, 2003; Kosloski, Montgomery, & Youngbauer, 2001; Zarit, Stephens, Townsend, Greene, & Leitsch, 1999) and the health effects of caregiving (Bookwala, Zdaniuk, Burton, Lind, Jackson, & Schulz, 2004).

Results of studies of the association between care recipient and caregiver health status and use of adult day services have been mixed (Gottlieb & Johnson, 2000). For example, Montgomery and colleagues (Kosloski & Montgomery, 1993; Montgomery & Borgatta, 1989) reported that adult day service use tends to lead to lower perceptions of subjective burden by caregivers. However, Lawton, Brody, and Saperstein (1989) did not find that respite service use affected caregivers’ levels of subjective burden. Adult day program use also is postulated to decrease caregivers’ depressive symptomatology. While some studies reported null effects (Lawton et al., 1989; Gottlieb & Johnson, 1995), others found that fewer depressive symptoms are associated with adult day program use after 3-month and 1-month periods (Zarit, Stephens, Townsend, & Greene, 1998).

The following review begins with an overview of national statistics about adult day programs and their patients, including a review of caregiver and care recipient background characteristics and program factors that affect adult day service utilization. This discussion is followed by a review of findings related to the health status of care recipients and caregivers who use adult day programs.
2.1.1 Program & Patient Descriptions

The National Adult Day Services Association (NADSA; n.d.) defines adult day programs as “community-based group programs designed to meet the needs of functionally and/or cognitively impaired adults through an individual plan of care.” Moreover, adult day programs “provide a variety of health, social, and other related support services in a protective setting during any part of a day, but less than 24-hour care.” The National Study of Adult Day Services (2002) reported that 20% of adult day programs in their sample catered specifically to patients with a diagnosis of dementia.

Services commonly provided by adult day programs include therapeutic activities (97%), personal assistance (96%), meals (84%), social services (82%), health-related services (74%), medication management (70%), and transportation (68%). Sixty percent of the programs surveyed indicated that they provided caregiver support groups among their service offerings. Most programs were open Monday through Friday, with 16% open on Saturdays and 6% open on Sundays. Most programs (82%) were open eight or more hours per weekday of operation. Eighty percent of programs averaged ten or more participants in daily attendance.

Researchers have examined the relationship of adult day programs’ organization and environment to service utilization. Bookwala and colleagues (2004) found that service use at baseline was the strongest predictor of service use after a three-month interval ($b = .54, p < .001$). Kosloski et al. (2001) asked their respondents to indicate the importance of four organizational factors to their decision to use adult day programs. The factors they assessed were: (a) availability of transportation, (b) programs’ adherence to a schedule (i.e., offering services regularly), (c) having the ability to choose times for
service utilization (i.e., flexibility), and (d) how much per hour they would be willing to pay for services. Users rated schedule adherence and flexibility more highly than did nonusers. Additionally, the importance caregivers placed on programs offering services regularly was a significant predictor of service utilization. However, the importance ratings of availability of transportation and program cost were unrelated to caregivers’ status as a service user. Participants in Dabelko’s (2004) study were more likely to discharge from adult day programs within the two-year study period if they were reliant upon public funding. This finding suggests that it may be the funding source, rather than the cost per se, that influences length of stay in adult day programs. Additional research is needed to clarify this issue.

Adult day program participants have an array of service needs related to conditions such as Alzheimer’s disease, developmental disabilities, traumatic brain injury, HIV/AIDS, and mental illness. According to the National Study of Adult Day Services (2002), half of adult day center participants have a diagnosis of dementia and 41% are classified as frail elderly (age 60+ in need of supervision and/or at-risk of social isolation; no dementia). Nearly one quarter of the sample participants have a diagnosis of mental retardation/developmental disability (MR/DD) or are physically disabled and cognitively intact (e.g., stroke, Parkinson’s disease, multiple sclerosis). The primary activities of daily living for which participants required assistance were toileting (43%), walking (37%), and eating (24%). The national study reported that over 80% of adult day program participants were age 65 years or older. The average age of participants was 72. Participants stayed in programs an average of two years. Length of stay ranged from one
month to eight years. The three most common reasons for discharge were institutionalization, death, and decline in functional status.

Among background characteristics, race, marital status, and age were related to service use. Three studies found significant relationships between race and service use (Bookwala et al., 2004; Dabelko, 2004; Kosloski et al., 2001). Samples in two studies consisted primarily of respondents identifying as White or Caucasian (Bookwala et al., 2004; Kosloski et al., 2001; 97.3% and 93%, respectively). Bookwala et al. found that caregiver race was a significant predictor of service use after a three-month period ($b = .21, p < .001$), such that caregivers identifying as White were more likely to have care recipients enrolled after three months than were non-White caregivers. Dabelko’s (2004) sample of adult day program clients was divided between White/Caucasian care recipients (52%) and African American or other participants (48%). Dabelko reported that non-White clients were more likely to have been discharged from adult day programs during the two-year period of study.

Dabelko (2004) also found that older clients and those who were married were more likely to have been discharged by the end of the study than were younger participants. Gaugler et al.’s (2003) results support the finding that older care recipients are likely to discharge from adult day programs earlier than are younger participants. They also reported that male caregivers were more likely to drop out of service use within three months than were female caregivers. Zarit et al. (1999) also found that brief users of adult day programs were more likely to be married than were those who used services for one year or more. Zarit et al. suggest that the different drop out rates for
spousal caregivers may reflect “that the relationship between a husband and wife has different norms, expectations, and much different history than that between parent and child” (p. 360).

Generational differences in perceived duty to care may also help explain some of the differences in service use by spouses and adult children. In fact, Kosloski et al. (2001) found that adult day program users reported less perceived duty to care than did individuals who were classified as non-seekers of adult day services. A small negative correlation was reported between perceived duty to care and service use ($r = -.10, p < .05$). No other background characteristics were found to relate to or predict service use.

Gottlieb and Johnson (2000) reviewed literature up to 1999 on the use and effects of adult day service use among caregivers of individuals with dementia. With respect to service utilization, Gottlieb and Johnson noted several trends in the literature. First, demand for services tended to be greater than actual service use, even when financial barriers were removed. Second, caregivers tend to avail themselves of respite services relatively late in the course of caregiving, often at a time of heightened levels of stress appraisals. Third, use of adult day programs may facilitate the transition to long-term care facilities. Caregivers and care recipients may use adult day programs to test the formal care services available in their community. Finally, the frequency of use tends to be rather low. Gottlieb and Johnson reported that service use by caregivers in the studies reviewed tended to be roughly two days per week. In summary, caregivers make less frequent and later use of adult day programs compared to their self-reported needs.
2.1.2 Care Recipient-Related Factors

Common indicators of care recipient-related health factors that might influence service use include measures of activities of daily living (ADLs), instrumental activities of daily living (IADLs), memory problems, and problematic behaviors. All studies reviewed found some relationship between activities of daily living and service use; however, ADL limitations did not predict service use. Among participants in Dabelko’s (2004) sample, 46% reported either urinary or bowel incontinence. Most clients enrolled during her two-year study period were classified as having a “moderate” level of ADL limitations. Kosloski et al. (2001) found that adult day program care recipients reported more ADL limitations than did nonusers. Bookwala et al. (2004) found that instrumental activity of daily living limitations measured three months after program enrollment predicted continued use of services at three months. That is, individuals with more limitations in IADLs at three months were more likely still to be enrolled in an adult day program than were those clients with fewer IADL limitations.

Dabelko (2004) also assessed care recipients’ mental health status. Among her sample of 280 participants of adult day programs in Central Ohio, 20% were diagnosed with a psychological disorder, such as depression, bipolar disorder, or an anxiety disorder. Furthermore, presence of a mental illness was related to longer enrollment in the adult day programs. Of the literature reviewed herein, Dabelko’s study was the only one that assessed the mental health of care recipients.

Results were mixed with respect to the relationship of care recipients’ memory and behavior problems to use of adult day services. For instance, Bookwala et al. (2004) found that clients with more memory and behavior problems were less likely to use adult
day programs both at baseline and after a three-month interval. However, Kosloski et al. (2001) found no relationship between care recipients’ behavior problems and service use. Gaugler et al. (2003) reported that care recipients who used adult day programs briefly (i.e., less than three months) reported more behavior problems at baseline. It may be that greater memory or behavioral problems are reason for discharge from adult day programs. This supposition is supported by discharge information reported by Dabelko (2004) and Zarit et al. (1999). Clients frequently are discharged from adult day programs because the services no longer meet the needs of clients, often when physical and/or mental health declines “to the point of not being able to attend and/or benefit from the adult day service program” (Zarit et al., 1999; p. 360).

2.1.3 Caregiver-Related Factors

In addition to the status of care recipients’ functioning, studies have examined the relationship between caregivers’ functioning and adult day service utilization. Kosloski et al. (2001) compared the characteristics of caregivers who use adult day programs with those of caregivers who do not utilize such programs. No differences were found between users and non-users with respect to caregivers’ physical health or subjective burden.

Bookwala et al. (2004) examined the association of five caregiver-related factors to service utilization. The authors measured the amount of assistance caregivers provide (indicated as the sum of ADLs and IADLs for which the caregiver assists the care recipient), restriction in personal and social activities due to caregiving duties, as well as caregivers’ physical health, depressive symptoms, and general caregiver mastery. All five caregiver-related factors were assessed at the time of adult day program enrollment and again at three months. Physical health was the only caregiver-related variable that was
unrelated to service utilization at either time of measurement. The authors note that over 70% of caregivers reported relatively favorable health ratings.

The other four caregiver-related variables were moderately correlated with service utilization at Time 1 (baseline) and Time 2 (3 months). Caregivers who provided more assistance with ADL and IADL limitations, were more restricted in their social and personal activities, reported more depressive symptoms, and reported less perceived caregiver mastery were likely to use adult day services at both Time 1 and Time 2. Caregivers’ depressive symptoms were the only caregiver-related variable to predict service use at baseline. Depressive symptoms and care recipients’ memory and behavior problems combined to account for 17.7% of the variance in service utilization at baseline.

Time 2 service utilization was predicted by two caregiver-related factors: Time 2 activity restriction and Time 2 depressive symptoms. These two caregiver-related factors, along with Time 2 IADL limitations and Time 2 memory and behavior problems, accounted for 7.7% of the variance in Time 2 service utilization beyond that explained by caregiver race and Time 1 service utilization. Service utilization at baseline was the strongest predictor of service utilization at three months.

Zarit et al. (1999) reported that brief users were more likely than sustained users to experience greater role captivity, fewer depressive symptoms, and more positive affect. Role captivity refers to a caregiver’s feeling of being trapped in the caregiving role. Gaugler et al. (2003) found that adult day program users reported more worry, role overload, depressive symptoms, and anger at baseline than did non-users.
While the studies described above sought to identify factors contributing to service utilization and length of stay, Gaugler et al. (2003) explored the effect that use of adult day programs has on caregivers’ self-ratings of caregiving hours and demands due to ADLs, IADLs, and care recipient behavioral problems. The authors compared caregivers utilizing adult day programs in New Jersey with caregivers in Northeastern Ohio who do not use adult day services. Several variables were assessed at a baseline measure and again after a three-month interval. Differences in the two samples as well as differences due to attrition limit the degree to which the study’s finding can be generalized. For instance, the caregivers in the treatment sample were more likely to live with the care recipient and had larger incomes than did the comparison sample. Additionally, male caregivers and older caregivers were more likely to have dropped out of the study before the second assessment period at three months.

Adult day program services effected caregiving demands and time spent addressing behavioral problems. From Time 1 to Time 2, users reported decreases in limitations of activities of daily living, while non-users reported slight increases in their care recipients’ ADL limitations. Adult day service utilization did not, however, affect the amount of time caregivers spent addressing ADLs with their care recipients. No differences were reported for instrumental activities of daily living limitations. Both users and non-users reported decreased hours spent addressing problematic behaviors, however the decrease in time for users was greater than that for non-users. Adult day service use had significant effects on time spent addressing behavioral problems and on decreases in behavioral problems over the three-month study period. The authors concluded that
“adult day services may not only restructure the time family members spend dealing with certain types of care demands, but the intensity of these problems may be alleviated to some extent as well” (Gaugler et al., 2003; p. 54).

The results of these studies suggest a rather complex relationship among care recipient functional status, caregiver health and well-being, and adult day program utilization. While adult day programs may alleviate the caregiving demands due to care recipients’ functional limitations and behavioral problems (Bookwala et al., 2004; Kosloski et al., 2001), the benefits of adult day programs for these problems may dissipate after a certain level of functional decline, as evidenced by information gleaned at discharge (Dabelko, 2004; Zarit et al., 1999). Caregivers utilizing adult day programs for support are likely to provide more assistance to their patients, experience greater personal restrictions, and more depressive symptoms than do brief users or non-users. Because adult day programs attract different caregivers and care recipients than those found in the overall population, findings based upon samples of adult day program consumers will be limited in how well they generalize to caregivers and care recipients at large.

2.2 Beliefs About Self

Beliefs about self refer to various self-conceptualizations postulated to influence an individual’s beliefs about death and his or her past- or future-related regrets (Tomer & Eliason, 1996, 2000a). Tomer and Eliason specifically identified self-esteem as one such self-belief that is theoretically related to death attitudes and death anxiety. Another self-belief that may have implications to the death attitudes of family caregivers is caregiving
self-efficacy. The following section reviews the concepts of caregiving self-efficacy and self-esteem as well as correlates of these constructs that are relevant to the present study.

2.2.1 Caregiving Self-Efficacy

In this study, caregiving self-efficacy will be defined as a caregiver’s perceived confidence in completing the tasks and responsibilities associated with caregiving. Caregiving encompasses many activities ranging from meeting the physical needs of the care recipient to responding effectively to a loved one’s anger to satisfying the caregiver’s mental and physical health needs. The following section provides a review of self-efficacy theory, using examples relevant to caregiving, and correlates of caregiving self-efficacy that have been reported in the literature.

2.2.1.1 Self-Efficacy Theory

Self-efficacy theory (Bandura, 1997; Figure 4) provides a comprehensive model of the factors that influence the development of confidence in a behavioral domain as well as the potential outcomes of that confidence. Self-efficacy refers to an individual’s judgment of her or his confidence to perform a given behavior successfully (Bandura, 1997). Self-efficacy expectations have been assessed with respect to a variety of behavioral domains including caregiving (Gottlieb & Rooney, 2003, 2004; Steffan, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002), hospice volunteering tasks (Robbins, 1992), and coping (Gignac & Gottlieb, 1996).

Self-efficacy expectations are based upon four sources of information: performance accomplishments, vicarious learning, social persuasion, and emotional arousal (Bandura, 1997; Figure 4). Each of the four sources may operate in conjunction with one or more of the other sources. Performance accomplishments, or personal
mastery experiences, are postulated to be the most influential source of efficacy information (Bandura, 1997). Successful completion of a challenging task builds self-efficacy in that it demonstrates to an individual his or her ability to execute the behaviors necessary for success.

Several factors influence individuals’ development of self-efficacy through mastery experiences including their evaluations of their capabilities, the difficulty of the task, their expended effort, and the level of assistance received from others (Bandura, 1997). The greatest effect of performance accomplishments occurs with prolonged and consistent application of “the cognitive, behavioral, and self-regulatory tools for creating and executing effective courses of action” (Bandura, 1997; p. 80). Additionally, mastery experiences are bolstered when others reinforce an individual’s efficacy. “Skill transmission and success feedback alone achieved little with individuals beset with strong doubts about their capabilities. But skill transmission with social validation of personal efficacy produced large benefits” (Bandura, 1997, p. 81). Performance accomplishments generalize most to activities closely related to the behavioral domain in question. For instance, the confidence in providing care to young children may influence initial levels of confidence in providing care to an elderly family member.

A second source of efficacy information is vicarious learning, or modeling. Evaluations of one’s efficacy are conducted with reference to one’s perceptions of others’ performance outcomes. For example, caregivers who perceive others as providing lower levels of care are likely to experience an elevation in their caregiving self-efficacy, while those caregivers who compare themselves less favorably to other caregivers are likely to experience a decline in their caregiving self-efficacy. Several factors maximize the
effectiveness of vicarious learning experiences, including the presence of an unambiguous success outcome and the observation of many models who exhibit a variety of characteristics (Bandura, 1997). This last factor provides the viewer with the sense that if others achieve success then the viewer should be able to perform similarly.

Verbal persuasion, the third source of efficacy information, refers to the supportive and encouraging comments meant to suggest to an individual that he or she can perform successfully. Bandura (1977) noted, “in the face of distressing threats and a long history of failure in coping with them, whatever mastery expectations are induced by suggestion can be readily extinguished by disconfirming experiences” (p. 198). Thus, verbal persuasion will be most powerful when accompanied by successful performance accomplishments. Encouraging appraisals from individuals viewed as credible or knowledgeable in the specific behavioral domain are likely to have greater persuasive power. For example, positive appraisals of caregiving abilities from a health care professional are likely to have a greater influence on a caregiver’s efficacy appraisal than would the evaluations of a neighbor with little to no caregiving experience or expertise.

Emotional arousal in response to stressful situations is the fourth source of self-efficacy information (Bandura, 1997). The degree to which one experiences aversive physiological and emotional states influences judgments of confidence to perform at a given time, under certain conditions. “Somatic indicators of personal efficacy are especially relevant in domains that involve physical accomplishments, health functioning, and coping with stressors” (Bandura, 1997, p. 106). According to Bandura (1977), “individuals who come to believe that they are less vulnerable than they previously assumed are less prone to generate frightening thoughts in threatening situations” (p. 198).
Acquiring coping skills to minimize aversive emotional and physiological reactions to stressors may lessen the emotional arousal and subsequently increase perceived control. Emotional arousal may affect individuals’ appraisals of caregiving self-efficacy if they experience heightened levels of anxiety, depression, or fatigue that they attribute to their caregiving experiences.

Self-efficacy expectations are postulated to lead to three behavioral outcomes: initiation of change behavior, degree of effort, and extent of persistence (Bandura, 1997; Figure 4). First, efficacy expectations are postulated to inform one’s decision to initiate change behavior by either approaching or avoiding situations requiring the specific behavior in question. Individuals with low efficacy expectations are likely to avoid change behaviors, whereas individuals with higher efficacy expectations will be more inclined to initiate change behaviors (Bandura, 1997). For example, caregivers of frail elderly relatives with higher caregiving efficacy expectations likely will engage actively in caregiving tasks, whereas caregivers with lower efficacy expectations may be more inclined to avoid caregiving, perhaps by minimizing the needs of their loved one or by institutionalizing their relative.

Second, one’s performance or the level of effort expended is postulated to depend upon one’s efficacy expectations (Bandura, 1997). With higher confidence in one’s ability to perform a given behavior, an individual likely will exert more effort to complete the behavior. For instance, a caregiver of a frail older adult who has a high degree of confidence in providing care for their relative, likely will work harder to provide care than will a caregiver with lower confidence in their caregiving abilities. Additionally, caregivers with greater confidence in their ability to provide care may be
more adept at using community services, managing the needs of their loved one, and managing their own physical and mental health needs.

Finally, self-efficacy determines the extent to which an individual persists in a given behavior in the face of challenge or failure (Bandura, 1997). Those caregivers with a higher degree of efficacy in providing care will persist in caregiving longer than those with lower confidence in providing care. Again, caregivers with lower confidence in their caregiving abilities may be inclined to institutionalize their relative earlier than a caregiver with higher efficacy expectations. Therefore, with a strong sense of self-efficacy, an individual will likely choose to engage in situations requiring the performance of a behavior. He or she will likely persist in the task despite failed attempts.

Self-efficacy theory can be usefully applied to almost any well-specified behavioral domain important to human functioning. The area of caregiving provides such a domain. Zeiss, Gallagher-Thompson, Lovett, Rose, and McKibbin (1999) identify three hypotheses regarding the outcomes of caregiving self-efficacy based upon Bandura’s (1997) overarching theory: (1) family members high in self-efficacy will be more likely to take on caregiving roles than will those with lower self-efficacy for caregiving activities; (2) caregivers with high self-efficacy will be more likely to persist in caregiving as the demands become more exacting; and (3) caregivers with high self-efficacy will be more likely to maintain caregiving “without developing debilitating emotional reactions” (Zeiss et al., 1999, p. 222). The first hypothesis is directly relevant to the present study.

One eventual task of caregiving for a frail elder is likely to be preparation for the loved one’s death and dying (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995).
Such preparation may involve the development of belief in one’s ability to adequately cope with and accept the reality of a loved one’s death. Therefore, one outcome of higher levels of caregiving self-efficacy might be more positive attitudes toward death. Additionally, a reciprocal relationship between death attitudes and caregiving self-efficacy may exist such that more positive attitudes about death and coping with a loved one’s death are likely to lead to greater caregiving self-efficacy, while more negative attitudes and death fears are likely to result in lower levels of caregiving self-efficacy. These are empirical questions that have yet to be explored fully. The present study adds to the limited literature that addresses the nature of the relationship between death attitudes and caregiving self-efficacy.

2.2.1.2 Correlates of Caregiving Self-Efficacy

Caregiving self-efficacy is a relatively recent subject of empirical study. Zeiss, Gallagher-Thompson, Lovett, Rose, and McKibbin (1999) were first to develop an instrument to assess caregiving self-efficacy. Since their original contribution, Zeiss, Gallagher-Thompson and colleagues (Steffan, McKibbin, Zeiss, Gallagher-Thompson, and Bandura, 2002) have revised their Caregiving Self-Efficacy Scale, and Gottlieb and Rooney (2003, 2004) have developed the RIS Eldercare Self-Efficacy Scale. Both scales assess caregivers’ beliefs about their abilities to complete tasks related to providing care for an elderly relative with a dementing disorder, such as Alzheimer’s disease. The original Caregiving Self-Efficacy Scale (Zeiss et al., 1999) assessed behaviors falling into two subscales that were labeled self-care self-efficacy and problem-solving self-efficacy. The Revised Scale of Caregiving Self-Efficacy (Steffan et al., 2002) expanded the types
of behaviors assessed within three subscales: obtaining respite, responding to disruptive patient behaviors, and controlling upsetting thoughts about caregiving.

Gottlieb and Rooney’s (2003, 2004) scale assesses three dimensions of caregiving behavior that give rise to the RIS acronym: relational self-efficacy, instrumental self-efficacy, and self-soothing self-efficacy. Relational self-efficacy items refer to caregivers’ beliefs about minimizing conflict with the relative, making time with the relative enjoyable, and obtaining the relative’s cooperation. Instrumental self-efficacy includes caregivers’ beliefs about their ability to provide for the care recipient’s physical needs and to solve problems appropriately that arise during caregiving. Lastly, self-soothing self-efficacy taps caregivers’ beliefs about their ability to manage their own emotional reactions and needs such as relaxation, pleasure, support, and decreased worry.

Studies of the development and validation of the two caregiving self-efficacy scales examined the correlations of the dimensions of caregiving self-efficacy with indicators of mental health and personality (Gottlieb & Rooney, 2003, 2004; Steffan, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002; Zeiss, Gallagher-Thompson, Lovett, Rose, and McKibbin, 1999). Additionally, the authors conducted regression analyses of the dimensions of self-efficacy onto depression, caregiver burden, coping effectiveness, and general mental health. Gottlieb and Rooney (2003, 2004) also used personality variables as a predictor of the caregiving self-efficacy dimensions. The authors operationally defined mental health using a general mental health composite as well as measures of depression, caregiver burden, social support, and coping. Dimensions of personality that demonstrated significant correlations with caregiving self-efficacy included trait anxiety, trait anger, and optimism.
Gottlieb and Rooney (2003) found that mental health, as measured by a composite score from the SF-36 (Tarlov, Ware, Greenfield, Nelson, Perrin, & Zubkoff, 1989), correlated positively with relational and instrumental self-efficacy. However, Gottlieb and Rooney (2004) conducted regression analyses of several caregiving variables on mental health and reported that neither relational nor instrumental self-efficacy scores added to the prediction of mental health subscale scores. The authors did not examine the role of self-soothing self-efficacy in the study because it “was not deemed relevant to caregivers’ judgments of their effectiveness in coping with the memory and behavioral problems they selected” (Gottlieb & Rooney, 2004, p. 367).

Contrary to their arguments for removing self-soothing efficacy from their analyses, Gottlieb and Rooney (2004) reported that emotional inhibition, as a coping method, was a significant predictor of caregivers’ mental health scores. As such, examining the relationship of self-soothing efficacy and mental health indicators would be worthwhile. Additionally, self-efficacy theory suggests that affective arousal may influence an individual’s self-efficacy evaluations. As such, it would be worthwhile to conduct regression analyses of mental health factors on dimensions of caregiving self-efficacy.

Zeiss and colleagues (Steffan et al., 2002; Zeiss et al., 1999) examined the relationship of depression to their initial and revised caregiving self-efficacy scales among two samples of caregivers. Depression was found to correlate negatively with the three dimensions of caregiving self-efficacy assessed by the Revised Scale of Caregiving Self-Efficacy. Additionally, Steffan et al. (2002) reported that participants in the first sample endorsed more depressive symptoms than did participants in the second sample.
They hypothesized that caregivers with more depressive symptomatology would report lower levels of caregiving self-efficacy. Multivariate analysis of variance supported this hypothesis; the caregivers in the first sample with more depressive symptoms reported lower levels for all three types of caregiving self-efficacy than did participants in the second sample. In their initial development study, Zeiss and colleagues (1999) reported that the two dimensions of self-efficacy (self-care & problem-solving) accounted for 21% of variance in scores on a commonly used depression scale.

In addition to examining the predictive value of the self-efficacy dimensions on depression, Zeiss et al. (1999) also conducted regression analyses of self-care self-efficacy and problem-solving self-efficacy on indicators of objective burden (total number of memory and behavior problems of care recipient) and subjective burden (degree of upset from care recipient’s problematic behaviors). Self-care and problem-solving self-efficacy together explained 23% of variance in caregivers’ objective burden scores. On the other hand, only problem-solving self-efficacy was found to be a significant predictor of subjective burden scores, accounting for 6% of variance in these scores.

As discussed above, self-efficacy evaluations are influenced by mastery experiences that, in turn, are affected by individuals’ perceptions of factors such as task difficulty and expended effort. Assessments of task difficulty and expended effort may also be incorporated in evaluations of caregiver burden. Therefore, evaluations of burden may serve as an indirect source of efficacy information obtained through mastery.
experiences. Self-efficacy theory would suggest that caregiver burden would be a predictor of self-efficacy expectations. This is an empirical question that needs to be addressed by further study.

Mental health also has been operationally defined by measures of social support, coping efficacy, and coping effectiveness (Gottlieb & Rooney, 2003, 2004; Steffan, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002). Steffan et al. (2002) found that social support was related positively to obtaining respite but was not related significantly to the other two dimensions of caregiving self-efficacy. Gottlieb and Rooney (2003) reported that perceived social support correlated positively with relational, instrumental, and self-soothing self-efficacy.

Gottlieb and Rooney (2003, 2004) also examined the relationships of coping efficacy and coping effectiveness with their proposed dimensions of caregiving self-efficacy. Coping efficacy, a caregiver’s perceived confidence in their ability to enact coping strategies, was related positively to the three dimensions of caregiving self-efficacy. Additionally, Gottlieb and Rooney (2004) reported a positive correlation of effectiveness of coping with both relational and instrumental self-efficacy. Furthermore, relational self-efficacy and optimism were found to be significant predictors of coping effectiveness over and above caregiver’s gender, living status, and the memory and behavior problems of the care recipient.

Three dimensions of personality have been found to be related to dimensions of caregiving self-efficacy. Gottlieb and Rooney (2003, 2004) report that optimism was a significant predictor of relational, instrumental, and self-soothing self-efficacy above and beyond caregivers’ age and gender, duration of caregiving, living arrangement, and
frequency of memory and behavioral problems. Steffan et al. (2002) hypothesized that
trait anxiety would correlate negatively with controlling upsetting thoughts about
caregiving, and that trait anger would correlate negatively with managing disruptive
patient behaviors. Hypothesized relationships were supported by data from two
independent samples.

As discussed above, the present study examines the relationship between
caregiving self-efficacy and death attitudes. A review of the literature yielded one
correlational study of the relationship between death attitudes and a measure of general
self-efficacy. Tang, Wu, and Yan (2002) examined the relationship between three
measures of death anxiety and a measure of “Generalized Self-Efficacy” (Schwarzer,
1993) among a sample of 282 Chinese university students in Hong Kong. Scores on the
self-efficacy scale were negatively correlated with two general measures of death anxiety
and with four of eight subscales of the Multidimensional Fear of Death Scale (Neimeyer
& Moore, 1994). The four subscales with significant negative correlations with self-
efficacy were: fear of the dying process, fear of the dead, fear of being destroyed, and
fear for the body after death. Correlations ranged from $r = -0.17$ to $r = -0.28$ and were
significant at the 0.01 level.

2.2.1.3 Summary

Self-efficacy is a domain-specific construct “concerned with judgments of how
well one can execute courses of action required to deal with prospective situations”
(Bandura, 1982, p. 122). Self-efficacy is postulated to influence the choice of engaging or
avoiding those courses of action, how much effort one expends in action, and the duration
of persistence in spite of obstacles. While four sources of efficacy information (e.g.,
performance accomplishments, vicarious learning, social persuasion, and emotional arousal) have been proposed, prior successful experience has been shown to be the most influential source of self-efficacy expectations (Bandura, 1997). Self-efficacy expectations have been examined with respect to a variety of behaviors including caregiving (Gottlieb & Rooney, 2003, 2004; Steffan, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002).

Caregiving self-efficacy may be defined as a caregiver’s judgment of how well she or he can complete the tasks necessary for care of an elderly relative. Several dimensions of caregiving self-efficacy reflect the behaviors needed for successfully providing care to elderly and demented patients. These dimensions address tasks such as meeting the physical needs of a care recipient, maintaining a harmonious relationship with the care recipient, managing reactions to upsetting behaviors by the care recipient, and satisfying the caregiver’s needs for support and respite.

2.2.2 Self-Esteem

Self-esteem is a term with common usages as well as particular psychological meanings and implications. In common parlance, self-esteem refers to one’s value or respect for himself or herself. We label people who seem to like themselves as having high self-esteem. Generally, self-esteem is viewed as a desirable, positive attribute. Laypersons’ understanding of self-esteem makes the psychological conceptualization and measurement of self-esteem more difficult. Blascovich and Tomaka (1991) argue that use of “implicit, common-language notions of self-esteem” in place of “more precise, explicit, scientific definitions” results in an illusory perception of a well-defined
conceptualization of self-esteem (p. 116). Additionally, the social desirability of self-esteem creates a challenge for the measurement of self-esteem in psychological research. Scores on self-esteem scales may be inflated due to the social desirability effect (Blascovich & Tomaka, 1991). Moreover, high self-esteem may not reflect optimal psychological functioning, as individuals high in narcissism, defensiveness, and conceit exhibit high self-esteem (Baumeister, Campbell, Krueger, & Vohs, 2003).

Lay definitions and conceptualizations of self-esteem are not the only limitations to the psychological study of self-esteem. In their review of widely used measures of self-esteem, Blascovich and Tomaka (1991) conclude that self-esteem is defined primarily in terms of measurement and correlates rather than by an established, well-developed theory. They propose a definition of self-esteem that is consistent with widely used measures of self-esteem: “the overall affective evaluation of one’s own worth, value, or importance” (p. 115). Synonyms include self-worth, self-regard, self-respect, and self-acceptance. Lack of clearly delineated relationships between self-esteem and other self-constructs also raises the level of confusion within the self-esteem literature. It appears to be generally accepted that self-esteem is a narrower construct than self-concept, which refers to an individual’s overall representation of the self that includes affective (i.e., self-esteem), cognitive, and behavioral components. Moreover, “self-esteem is more global than the evaluation of a specific attribute (e.g., height or academic ability) or a circumscribed set of related attributes (e.g., one’s body or intelligence)” (p. 116).

In his discussion of the differences between self-esteem and self-efficacy, Bandura (1997) observes that some existing measures of self-esteem confound self-worth and self-efficacy. “Perceived self-efficacy is concerned with judgments of personal
capability, whereas self-esteem is concerned with judgments of self-worth” (Bandura, 1997, p. 11). Bandura suggests that the relationship between perceived self-efficacy and perceived self-esteem depends upon an individual’s degree of investment in performing well in a given domain of functioning. Being inefficacious in a domain of little importance to an individual would have little influence on his or her perceived self-esteem, while being inefficacious in a domain of great importance to one’s self-worth would have a greater impact on self-esteem. Following this analysis, Bandura argues that measuring self-esteem as a global self-evaluation fails to capture the full picture of self-esteem. “Domain-linked measures of self-worth reveal the patterning of human self-esteem and the areas of vulnerability to self-disparagement” (p. 12). Bandura identifies two sources of self-esteem: (1) meeting individual “standards of merit” and (2) possessing attributes or social status of value to one’s culture.

2.2.2.1 Conceptualizations of Self-Esteem

Several conceptualizations of self-esteem have been proposed in the literature. Below are brief descriptions of three of these perspectives: an attitudes approach (Rosenberg, Schooler, Schoenback, & Rosenberg, 1995), sociometer theory (Leary & Baumeister, 2000), and the terror management approach (Pyszczynski, Greenberg, Solomon, Arndt, & Schimel, 2004). A summary of major points of convergence and divergence among the three perspectives also is presented.

Rosenberg, Schooler, Schoenbach, and Rosenberg (1995) propose that self-esteem be considered as an attitude. Taking an attitudes approach to self-esteem, researchers can consider cognitive and affective components of participants’ self-evaluations. They suggest that the cognitive component of self-esteem is that it represents
a thought or evaluation about a particular object; in this case, one’s self. The affective
dimension of self-esteem is the direction (negative or positive) and intensity of feeling
about the self.

Additionally, Rosenberg et al. (1995) argue that self-esteem can involve general
or specific facets of self-esteem evaluations. Attitude theory suggests that more specific
attitudes will have a greater effect on behavior than will more general attitudes
(Rosenberg et al., 1995). This implies that measures of specific self-evaluative
dimensions of worth will have a stronger relationship to behavior than will global
measures of self-esteem, such as Rosenberg’s Self-Esteem Scale (1965). Rosenberg et al.
propose that general measures of self-esteem will have a stronger relationship to
indicators of psychological well-being, such as depression, general anxiety, life
satisfaction, and positive and negative affective states. The results of Rosenberg et al.’s
correlational and regression analyses provided support for their hypotheses regarding the
relationship of general and specific self-esteem to psychological well-being and specific
behaviors, respectively.

A second perspective, sociometer theory (Leary & Baumeister, 2000; Leary,
Tambor, T verdal, & Downs, 1995), distinguishes between state self-esteem and trait self-
estee m. Individuals’ self-esteem is likely to have a stable component (trait self-esteem) as
well as to fluctuate during the individuals’ daily experience (state self-esteem).
Sociometer theory posits that state self-esteem functions to alert us to the level of social
inclusion we experience from the social group, like an automobile’s gas gauge indicates
the level of gasoline available in the tank. State self-esteem represents a measure of the
perceived levels of social exclusion and social inclusion that individuals experience from
others in their environment. Individuals who are included by others are likely to experience greater self-esteem than those who detect more exclusion from their environment. According to sociometer theory, the sociometer system is more sensitive to threats of rejection, and, therefore, individuals are motivated to minimize the likelihood of being excluded or rejected. “From this perspective, what have previously been viewed as threats to self-esteem are, at a more basic level, events that make the possibility of social exclusion salient” (Leary, Tambor, Terdal, & Downs, 1995, p. 520).

Sociometer theory posits that changes in self-esteem are likely to correlate strongly with changes in the degree of perceived inclusionary status. However, the authors seem to suggest that it is not simply inclusion, per se, that the individual seeks to achieve, but rather “inclusion by certain other people” (Leary et al., 1995; p. 520). The authors assert that sociometer theory “explains why people place varying degrees of importance on different domains of the self (e.g., intellectual, athletic, social), as well as why the importance people place on these domains correlates highly with the importance they think others place on them” (p. 520). Additionally, the theory postulates that compensatory behaviors may be elicited in response to real, potential, or imagined social exclusion.

Terror management theory (TMT) offers a third perspective on the nature and function of self-esteem. As discussed above, terror management theory proposes that self-esteem and cultural worldviews developed to defend against the terror stimulated by unconscious awareness of one’s mortality. Terror management theory “posits that self-esteem is a sense of personal value that is obtained by believing (a) in the validity of one’s cultural worldview and (b) that one is living up to the standards that are part of that
worldview” (Pyszczynski, Greenberg, Solomon, Arndt, & Schimel, 2004; p. 436-437). This conceptualization of the sources of self-esteem echoes that of Bandura (1997) presented above.

Self-esteem involves a process of consensual validation, whereby individuals’ perceptions of worth are based upon perceived socio-cultural evaluations as well as self-evaluations of the degree to which one meets the culturally prescribed contingencies of value. Self-esteem is likely to be high when an individual perceives himself or herself as adhering to the conditions of worth held by his or her cultural worldview. When an individual perceives himself or herself as falling short of meeting the standards set forth by his or her worldview, then self-esteem is likely to be lower. The lowering of self-esteem consequently weakens defenses against the “deeply rooted fear of death inherent in the human condition” (Pyszczynski, Greenberg, Solomon, Arndt, & Schimel, 2004, p. 437).

According to the TMT perspective, the primary function of self-esteem is to alleviate fear of annihilation or nonexistence (Greenberg, Solomon, & Pyszczynski, 1997; Pyszczynski et al., 2004). The theory’s proponents suggest that self-esteem mitigates this type of death anxiety in one of two ways. First, when individuals are reminded of their mortality in a threat situation, the individual enacts “defensive behavior aimed at shoring up whatever aspect of one’s worldview or self-evaluation has come under threat or at more generally bolstering self-worth through compensatory efforts” (Pyszczynski et al., 2004, p. 437). Pyszczynski et al. (2004) review several studies that have provided support for the hypothesis that mortality salience increases self-esteem striving (e.g., Greenberg, Pyszczynski, Solomon, Pinel, Simon, & Jordan, 1993;
Greenberg, Pyszczynski, Solomon, Simon, & Breus, 1994). The results of the mortality salience studies seem to suggest that individuals will temporarily boost their self-esteem in response to a mortality threat.

Individuals with a higher level of dispositional self-esteem tend to exhibit less defensiveness in the face of mortality threats. Dispositional self-esteem is therefore a second way in which self-esteem defends against death anxiety (Greenberg, Solomon, & Pyszczynski, 1997; Pyszczynski et al., 2004). The proponents of TMT argue that individuals strive for high levels of self-esteem even when death thoughts are not consciously active. Moreover, research has indicated that the effect of mortality salience on self-esteem striving is reduced by beliefs in what the authors call literal immortality, such as the belief in an afterlife or reincarnation (e.g., Dechesne, Pyszczynski, Arndt, Ransom, Sheldon, von Knippenberg, & Janssen, 2003).

These three perspectives appear to converge and diverge on a number of points. The theories seem to converge on two main points. All of these perspectives seem to agree that self-esteem evaluations involve both cognitive and affective dimensions. They also suggest that humans are prone to self-esteem striving in some particular way, whether it is by meeting individually determined contingencies of worth, by bolstering perceived social inclusion status, or by acting to alleviate existential anxiety.

On some points, two or more theories appear to agree on general principles, but differ in terms of more specific processes or functions. For example, the attitude perspective and sociometer theory distinguish different types of self-esteem, although these different types are somewhat distinct. Rosenberg et al. (1995) distinguish general versus specific self-esteem, which they propose have different relationships with
behavioral and psychological outcomes. While terror management theory does not explicitly distinguish different levels of self-esteem, it seems implied in their discussion of experimentally-induced versus dispositional self-esteem. Additionally, terror management theory and sociometer theory each specify a socially mitigated process of self-esteem development, however, they differ as to the exact role of sociocultural influences on self-esteem. Finally, each theory suggests some level of general versus domain-specific self-esteem, yet differ in terms of the degree to which this distinction has been fully or clearly articulated.

For the purposes of the present study, self-esteem is conceptualized in accordance with Rosenberg’s (1965) approach and will be measured using the Rosenberg Self-Esteem Scale. Self-esteem is defined herein as “the individual’s positive or negative attitude toward the self as a totality” (Rosenberg et al., 1995; p. 141). Self-esteem is included as an indicator of beliefs about the self, consistent with Tomer and Eliason’s (1996, 2000a) comprehensive model of death anxiety. This model also is informed by the terror management perspective that self-esteem will buffer the level of death anxiety experienced in the face of threats to one’s mortality.

2.2.2.2 Self-Esteem Across the Lifespan

Because participants in the present study are expected to be middle-aged to older adults, it is important to consider how self-esteem seems to develop and change across the lifespan. Robins and Trzesniewski (2005) reviewed three recent studies on the development of self-esteem across the lifespan, including one meta-analysis, one cross-sectional study, and one cohort-sequential longitudinal study.
Robins and Trzesniewski identified two general trends in the data. First, the studies reviewed indicate that self-esteem follows a particular trajectory across the lifespan. Participants report the highest levels of self-esteem during childhood, experience a drop in self-esteem during adolescence, with a steady increase during adulthood until their mid-60s, and then report a second decline during older adulthood. Over the age of 75, self-esteem shows a decline to levels similar to those reported by adolescents. This pattern appears for both men and women, although women generally report lower levels of self-esteem across the lifespan than do men. Additionally, there appears to be evidence of rank-order stability in reported self-esteem, such that individuals with high self-esteem will report higher self-esteem later in life, while individuals with low self-esteem will report lower self-esteem at a later time. In summary, individuals’ self-esteem appears to maintain rank-order stability over time, while following a trajectory of ups and downs throughout the lifespan.

The review of the lifespan development of self-esteem is limited by a number of factors (Robins & Trzeskiewski, 2005). There are relatively few studies that have measured self-esteem changes during older adulthood. Additionally, there has been limited research examining the mediating factors underlying the changes in self-esteem across the lifespan. Robins and Trzeskiewski also identify several methodological issues that need to be addressed by studies of self-esteem development, including the use of more representative samples, sophisticated statistical models and longitudinal studies, and studies of the genetic contributions to self-esteem. Finally, echoing the review by

Of particular interest to the present study is the nature of self-esteem during older adulthood. As discussed above, self-esteem during adulthood seems to peak around age 65 then decline beginning around age 70. Robins and Trzesniweski provide possible explanations for this pattern. First, they suggest that the decline in self-esteem may be due to the many changes occurring during older adulthood, “including changes in roles (e.g., retirement), relationships (e.g., the loss of a spouse), and physical functioning (e.g., health problems), as well as a drop in socioeconomic status” (p. 160). Second, older adults may have more balanced self-concepts including both positive and negative self-assessments that result in declines in self-esteem. The authors go on to elaborate this point when discussing the rank-order stability of self-esteem. Following Erikson’s (1985) model of lifespan development, the authors note, “as individuals grow older they begin to review their lifelong accomplishments and experiences, leading in some cases to more critical self-appraisals (ego despair) and in other cases to increased self-acceptance (ego integrity)” (p. 160). A third potential explanation, not addressed by Robins and Trzeskiewski, parallels their explanation for gender differences in self-esteem, namely, different social-contextual factors associated with the different treatment of older adults negatively affect older adults’ self-appraisals and reported levels of self-esteem (McCoy, Pyszczynski, Solomon, & Greenberg, 2000).
2.2.2.3 Correlates of Self-Esteem

Self-esteem is hypothesized to relate to a number of variables. For examples, studies of self-esteem in educational contexts are based on the hypothesis that self-esteem will be positively correlated with indicators of task performance, persistence, mastery, and healthier lifestyles (Baumeister, Campbell, Krueger, & Vohs, 2003). Additionally, measures of self-esteem are postulated to correlate positively with indicators of beneficial psychological outcomes such as life satisfaction, coping, and positive affect, and to correlate negatively with indicators of adverse psychological outcomes such as depression, anxiety, and negative affect. Furthermore, as discussed above, terror management theory proposes that self-esteem will protect individuals from unconscious awareness of death anxiety. Therefore, measures of death anxiety are postulated to correlate negatively with measures of self-esteem. The following section provides brief reviews of research findings about these hypothesized correlates of self-esteem.

Public policy, educational curricula, and psychological treatments have been predicated on the belief that boosting self-esteem will increase performance on a variety of desirable behaviors (Baumeister et al., 2003). Baumeister et al. (2003) argue that studies relying on self-report outcome measures are likely to result in inflated correlations with self-esteem measures. Self-report measures are sensitive to the self-enhancement bias associated with high self-esteem. Therefore, they reviewed research using objective measures of task performance and persistence. Their review indicated that observed correlations were lower than when self-reports of task performance were used. Additionally, when tasks are performed under ego threat, self-esteem may serve a protective function; individuals with high self-esteem are more likely to perform
successfully than are individuals with low self-esteem (Dutton & Brown, 1997). Finally, high self-esteem individuals are more likely to use self-regulatory strategies, including attending to cues regarding when to desist efforts or pursue alternative goals, than are low self-esteem individuals (Baumeister et al., 2003).

Two studies of the relationship of self-esteem with health and stress processes appear to be directly relevant to the present study. First, Forthofer, Janz, Dodge, and Clark (2001) conducted a study of older adults (age 60 and over) with cardiovascular disease. The authors examined factors influencing participants’ level of functioning over a one-year period. Self-esteem and stress were the strongest predictors of functioning, especially among women. These two factors were stronger predictors than were demographic and clinical factors (e.g., symptoms, medication compliance, and health care use). Additionally, comparisons of women in the lowest quartile on self-esteem to women in the highest quartile indicated that the women in the highest quartile were approximately five times as likely to maintain or improve functioning as were women in the lowest quartile. Thus, women diagnosed with high self-esteem and heart disease are more likely to report better functional abilities than are similarly diagnosed women with lower self-esteem.

Second, Noonan and Tennstedt (1997) studied the effect of caregivers’ positive beliefs about their selves and the perception of beneficial outcomes of caregiving (labeled as “meaning in caregiving”) on several outcomes postulated by the stress process model of caregiving (Pearlin, Mullan, Semple, & Skaff, 1990). Caregivers with high self-esteem were likely to experience less subjective burden, more emotional support, and more meaning in caregiving. These three factors accounted for 29% of the variance in self-
esteem scores among the caregivers. The results of this study suggest that the quality of
the caregiving experience, as evidenced by burden, support, and meaning, can influence
caregivers’ level of self-esteem.

Positive psychological outcomes are expected to have positive relationships with
self-esteem. In short, people who feel good about their selves are expected to feel good in
a more general way. Baumeister et al. (2003) observe that a strong positive correlation
between self-reported happiness and self-esteem has been reported consistently in the
literature. For instance, Rosenberg’s (1965) self-esteem scale correlated positively with
measures of life satisfaction and happiness in Rosenberg, Schooler, Schoenbach, and
Rosenberg’s (1995) study. Positive correlations between self-esteem and indicators of
confidence have been reported (Fleming & Courtney, 1984; Lorr & Wunderlich, 1986).
Finally, informal caregivers of the elderly who reported more emotional support and
found more meaning in caregiving were more likely to have high self-esteem (Noonan &
Tennstedt, 1997).

If self-esteem is hypothesized to lead to positive outcomes, then self-esteem may
be expected to be negatively related to adverse outcomes and psychological phenomenon.
In particular, it is postulated that individuals with low self-esteem also are likely to
endorse symptoms of depression and anxiety. For instance, Rosenberg et al. (1995) found
that self-esteem correlated negatively with measures of depression, resentment, negative
affect, and irritability. Baumeister and colleagues (2003) note that the literature generally
indicates a negative correlation between self-esteem and depression. However, the
relationship between self-esteem and depression may be more complex than a simple
linear relationship. For instance, they cite a study by Metalsky, Joiner, Hardin, and
Abramsom (1993) who found that more depressive symptoms among their participants were associated with three criteria: (1) an experience of subjective failure; (2) a self-blaming attributional style; and (3) low self-esteem.

Findings by Li and Seltzer (2003) also provide support for the role of individuals’ perceptions of events in the relationship between self-esteem and depressive symptoms. Li and Seltzer (2003) used structural equation modeling to examine the relationships among adult daughters’ perceptions of their self-esteem, depressive symptoms, and their relationship with a parent. Three groups of participants were solicited: adult daughters providing care for an elderly parent with cognitive and physical impairments, adult daughters providing care for a parent with physical impairments, and adult daughters who were non-caregivers. Participants in the three subsamples showed no differences in self-esteem and depressive symptoms.

However, global self-esteem, as measured by the Rosenberg (1965) Self-Esteem Scale, mediated the relationship between daughters’ perceptions of the daughter-parent relationship and daughters’ self-reported depressive symptoms among a sample of nearly 200 adult daughters (Li & Seltzer, 2003). Daughters who perceived a more positive relationship with their parent were more likely to report a high level of self-esteem and fewer depressive symptoms. This relationship held whether or not daughters were providing care to parents with cognitive and/or physical impairments.

Studies also have been conducted to examine the relationship between self-esteem and anxiety. For example, Rosenberg’s (1965) self-esteem scale has been shown to correlate negatively with measures of general anxiety and tension (Fleming & Courtney, 1984; Rosenberg et al., 1995). Furthermore, as will be discussed further in the section on
death attitudes below, Davis and colleagues have reported negative correlations between death anxiety and self-esteem among college students (Buzzanga, Miller, Perne, Sander, & Davis, 1989; Davis, Martin, Wilee, & Voorhees, 1978; Miller, Davis, & Hayes, 1993). Additionally, support has been garnered for the anxiety buffering function of self-esteem postulated by terror management theory (Cicirelli, 2002; Greenberg, Solomon, & Pyszczynski, 1997; Pyszczynski, Greenberg, Solomon, Arndt, & Schimel, 2004).

2.2.2.4 Summary

Self-esteem refers to an individual’s affective evaluation of his or her own worth or importance, and has been shown to be related to a number of other variables. Evidence supports the positive correlations of self-esteem and positive affect, life satisfaction, task performance, and well-being. Additionally, support has been found for a negative relationship between self-esteem and indicators of negative affect, depression, and anxiety. Longitudinal data indicate that self-esteem ebbs and flows throughout the lifespan, tending to decrease during adolescence and again in older adulthood. The adult years (ages 25-65) are characterized by a steady increase in reported levels of self-esteem. Self-esteem is important to the present study not only because it is a construct of great interest to psychologists and the general public, but primarily for its hypothesized relationship to death anxiety proposed by terror management theory and incorporated into the comprehensive model of death anxiety (Tomer & Eliason, 1996, 2000a).

2.3 Death Anxiety & Death Attitudes

The terms death anxiety and death attitudes have been used interchangeably in the literature, creating a problem of definition (Neimeyer, Moser, & Wittkowski, 2003; Tomer, 1994). In addition to the ambiguity of these terms, research on death attitudes and
death anxiety has been affected by other limitations. In particular, researchers often fail to clearly articulate the theory underlying their studies (Neimeyer, 1994). Additionally, instruments may be selected without reference to their psychometric properties or to the theory upon which they are based (Neimeyer, 1994; Tomer, 1994). Furthermore, the majority of research on death anxiety and death attitudes utilizes correlational, cross-sectional designs rather than more sophisticated analyses and methodologies such as longitudinal designs and structural equation modeling (Neimeyer, 1994; Tomer, 1994).

The following section begins with an examination of three problems of definition with respect to death anxiety and death attitudes. Definitions of these constructs for the present study will be proposed and discussed with respect to common measures of death anxiety and death attitudes. A summary of theories of death anxiety, including the comprehensive theoretical model of death anxiety that serves as the foundation of the present study, will follow. This section concludes with an overview of some correlates of death anxiety and death attitudes relevant to the present study.

2.3.1 Three Problems of Definition

The literature on death anxiety and death attitudes is plagued by three problems of definition (Neimeyer, Moser, & Wittkowski, 2003; Neimeyer & Van Brunt, 1995; Tomer, 1994). First, distinctions among concepts such as death anxiety, death fear, and death attitudes often are unclear even within a single article. For instance, Neimeyer et al. (2003) remark that “relatively little thought has been given by empirically oriented researchers to the meaning of ‘death anxiety,’ beyond the common sense association of the term with some form of personal discomfort concerning the state of death or the process of dying” (p. 47). Another term used interchangeably in the death anxiety
literature is death attitude. “Although these terms sometimes can be (and have been) used interchangeably, in other cases they reflect important conceptual distinctions, often accompanied by attempts to develop scales focused on one concept or another” (Tomer, 1994, p. 4).

Measures of death attitudes and death anxiety may attempt to reflect these conceptual distinctions. For instance, fear of death seems to be conceptually distinct from the more positive concepts of death acceptance (Wong, Reker, & Gesser, 1994) or death competence (Robbins, 1990-91), and thus a researcher may find that measures of fear of death differ conceptually from measures of death acceptance or coping with death. For example, Robbins (1990-91) reported that Bugen’s (1980-81) Coping with Death Scale correlated moderately and negatively with two common measures of death anxiety.

Wong, Reker, and Gesser (1994) argue, “It would not be fruitful to study fear of death in isolation. It is possible that the same level of fear of death may reflect very different death attitudes…Therefore, it is the patterns of different death attitudes rather than the magnitude of a single death attitude that best captures individual differences” (p. 141). Indicators of death attitudes that reflect more positive beliefs about death and coping with death allow for measurement along a broader continuum. Death acceptance and death competence also “may have different implications than measures of death anxiety, including improved prediction of certain death-related behaviors” (Robbins, 1990-91; p. 287). In fact, some level of death acceptance may co-occur with death anxiety. As Robbins (1990-91) remarked, “despite the lack of literature on death competence, we obviously manage to cope effectively with death in many respects, completing a whole variety of behaviors associated with death and dying” (p. 287).
A second problem of definition in this literature is related to the distinction between the state of death and the process of dying. This problem is apparent when one begins to examine distinctions among measures of death anxiety and death attitudes. Some instruments focus more on the fear of death itself, while others focus more on the physical pain and psychological discomfort that participants may expect to accompany the dying process. In fact, some instruments include subscales assessing both the process and state dimensions of death anxiety or attitudes for oneself and for others (e.g., Collett-Lester Fear of Death Scale, Collett & Lester, 1969; Lester, 1994; Lester & Abdel-Khalek, 2003).

Examples of items assessing fears about the state of death include: “Never thinking or experiencing” (self), “The disintegration of your body after you die” (self), “Having to see the person’s dead body” (others), and “Growing old alone without the person” (others). These items address the consequences of one’s death or that of others. Fears about the process of one’s own dying and others’ dying are assessed with items such as “The pain involved in dying” (self), “The grief of others as you lie dying” (self), “Having to be with someone who is dying” (others), and “Watching the deterioration of the person’s mental abilities” (others). More recently, the Multidimensional Fear of Death Scale (MFODS; Hoelter, 1979; Neimeyer & Moore, 1994) was empirically derived to assess several dimensions of death anxiety including fears of dying and the state of death. Eight factors of the MFODS have been identified, including “Fear of the dying process,” “Fear of being destroyed,” and “Fear for the body after death.”

A third problem with defining death anxiety and death attitudes relates to the question of whether these are unidimensional or multidimensional constructs. In their
review of death anxiety measures, Neimeyer et al. (2003) observe that “the evolution of
measures of death attitudes has been in the direction of greater differentiation and
specificity, moving from global assessments to more multidimensional scales, and from
the general measurement of death anxiety to attitudes of particular relevance in various
life contexts” (p. 49). Early measures of death fears, such as Templer’s (1970) Death
Anxiety Scale, assumed that death anxiety was a unidimensional construct. Factor
analyses of unidimensional scales, however, indicated that several factors were being
measured (Neimeyer, 1994). Newer instruments have been created with the assumption
that death attitudes are multidimensional in nature and have had their factor structure
examined. Indeed, the first two problems of definition addressed above also reflect the
problem of the multidimensional nature of death attitudes.

For the purpose of this study, death attitudes will be considered to subsume death
anxiety. Using definitions provided by Neimeyer et al. (2003), death anxiety will be used
herein to refer to “a cluster of death attitudes characterized by fear, threat, unease,
discomfort, and similar negative emotional reactions, as well as anxiety in the
psychodynamic sense as a kind of diffuse fear that has no clear object” (p. 47). On the
other hand, the term death attitudes will be used as a more general term that includes the
positive and negative beliefs and feelings one attributes to death in one’s conscious
awareness; thus, a subclass of death attitudes are the negative feelings about death
associated with the term death anxiety. This definition, which emphasizes the positive
and negative attributions an individual makes about death, suggests that an alternative
descriptor of death attitudes is meaning of death. Thus, the terms death attitudes and
meaning or meaningfulness of death will be used interchangeably herein.
2.3.2 Historical and Theoretical Perspectives

According to Neimeyer, Wittkowski, and Moser (2004), there have been three waves of interest in death anxiety and death attitudes. The first wave began with the work of Herman Feifel in the 1950s (Feifel, 1956, 1959) when death anxiety was measured primarily by projective means. The introduction of objective measures of death anxiety in the 1970s ushered in the second wave of research. These two waves of research also reflect a finer distinction in death attitudes: that between unconscious and conscious beliefs about death. It was believed that projective measures provided evidence of deeper, unconscious beliefs, while objective measures indicate consciously held death attitudes. This distinction is preserved in the current research climate as evidenced by the work of terror management theorists (unconscious death anxiety; e.g., Greenberg, Solomon, & Pyszczynski, 1997) and researchers using objective measures of death anxiety (conscious death anxiety; e.g., Lester & Abdel-Khalek, 2003).

Finally, Neimeyer et al. (2004) suggest that a third wave of interest in death anxiety and death attitudes began in the 1980s and continues today. In particular, they suggest that scientific and cultural forces have motivated this interest. Scientific forces have influenced the development and validation of new assessment tools, as well as the introduction of professional journals devoted to death studies (e.g., Death Studies and Omega). Meanwhile, “heightened public awareness of such global threats to survival as nuclear proliferation, terrorism, and the AIDS pandemic” has also motivated this third wave of interest in death anxiety and death attitudes (Neimeyer et al., 2004, p. 312).

Tomer (1994) reviews several theories of death anxiety from both philosophical and psychological traditions. Tomer (1994) acknowledges that his review of death
anxiety theories is concerned with one’s state of death rather than the process of dying or the deaths of significant others. Several themes recur in the various theories of death fears, including “annihilation of the self, death as radical transformation, death as threat to life’s meaningfulness, and death as threat to realization of basic life projects” (Tomer, 1994, p. 4). Tomer distinguishes between philosophical and psychological theories of death anxiety, although philosophical theories have been used as models for psychological examinations of death anxiety. The theories discussed below were selected as representatives due to their influence on the field of death studies, and as precursors of Tomer and Eliason’s (1996, 2000a) comprehensive model of death anxiety. The present section will conclude with an overview of Tomer and Eliason’s (1996, 2000a) model.

Philosophical approaches include existential-phenomenological approaches such as those of Heidegger and Sartre. Heidegger (1927/1962) in Being and Time argues that while death is a threat of nonexistence, it is the realization of our eventual nonexistence that forms the foundation for establishing a sense of meaning for our lives. One will experience threat or anxiety in the face of his or her mortality provided he or she has failed to find a sense of meaning for his or her existence. Freedom from anxiety occurs when one gains a larger understanding of her or his life.

On the other hand, Sartre (1943/1966) concludes that death limits one’s ability to self-actualize, and is therefore meaningless. “Given this, a person who has realized his or her central life projects to a great extent is less likely to be anxious about death than one whose projects remain incomplete” (Tomer, 1994, p. 5). From such a perspective, one may hypothesize that younger individuals, who have had less time to complete their “life projects,” will experience more anxiety about death than will their elders. Whereas
Heidegger’s perspective suggests that if a younger person has a greater sense of meaning than does her or his elder, then the younger person is likely to experience less death anxiety than would the elder. Philosophical approaches have provided a foundation for some of the psychological theories and models.

Tomer (1994) identifies several psychological theories of death anxiety, including self-realization theories, search-for-meaning theories, and theories of denial. First, self-realization theories, based on the work of Maslow (1968) and Rogers (1959), relate to death fears in that an individual with an ability to maintain his or her self-esteem as he or she ages and approaches death will experience fewer defenses, fears, and discrepancies between the self and the ideal self. According to self-realization theories, one can expect greater self-esteem to be related to less anxiety about death. Second, search-for-meaning theories (Frankl, 1963; Thompson & Janigian, 1988) emphasize the process of regaining a sense of the meaningfulness of life “in spite of death” (Tomer, 1994, p. 8) by changing one’s perceptions, life narratives, and attitudes in the face of threat. In this way, meaningfulness of life will correlate negatively with fear of death.

A third category of death anxiety theories is based upon personal construct theory (Kelly, 1955). An important concept from the personal construct theory is integration of the meaning of death with one’s beliefs about the self. With respect to death anxiety, personal construct theory postulates that to the extent that death is difficult to understand and lies outside the existing belief structure, thoughts of death will result in anxiety. Robinson and Wood (1983, 1984) propose a model of death anxiety that assumes two types of integration processes: actualization, the extent to which self and ideal self are integrated; and integration, the extent to which self and death are integrated into a single
belief structure. For example, if an individual construes death as an event that happens to ‘not-me,’ then such an individual will experience heightened anxiety and fear when diagnosed with a terminal illness.

Theories in the fourth category of psychologically-based death anxiety theories emphasize the roles of denial and positive illusions in minimizing death fears. This category includes terror management theory (Greenberg, Solomon, & Pyszczynski, 1997) and Taylor and colleagues’ theory of positive illusions (Taylor, 1983; Taylor & Brown, 1988; Taylor, Collins, Skokan, & Aspinwall, 1989). These theories postulate that experiences with death will lead individuals to adhere more strongly to culturally-valued roles and activities (Greenberg, Solomon, & Pyszczynski, 1997), and to attempt to maintain a sense of personal control or agency over their environment and future (Taylor & Brown, 1988). Additionally, terror management theory postulates that self-esteem will buffer an individual from the threat inherent in experiences with death (Greenberg, Solomon, & Pyszczynski, 1997).

Terror management theory (Greenberg, Solomon, & Pyszczynski, 1997) is based upon the work of anthropologist Ernest Becker (1973) among others. According to Becker (1973), the fear of death “is a mainspring of human activity – activity designed largely to avoid the fatality of death, to overcome it by denying in some way that it is the final destiny for man” (p. ix). Cultural worldviews define immortality and the methods by which individuals attain life after death (e.g., avoiding sin, becoming enlightened). “By successfully meeting these standards, by fulfilling our role in this socially orchestrated world, we feel of value and are able to derive self-esteem. It is this self-esteem that provides our primary barrier against the paralyzing fear of non-being” (McCoy,
Pyszczynski, Solomon, & Greenberg, 2000, p. 39). Thus, individuals with a higher level of dispositional self-esteem or experimentally-induced increases in self-esteem, will report lower levels of anxiety in response to a death-related threat conditions (Greenberg, Solomon, & Pyszczynski, 1997). Individuals maintain self-esteem by adhering to culturally valued roles, activities, and attitudes, and by defending the cultural worldview when self-esteem is threatened.

Two primary hypotheses derive from terror management theory: (a) self-esteem buffers the individual from anxiety induced under conditions of threat, and (b) individuals increase their adherence to cultural values when reminded of their mortality (Greenberg, Solomon, & Pyszczynski, 1997). Greenberg et al. (1997) review correlational and experimental studies providing support for both hypotheses. Of particular interest to the present study are findings regarding the effect of reminders of a loved one’s death on defense of cultural values.

Greenberg, Pyszczynski, Solomon, Simon, and Breus (Study 1, 1994) examined the effect of mortality salience conditions on worldview defense in a sample of college students. In particular, Greenberg, Pyszczynski, Solomon, Simon, and Breus tested the effect of level of processing the threat (e.g., subtle or deeper) and object of threat (e.g., self or loved one) on worldview defense. Subjects in the ‘subtle’ condition were asked to briefly describe the emotions raised by the thought of their death or that of a loved one, and to report their beliefs about the physical effects of the process of dying and the state of death (for self or others). The ‘deeper’ condition included the same two mortality salience questions as the ‘subtle’ condition. Additionally, subjects in the ‘deeper’ condition “were instructed to consider their deepest emotions about their (or a loved
one’s) death” (p. 628) and encouraged to imagine that they or a loved one had been diagnosed with a terminal illness to facilitate access to these emotions.

Subjects were randomly assigned to five conditions (subtle-self, subtle-other, deeper-self, deeper-other, and TV), where a TV salient condition asked subjects to report their feelings as they watched television, and their beliefs about what happens to them physically when they watch and have watched television. Subjects also evaluated the authors of two essays, one pro-American and one anti-American, supposedly composed by international students.

Subjects in the subtle-self condition rated the pro-American essay author the most favorably, although respondents in the subtle-other, deeper-self, and deeper-other conditions reported greater preference for the pro-American essay author than did students in the TV salience condition. The authors conclude, “That inducing subjects to think about the death of a loved one also produced increased defense of the worldview suggests that such effects may not be limited to thoughts specifically about one’s own death. However, these findings also suggest that reminders of the mortality of others are less potent instigators of such effects” (Greenberg et al., 1994, p. 629). Greenberg et al. acknowledge that increased defense of the worldview may occur when thoughts of another’s death induce thoughts of one’s own mortality, although the effect on adherence to cultural values will be weaker than in a self-mortality threat condition.

In addition to the effect of thoughts of another’s death on defense of cultural values, Greenberg and colleagues (Jonas, Schimel, Greenberg, & Pyszczynski, 2002; Rosenblatt, Greenberg, Solomon, Pyszczynski, & Lyon, 1989) have demonstrated that mortality salience conditions will induce prosocial behaviors consistent with cultural
values. For instance, Jonas et al. (2002) report that individuals under mortality salience conditions were more likely to give more money to charity than were participants in a control condition. Extended to the present study, these findings suggest that individuals faced with the impending death of a loved one will increase their adherence to prosocial cultural values. Caregiving for loved ones may be one such prosocial cultural value for many individuals. Furthermore, caregivers with higher self-esteem will likely experience less anxiety and other adverse effects from caregiving for their frail relative than will caregivers with lower self-esteem. Alternatively, caregivers with lower self-esteem may be inclined to greater adherence to the caregiver role as a defense from their fears about death. Efforts to adhere more to the caregiver role would likely be reflected by greater levels of caregiving self-efficacy reported by caregivers with lower self-esteem.

Taylor and Brown’s (1988) theory of positive illusions and other illusions of self-control provides another perspective on death anxiety, according to Tomer (1994). Taylor and Brown (1988) observe that individuals’ perceptions of reality are influenced by what the authors describe as illusions. Taylor and Brown define an illusion as “a perception that represents what is perceived in a way different from the way it is in reality. An illusion is a false mental image or conception which may be a misinterpretation of a real appearance or may be something imagined. It may be pleasing, harmless, or even useful (p.194).”

Taylor and Brown identified three prevalent illusions held by many so-called normal individuals: unrealistically positive views of the self, exaggerated perceptions of personal mastery, and unrealistic optimism. Individuals with higher levels of self-esteem are likely to focus more on their strengths than their weaknesses, to perceive a greater
sense of mastery that will promote goal-directed behavior and persistence, and to expect positive future outcomes. On the other hand, individuals experiencing depression or who are low in self-esteem “consistently display an absence of such enhancing illusions” (p. 197). The theory of positive illusions suggests that death competence will be positively correlated with self-esteem and with measures of mastery in providing care to a loved one.

2.3.3 A Comprehensive Model of Death Anxiety & Death Attitudes

Tomer (1994) identified multiple philosophical and psychological theories of death anxiety that evidence some overlap as well as important conceptual distinctions. Tomer (1994) and Neimeyer (1994) offer researchers several suggestions for navigating this theoretical quagmire. Both authors emphasize the need for explicating implicit assumptions and operational definitions of vague concepts like death anxiety and death attitudes. They also encourage researchers to attempt integrating existing theories. For instance, Tomer (1994) argues that different theoretical perspectives may explain fear of death at different levels (e.g., unconscious versus conscious) or during different developmental periods. Neimeyer (1994) identifies two benefits of theoretical integration: “(1) avoidance of conceptual duplication across theories; and (2) “development of more comprehensive theories that articulate or reconcile the sometimes competing predictions of their predecessors” (p. 265). One attempt at integration is the model of death anxiety proposed by Tomer and Eliason (1996, 2000a; Figure 1).

Tomer and Eliason’s (1996, 2000a) model is an attempt to integrate existing theories of death anxiety in a way that may also explain general trends observed in research findings. Their model identifies several possible determinants of death anxiety
and their relationships with one another. For their purposes, Tomer and Eliason define death anxiety as “a negative emotional reaction provoked by the anticipation of a state in which the self does not exist” (p. 345). While their definition of death anxiety excludes the fear of another’s death or dying, the authors do indicate that the illness or death of others may result in an increase in death salience. Death salience is defined as “the extent to which the individual contemplates or ponders his or her mortality (Tomer & Eliason, 1996; p. 346).” Therefore, the model attempts to explain the antecedents of fear of one’s death or dying, which may be evoked by illness or death threats (e.g., injury, attack, natural disaster) to one’s self or others.

According to the model, there are three direct antecedents of death anxiety: meaningfulness of death, past-related regrets, and future-related regrets. A high degree of death anxiety will be experienced when an individual perceives death as senseless and regrets what has been unaccomplished in one’s past and the future life goals that will remain unfulfilled. Death salience affects these three variables either directly, by altering intermediate determinants such as beliefs about self and/or world, or by activating coping processes such as life review, life planning, or identification with one’s culture. Coping processes are postulated to moderate beliefs about self and world. For instance, the coping process of life review may facilitate resolution of intrapersonal and interpersonal conflicts, thereby increasing an integrated sense of self that subsequently modifies one’s beliefs about the meaningfulness of death and life regrets.

Tomer and Eliason (1996, 2000a) encourage use of the model to examine several concerns related to death anxiety. First, they suggest that the model may be useful in examining changes in death anxiety across the life span. For instance, it has been
proposed that death salience changes throughout the life course. Coping processes also may change as individual’s endeavor to manage death anxiety. The authors also argue that the model may help bridge theory and practice. Therapists may find that increasing a client’s use of life review or self-transcending practices may facilitate a decrease in death fears. Finally, the authors note that reciprocal relationships among model variables may provide a better fit to data and may be tested using structural equation modeling.

One possible reciprocal relationship identified by Tomer and Eliason (1996) is that between death attitudes and experiences with death (e.g., death salience). That is, our experiences of grief and loss may affect our level of death anxiety, and our level of death anxiety may influence our ability to cope with grief and loss. The authors have articulated a comprehensive, testable model of death anxiety that integrates existing theories of death anxiety as well as general trends in research findings. The model holds promise as a conceptual tool for practitioners as well. The major limitation to the model at present is the lack of empirical research to support or lead to modifications of the model.

Tomer and Eliason (2000b) present the findings of a study of a simplification and modification of the full model among samples of young and older adults. The young adults were college student volunteers (n = 102, mean age = 19.98, SD = 3.07) while the older sample were individuals over age 55 recruited from communities in Central Pennsylvania (n = 89, mean age = 69.04, SD = 9.73). The simplified model tested by the authors excluded the two types of regret as well as coping processes in the model tested. Additionally, they collapsed beliefs about self and beliefs about the world into one
variable in the path analysis. Religiosity and the background characteristics of age, gender, and education were added as possible antecedents of beliefs about self and world, death attitudes, and death anxiety.

The authors tested the model using path analyses of the data from the two samples of adults. Prior to the path analysis, regression analyses were used to reduce the number of variables in the final path analyses. For instance, the measure of death anxiety was regressed on several indicators of death attitudes. Only one indicator of death attitudes, neutral acceptance of death (e.g., death is a natural part of life), reached significance at the $p < .01$ level, and was retained for the path analysis. The authors note that the reduction of model variables reduced the amount of variance explained in death anxiety by roughly three percent.

Path analyses were conducted to examine the fit of the data from the two samples to three formulations of the simplified conceptual model. The authors found the data best fit a model that imposed equal raw path coefficients between the endogenous variables (e.g., beliefs about self, beliefs about world, neutral acceptance, and death anxiety), but not for the relationships between the endogenous and the exogenous variables (e.g., between religiosity and neutral acceptance). While the raw path coefficients between the endogenous variables were constrained to be equal in the two samples, standardized coefficients differed due to the different standard deviations in the two samples. The results were rather complex, and are discussed below as they relate to the present study.

Within both samples of adults, relationships between indicators of beliefs about self and world with death attitudes were in the expected direction. That is, a positive relationship existed between positive beliefs about self and world and neutral acceptance.
of death. Some differences between younger and older adults were observed. The positive relationship between death salience and fear of non-being was stronger among older adults than among younger adults. That is, as older adults increase the contemplation of their own death the more fear of non-being they will report. Additionally, religiosity had a direct and positive relationship with older adults’ neutral acceptance of death but not with younger adults’ death attitudes.

This initial test of Tomer and Eliason’s (1996, 2000a) comprehensive model of death anxiety provided some support for the postulated relationships among death salience, beliefs about self and world, death attitudes, and death anxiety. The differences reported between older and younger adults suggest that a general model may not hold across age groups. The authors note that the pattern and magnitude of effect for some variables may differ by age group. Including larger samples, using multiple indicators of latent variables, and conducting structural equation modeling would strengthen future testing of the model. Additionally, Tomer and Eliason (2000b) did not report race/ethnicity of participants. Future research with an ethnically diverse sample may provide additional information on the effect of cultural worldviews on death attitudes and death anxiety.

The present study is based upon a portion of Tomer and Eliason’s (1996, 2000a) comprehensive model of death anxiety. Specifically, the present study seeks to examine the relationships among death salience, beliefs about self, and death attitudes among a sample of family caregivers of older adults. As discussed above, one assumption of the study is that providing care for an elderly loved one evokes death salience indicated by the health status of caregivers and their care recipients. The increased awareness of
mortality evoked by health concerns for one’s self and one’s family member is expected to impact a caregiver’s level of self-esteem and confidence in their ability to successfully complete the tasks of caregiving. These beliefs about self will then influence a caregiver’s attitudes toward death and their beliefs about coping with death. Two paths of the comprehensive model will be examined herein. First, indicators of death salience and beliefs about self will be regressed on a measure of coping with death to examine factors influencing positive death attitudes (Figure 2). Second, indicators of death salience, beliefs about self, and death attitudes will be regressed on a measure of fear of death to examine predictors of death anxiety (Figure 3).

2.3.4 Correlates of Death Anxiety & Death Attitudes

Death attitudes and death anxiety have been examined in relation to variables such as health status, self-esteem, age, occupation, religiosity, and adherence to cultural worldview (Fortner, Neimeyer, & Rybarczyk, 2000; Neimeyer, Wittkowski, & Moser, 2004). The following section reviews the relationships of death attitudes and death anxiety to occupation, age, gender, ethnicity, health status, and self-esteem.

Several studies have examined death attitudes among healthcare workers, hospice volunteers and others in death-exposure or death-risk occupations. Some authors have suggested that a self-selection effect may occur with respect to choice of specialty area within healthcare in particular. That is, individuals with greater death anxiety may be more likely to select specialty areas with less exposure to death (Bene & Foxall, 1991; Viswanathan, 1996). Although researchers found differences in mean levels of death anxiety by specialty area, often the mean scores were within the range of average scores for the general population (Bene & Foxall, 1991; Viswanathan, 1996). Lower mean
scores on a measure of death anxiety should not necessarily be taken as evidence of a relative lack of death anxiety. Additionally, as death attitudes are multidimensional in nature, additional examination of differences in the types of death attitudes held by members of various specialties is warranted.

Death attitudes among physicians have received a fair amount of attention in the literature. Researchers have found death anxiety to correlate with dimensions of personality including impression management, self-control, tolerance, empathy, and perceived responsibility for negative events (Firth-Cozens & Field, 1991; Vargo & Black, 1984). Additionally, Viswanathan (1996) found that physicians’ preferences for mode of communicating the news of a patient’s death to next of kin related to levels of death anxiety. Physicians who preferred to inform next of kin via telephone that their loved one had a “critical” status reported higher levels of death anxiety than did those who preferred to give a death status notification via telephone following the patients’ unexpected death. Furthermore, Schulz and Aderman’s (1978-79) study suggests that a patient’s length of hospitalization prior to death is related to the attending physicians’ level of death anxiety. Patients of physicians with higher levels of death anxiety were likely to be hospitalized longer than were patients of physicians with lower levels of death anxiety. The implicit assumption here seems to be that physicians with higher levels of death anxiety will attempt more treatments to prolong the death of their patients than will physicians with lower levels of death anxiety. Additional study is needed of the behaviors associated with different death attitudes among health professionals, especially with increasing use of advance directives and sophistication of health technology.
In addition to differences among workers in various specialty areas, there appears to be a relationship between length of service and levels of death anxiety and death competence (Amenta, 1984; Robbins, 1992). However, Amenta (1984) and Robbins (1992) reported evidence of a confounding effect of age. Longer-term hospice volunteers tended to be older than were shorter-term volunteers. These reports are consistent with the majority of the death anxiety literature, which generally indicates a negative relationship between death anxiety and age (Kalish & Reynolds, 1977; Rasmussen & Brems, 1996; Thorson & Powell, 2000; Thorson, Powell, & Samuel, 1998). Exceptions to this linear relationship have been documented. For instance, Gesser, Wong, and Reker (1987-88) found a curvilinear relationship of age and fear of death, where death fear was greatest among middle-aged adults. Additionally, Mullins and Lopez (1982) reported an increase in death anxiety among the oldest-old residents of three nursing homes, suggesting that death anxiety may increase again as one approaches the very end of life.

The relationship of death anxiety with demographic factors such as age, ethnicity, and gender has become more sophisticated as researchers utilize multidimensional measures of death attitudes. For instance, Thorson and Powell (2000) examined mean score differences between younger and older adults on the 25 items of the Revised Death Anxiety Scale. Older adults scored significantly higher on one item related to “taking care of business,” while younger adults scored significantly higher on 19 of the remaining items. Using the Death Attitude Profile – Revised, Wong, Reker, and Gesser (1994) found that older adults reported the lowest levels of fear of death, however their mean score did not differ significantly from that of middle-aged adults. Additionally, older adults scored higher than middle and younger adults on the Escape Acceptance
dimension, suggesting that older adults are more likely to believe that death will provide relief from physical pain. Thorson, Powell, and Samuel (1998) examined age differences in death anxiety among samples of younger and older African American women. Younger women scored significantly higher on items related to fear of pain and concerns about decomposition of the body following death.

DePaola, Griffin, Young, and Neimeyer (2003) and Cicirelli (2000) report differences between older African American and Caucasian participants on dimensions of the Multidimensional Fear of Death Scale (Hoelter, 1979; Neimeyer & Moore, 1994). In both studies, African American participants reported more fear of conscious dying while Caucasians reported more fear of the dying process. DePaola, Griffin, Young, and Neimeyer (2003) explain these differences in terms of different socialization practices related to health care decisions and end-of-life care among African Americans and Caucasians.

Overall, evidence of gender differences in death attitudes is mixed (Neimeyer, and Van Brunt, 1995). In their review of the literature on death anxiety and gender, Neimeyer and Van Brunt (1995) observe that studies conducted primarily with college student samples have found that women report higher levels of death anxiety than do men. Two explanations for these differences have been proposed. First, it has been suggested that women’s greater reports of death anxiety is consistent with women’s tendency to be more emotionally expressive. The second explanation is based upon the results of Wong, Reker, and Gesser (1994) that men may attempt to avoid thoughts of death and dying more than do women. Neither explanation has been supported fully. In support of a possible socialization effect, Firth-Cozens and Fields (1991) found that
As with differences in death attitudes by age, the particular death attitudes endorsed by women and men may differ. DePaola, Griffin, Young, and Neimeyer (2003) found that older women reported higher levels of fear of the dead. No other gender differences were found. Using the Death Attitude Profile-Revised, Wong, Reker, and Gesser (1994) reported that men and women did not differ significantly in their levels of death fear. However, women did report more approach acceptance than did men.

Results of studies of death attitudes and psychological health indicate low to moderate correlations with both general measures of psychological health and indicators of depression and anxiety. With respect to general psychological well-being, Wong, Reker, and Gesser (1994) found that a measure of psychological well-being had low to moderate correlations in the positive direction with approach acceptance and neutral acceptance and negatively with fear of death and death avoidance on the Death Attitude Profile—Revised. Furthermore, a measure of depression had low to moderate correlations negatively with approach acceptance and neutral acceptance and positively with fear of death. Thorson and Powell (2000), using the Death Anxiety Scale (Templer, 1970) also found a moderate positive correlation between depression and fear of death.

In their meta-analysis of eight death anxiety studies among older adults that measured general psychological functioning, Fortner, Neimeyer, and Rybarczyk (2000) reported a weighted average correlation of $r = .28$ ($p < .05$). Additionally, support for a relationship between death anxiety and trait anxiety has been reported in the literature. Neimeyer, Moser, and Wittkowski (2003) note that many instruments of death anxiety
“are designed to assess the fear of dying and/or death as a relatively stable personality
disposition (trait)” and may not be truly independent from general anxiety (p. 47).
Neimeyer and colleagues (Neimeyer, Wittkowski, & Moser, 2004) subsequently call for
the development of “causal models of how death fears either exacerbate or are aggravated
by other forms of psychological distress” to increase understanding of the relationship
between death attitudes and psychological well-being.

In addition to psychological well-being, researchers also have examined the
relationship of death attitudes to indicators of physical health. The results have been
rather mixed. Researchers working in the 1980s, largely using the Death Anxiety Scale
(Templer, 1970), found that individuals with more physical health concerns (e.g.,
smokers, limited functional ability) were likely to report more death anxiety (Kureshi &
Husain, 1981; Mullins & Lopez, 1982; and Viney, 1984). However, Robinson and Wood
(1984) found no differences in levels of death anxiety as measured by the Threat Index
(Krieger, Epting, & Leitner, 1974), Death Anxiety Scale, and Collett-Lester scale among
four samples of participants: “healthy” participants, individuals seeking routine medical
check-ups, individuals with rheumatoid arthritis, individuals with diabetes, and
individuals with cancer.

More recently, Wong, Reker, and Gesser (1994) reported a moderate negative
correlation between physical well-being and escape acceptance on the Death Attitude
Profile-Revised. This suggests that individuals experiencing greater frailty or physical
pain were more likely to indicate an acceptance of death as an escape from bodily
suffering. In their meta-analysis of correlates of global health measures with death
anxiety among older adults in twelve studies, Fortner, Neimeyer, and Rybarczyk (2000) reported a weighted average correlation of $r = .17$ ($p < .05$).

Cicirelli (2000) reported that physical health status predicted scores on two dimensions of death attitudes: fear of being destroyed and fear of the body after death. Additionally, Cicirelli found that the interaction of health and self-esteem was a significant predictor of the fear of premature death. Neimeyer, Wittkowski, and Moser (2002) observe that “it is probable that much of the ambiguity in these results derives from the failure of investigators to measure relevant moderator variables that interact with health status to determine personal fear of death” (p. 316).

Finally, fear of death has been correlated with self-esteem, largely under the terror management model proposed by Greenberg and colleagues (Greenberg, Solomon, & Pyszczynski, 1997; Pyszczynski, Greenberg, Solomon, Arndt, & Schimel, 2004). These authors have found support for the anxiety buffering function of self-esteem postulated by terror management theory. For example, individuals with higher dispositional self-esteem are less likely than individuals with lower dispositional self-esteem to experience increased anxiety following a threat to their mortality (e.g., Greenberg, Pyszczynski, Solomon, Pinel, Simon, & Jordan, 1993). From this perspective, self-esteem is likely to moderate the relationship between death salience and existential anxiety.

While the terror management perspective tends to conceive of death anxiety as operating at an indirect, or unconscious, level of awareness, other studies have measured death anxiety at a more direct, conscious level of awareness by using self-report measures of death anxiety such as Templer’s (1970) Death Anxiety Scale (DAS) and the Multidimensional Fear of Death Scale (MFODS; Hoelter, 1979; Neimeyer & Moore,
1994). Davis and colleagues (Buzzanga, Miller, Perne, Sander, & Davis, 1989; Davis, Martin, Wilee, & Voorhees, 1978; Miller, Davis, & Hayes, 1993) have reported negative correlations between the Texas Social Behavior Inventory (a measure of self-esteem and social confidence; Helmreich & Stapp, 1974) and the DAS among three samples of undergraduate students. Additionally, analyses of variance have indicated a significant interaction effect between self-esteem and death anxiety where individuals with low self-esteem report more death anxiety than do high self-esteem individuals (Buzzanga et al., 1989; Davis et al., 1978).

Cicirelli (2002) sought to examine several hypotheses derived from terror management theory among older adult participants. Additionally, the author wanted to test hypotheses drawn from terror management theory using more direct, or conscious, measures of death anxiety. Cicirelli measured fear of death with the MFODS, which includes eight subscales such as Fear of the Dying Process and Fear of the Unknown. Analysis of the factor structure of the MFODS for Cicirelli’s sample indicated a two-factor solution. The Fear of the Unknown subscale loaded separately from the seven remaining subscales, which formed a second factor that Cicirelli labeled as Fear of the Known.

Cicirelli argued that the Fear of the Unknown factor most closely coincides with fear of annihilation, postulated by terror management theory to be the primary element of existential fear. Therefore, correlational and regression analyses that demonstrate a significant relationship between self-esteem and fear of annihilation would provide support for the terror management hypotheses. Weak, negative correlations of self-esteem with Fear of the Unknown ($r = - .11, p < .05$) and Fear of the Known ($r = - .11, p < .05$)
were reported. Contrary to terror management hypotheses, regression analyses indicated that self-esteem was not a significant predictor of either death fear factors. External locus of control appeared to mediate the relationship between self-esteem and death anxiety when examined with a path analysis.

The results provide partial support for hypotheses garnered from terror management theory. While a weak correlation was found between self-esteem and fear of annihilation, self-esteem was not found to be a significant predictor of Fear of the Unknown. Cicirelli (2002) proposes two potential explanations for these findings. First, he suggests that self-esteem influences suppression of death fear outside of one’s conscious awareness and that other variables influence death fears dealt with at the level of conscious awareness. Cicirelli reasoned that because he assessed death fear at a conscious level, the effect of self-esteem on death anxiety among his participants was weak. Second, “self-esteem may not be an important variable in relation to fear of death in a population of older adults except in terms of its indirect effect” (p. P364). With respect to the present study, Cicirelli’s (2002) findings suggest that a weak negative correlation may be expected between self-esteem and the Fear of Death subscale of the Death Attitudes Profile—Revised (Wong, Reker, & Gesser, 1994).

2.3.5 Summary

The present study considers death attitudes and death anxiety to be distinct, though related constructs. Death anxiety refers to a specific subset of death attitudes characterized by negative affective reactions such as fear, apprehension, threat, or discomfort. Death attitudes are conceptualized as a broader term encompassing death anxiety. Death attitudes, in general, refer to the positive and negative attributions (with
both cognitive and affective dimensions) that an individual consciously makes about death. Death attitudes are assumed to directly influence one’s level of conscious death anxiety.

Additionally, based upon Tomer and Eliason’s (1996, 2000a) comprehensive model of death anxiety, death salience is postulated to influence an individual’s death attitudes through her or his self-beliefs, such as self-esteem and self-efficacy. While death attitudes have been studied among college students and health care professionals, the death attitudes of informal caregivers of frail older adults have not been examined. The present study sought to extend the study of death attitudes to the experiences of caregivers of older adults. Moreover, the present study utilized regression analyses to test predictors of death attitudes and death anxiety based upon Tomer and Eliason’s comprehensive model of death anxiety.
CHAPTER 3

METHOD

3.1 Participants

Participants were recruited from eleven adult day programs affiliated with the Ohio Association of Adult Day Services (OAADS). The Ohio Association of Adult Day Services is a non-profit organization providing resources for professionals in the field of adult day services in the state of Ohio. Association members were provided with information on this study and invited to assist this researcher with participant recruitment at their April 2005 board meeting (Appendix A). Participating members were asked to mail questionnaire packets to their clients at the researchers’ expense, and to include a cover letter to their clients acknowledging the program’s support of the present study. Packets included a letter from the researcher to describe the study (Appendix B) and a debriefing letter (Appendix C) in addition to the questionnaire. The researcher provided participants with a postage-paid return envelope for completed questionnaire packets.

A total of 974 packets were distributed across the eleven programs, ranging from five packets at a small, rural program to 317 at a large, urban adult day program. It is possible that some packets distributed to a program were not mailed to prospective participants. A method for identifying such cases was not established. Two hundred
twenty-two packets were mailed back to the researchers. An additional 25 packets were returned to the researchers as undeliverable. Of the 225 returned packets, 22 were excluded due to an excess of missing data. In total, 203 participants sufficiently completed packets for use in the following analyses, representing a response rate of 20.8%. A review of the research literature describing the response rates of mail surveys to caregivers and/or the elderly indicated that response rates ranged from 9% to 55% (Jacoby, Lecouturier, Bradshaw, Lovel, & Eccles, 1999; Nemet & Bailey, 2000; Small, McDonnell, Brooks, & Papadopoulos, 2002; and Stebbins & Pakenham, 2001).

A summary of demographic information about the caregivers and their care recipients is provided below. Not all of the 203 caregivers in the final sample provided all demographic information. The fewest responses given were for an item requesting information about annual income; twenty caregivers failed to indicate their income level (N = 183). Caregivers’ age averaged 60.7 years (SD = 12.98) and ranged from 27 to 95 for 199 respondents. Care recipients’ mean age was 77.8 years (SD = 13.08) with a maximum age of 103 (N = 195). Caregivers were predominantly female (N = 159 for women vs. N = 41 for men), while care recipients’ gender was more evenly distributed (N = 114 women vs. N = 82 men). Three caregivers did not report their gender and seven did not report their care recipient’s gender.

With respect to race/ethnicity, caregivers identified themselves predominantly as European American/White (N = 123), African American (N = 45), or Native American (N = 19). Eight individuals identified their race/ethnicity as either Asian American/Pacific Islander or Other. Eight caregivers chose not to respond to this question. Similarly, care recipients’ race/ethnicity was identified as European American/Pacific Islander or Other.
American/White (N = 121), African American (N = 43), or Native American (N = 16). Eleven caregivers reported their care recipients’ race/ethnicity as Arab American, Asian American/Pacific Islander, or Other. Twelve caregivers did not report their care recipient’s race/ethnicity.

All but four individuals reported the nature of their relationship to the care recipient. Most caregivers identified as an adult child (N = 96), followed by spouse (N = 72), and other (N = 31). Examples of other relationships included niece and friend. When caregivers wrote in that they were the daughter-in-law or son-in-law of the patient, the kin relationship was coded as an adult child. Most caregivers reported that the care recipient lived with the caregiver (N = 153), while 29 patients live in their own home, 3 live in nursing homes, 1 lives in an assisted living center, and 8 had other living arrangements. Caregivers (80.7%) and care recipients (77.9%) lived primarily in urban or suburban settings.

Most caregivers had completed high school or at least some post-secondary education (93%), whereas nearly 30% of care recipients were reported to have less than a high school education. Eighty-eight caregivers indicated that they work at least part time, while 110 caregivers were not presently working. Those not presently employed identified their work status as a full time homemaker (N = 23), retired (N = 70), or unemployed (N = 17). Caregivers were asked to indicate their income in categories ranging from “less than $19,999” to “more than $100,000.” Over half of the caregivers responding to this item reported an annual income of less than $40,000.

Caregivers indicated the total time they have provided care in categories ranging from “0 to 1 year” to “more than 5 years.” Space was provided for caregivers to write-in
the total time beyond five years that care has been provided. The write-in values ranged from 6 years to 65 years for one caregiver’s adult child with mental retardation/developmental disabilities. The median value for the total time providing care is reported due to the extreme outliers. The average time of care provided was four years, which is consistent with data based on a national sample (National Alliance for Caregiving & AARP, April, 2004).

Most caregivers (N = 112) reported providing care for more than 40 hours per week. Self-reports of average care time per week are subject to response biases and fail to accurately assess the specific types of care activities caregivers complete during a week. Caregivers also reported the time their care recipient spends at an adult day program during an average week. Many caregivers reported using an adult day program for more than 30 hours per week (N = 60), while 76 caregivers reported using adult day programs for 15 hours or less during a week. Aside from an adult day program, friends and family members were identified as a source of respite by 107 caregivers.

3.2 Instruments

Participants completed the following self-report instruments: Coping with Death Scale (Appendix D; Bugen, 1980-81; Robbins, 1994), Death Attitude Profile – Revised (Appendix E; Wong, Reker, & Gesser, 1994), RIS Eldercare Self-Efficacy Scale (Appendix F; Gottlieb & Rooney, 2003), Rosenberg’s Self-Esteem Scale (Appendix G; Rosenberg, 1965), and the SF-12v2 Health Survey (QualityMetric Incorporated, 2000). The SF-12v2 Health Survey is not presented in an appendix due to copyright restrictions. Caregivers also completed the Index of Activities of Daily Living (Appendix H; Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) and the Revised Memory and Behavior
Problems Checklist (Appendix I; Teri, Truax, Logsdon, Uomoto, Zarit, & Vitaliano, 1992) as assessments of the care recipients’ level of physical and cognitive functioning. The Revised Memory and Behavior Problems Checklist also assessed caregivers’ degree of upset from the cognitive and behavioral problems evidenced by care recipients. Additionally, participants provided demographic information (e.g., age, gender, SES, race/ethnicity), information regarding the age, gender of their care recipient, and information regarding the length and type of caregiving services they provide to their elderly relative (Appendix J).

The SF-12v2 was administered first in accordance with recommendations by the scale’s authors (SF-36.org, n.d.), while the measures of death attitudes were administered last. The authors of the SF-12v2 recommend administering their scale first in a battery of instruments to be consistent with administration standards followed when normative data were gathered. Researchers from a terror management theory perspective have used death attitudes/death anxiety measures as a way to operationally define mortality threat (Greenberg, Solomon, & Pyszczynski, 1997). Because mortality threat can affect subsequent reports of self-esteem and strength of adherence to values consistent with one’s worldview (e.g., caregiver self-efficacy), the two death attitudes measures were administered last.

One hundred copies each of ten versions of the questionnaire packet were created; the SF-12v2 was administered first and the two death attitudes measures were administered last. For each of the ten packet versions, the remaining instruments were assigned a number, and a random number generator determined the order of administration in between the SF-12 and the two measures of death attitudes. For
example, in one version, instruments were administered in the following order: SF-12v2, Rosenberg’s Self-Esteem Scale, Revised Memory and Behavior Problems Checklist, Index of Activities of Daily Living, RIS Eldercare Self-Efficacy Scale, demographic questionnaires, Coping with Death Scale, and Death Attitude Profile – Revised.

3.2.1 Death Attitudes

Two instruments were used to assess death attitudes: Bugen’s Coping with Death Scale (CDS; Bugen, 1980-81) and the Death Attitude Profile – Revised (DAPR; Wong, Reker, & Gesser, 1994). Bugen’s (1980-81) Coping with Death Scale was developed to assess coping abilities achieved through death education courses. The CDS is a thirty-item measure of coping skills associated with one’s own death and the death of others. Participants indicate their responses on a Likert-type scale ranging from 1 (“do not agree at all”) to 7 (“agree completely”). Sample items include: “I have a good perspective on death and dying,” “I understand my death related fears,” “I know who to contact when death occurs,” and “I can communicate with the dying.” For the present study, item responses were summed and divided by the number of items to yield a mean score for each participant. Higher scores indicate greater coping abilities.

Robbins (1990-91, 1994) examined evidence of the reliability and validity of the CDS among samples of undergraduate and graduate students and hospice volunteers. The CDS demonstrated a Cronbach’s alpha of .89 among a sample of undergraduate and graduate students (Robbins, 1990-91) and a Cronbach’s alpha of .90 among a sample of 320 hospice volunteers (Robbins, 1994). Internal consistency reliability for the present
study was $\alpha = .93$. Robbins (1990-91) also examined the test-retest reliability. Fifty-three participants completed the retest after an eight-week interval. The test-retest reliability reported was $r = .91$.

Bugen (1980-81) and Robbins (1990-91) also evaluated the validity of the Coping with Death Scale. For instance, Bugen reported that students enrolled in a death education course indicated increases in their ability to cope with death and dying in comparison to a control group. Robbins found that four out of five single-item measures of “effectiveness in living” constructs, such as competence, assertiveness, and purpose in life, were moderately and positively correlated with the CDS, but did not demonstrate significant correlations with two measures of death anxiety. Additionally, measures of specific death preparatory behaviors (e.g., estate planning, will writing, and organ donation) also were correlated more highly with coping with death and less so with two death anxiety measures. While the single item measures of life skills and death preparatory behavior have questionable reliability, this represents a positive first step toward examining behavioral outcomes of death attitudes.

Additionally, Robbins (1990-91) tested the convergent and discriminant validity of the CDS. Moderate, and significant, correlations with two other measures of death anxiety – Templer’s (1970) Death Anxiety Scale, and the Collett-Lester scales of fear of death and dying for self and other – support the convergent validity of the CDS. To evaluate discriminant validity, Robbins examined the relationship of the CDS to Spielberger’s (1983) State-Trait Anxiety Inventory and the Marlowe-Crowne Scale of Social Desirability. Social desirability and general anxiety have been associated with measures of death concern (Kastenbaum & Costa, 1977). No relationship was found
between the CDS and the measure of social desirability. However, state anxiety and trait anxiety were both significantly and moderately negatively correlated with coping with death.

Robbins (1990-91) suggests that these results indicate that discriminant validity was demonstrated partially. Many instruments of death anxiety “are designed to assess the fear of dying and/or death as a relatively stable personality disposition (trait)” and may not be truly independent from general anxiety (Neimeyer, Moser, & Wittkowski, 2003; p. 47). Additionally, the relationship of death concerns to social desirability may be explained by gender differences in reporting difficult emotions, such as anxiety. This explanation has been used to account for the consistent findings of a gender difference in reported death attitudes and death anxiety, where women report greater death fears and anxiety than do men (Neimeyer & Van Brunt, 1995).

The Coping with Death Scale demonstrates promise as an assessment of family caregivers’ death attitudes for three reasons. First, unlike many death attitude scales, the CDS assesses death attitudes more broadly. For instance, the CDS measures positive and negative attitudes toward the death and dying of one’s self and that of others. Additionally, items on the CDS assess specific death-related behaviors in addition to the respondent’s thoughts and feelings about death. Second, the CDS has evidenced adequate reliability and validity among volunteer caregivers of terminally ill patients, a sample one might expect to have experiences similar to family caregivers of frail elderly.

Finally, the CDS may be valuable as a screening tool for and outcome measure of interventions for caregivers due to its apparent relationship to level of death experience. Furthermore, because experience is more predictive of self-efficacy than is anxiety
(Bandura, 1997), the CDS may be more strongly related to measures of caregiver self-efficacy and coping self-efficacy than would measures of death anxiety (Robbins, 1990-91, 1991, 1994). In fact, Robbins (1994) found that healthcare workers participating in a self-efficacy theory-based training for discussing organ donation with family members “increased their perceived self-efficacy for offering the opportunity of donation and for dealing with donation as a personal issue. Most important, the interventions also resulted in increased donation-related behavior [among study participants]” (p. 159). The Coping with Death Scale is a promising measure of broad death-related attitudes, especially those related to perceived competence with death.

In addition to the CDS, participants completed the Death Attitude Profile-Revised (DAPR; Wong, Reker, & Gesser, 1994). Wong and colleagues developed the original Death Attitude Profile (Gesser, Wong, & Reker, 1987-88) to expand the measurement of death attitudes to positive dimensions such as death acceptance. Consistent with an existential theoretical framework, which posits that individuals are motivated to pursue personal meaning (Frankl, 1963), individuals who have made meaning of the fact of their mortality are likely to have come to some level of acceptance of death. Death anxiety and death acceptance may co-occur. Wong, Reker, and Gesser (1994) argue, “It would not be fruitful to study fear of death in isolation. It is possible that the same level of fear of death may reflect very different death attitudes…Therefore, it is the patterns of different death attitudes rather than the magnitude of a single death attitude that best captures individual differences” (p. 141).

The Death Attitude Profile - Revised was developed and initially validated with a sample of 100 young adults (ages 18-29), 100 middle-aged adults (ages 30-59), and 100
older adults (ages 60-90) recruited among the residents of a mid-sized city (Wong, Reker, & Gesser, 1994). The DAPR is a 32-item scale that assesses five dimensions of death attitudes: fear of death, death avoidance, neutral acceptance, approach acceptance, and escape acceptance. These five dimensions represent both positive attitudes toward death (acceptance subscales) and negative attitudes toward death (fear and avoidance subscales). Sample items include “Death is no doubt a grim experience” (Fear of Death), “I avoid death thoughts at all costs” (Death Avoidance), “Death is neither good nor bad” (Neutral Acceptance), “I believe that I will be in heaven after I die” (Approach Acceptance), and “Death will bring an end to all my troubles” (Escape Acceptance).

Participants indicate their responses on a 7-point, Likert-type scale ranging from “strongly disagree” to “strongly agree.” Scores for each subscale are summed and divided by the number of items to yield a mean subscale score for each participant. Higher scores indicate more acceptance, fear, or avoidance. In the present study, internal consistency reliability of the five subscales, as indicated by Cronbach’s alpha, ranged from $\alpha = .93$ (approach acceptance) to $\alpha = .53$ (neutral acceptance). Wong, Reker, and Gesser (1994) report internal consistency reliabilities ranging from $\alpha = .97$ (Approach Acceptance) to $\alpha = .65$ (Neutral Acceptance) among the validation sample. A subgroup (N = 90) of the original sample was administered the DAPR after a four-week period. Test-retest reliability for the five subscales ranged from $r = .95$ (Approach Acceptance) to $r = .61$ (Death Avoidance).

A principal components factor analysis of the 32 items yielded a five-factor solution accounting for 66.2% of the variance (Wong, Reker, & Gesser, 1994). Items on the five factors corresponded to the expected dimensions of death attitudes. In an
independent examination of the factor structure of the DAPR, Clements and Rooda (1999-2000) reported a six-factor solution where items on Wong et al.’s (1994) Neutral Acceptance subscale loaded on two separate factors. Clements & Rooda’s results, along with the relatively low internal consistency reported by Wong et al. (1994), suggest that the Neutral Acceptance subscale measures more than one construct. The four other subscales appear to have adequate levels of internal consistency.

Examination of the internal consistency and factor structure of the DAPR were conducted prior to subsequent analyses in the present study. As indicated above, the internal consistency reliability of the neutral acceptance subscale was consistent with the low reliability reported by Wong, Reker, & Gesser (1994), and less than the value recommended for use in research (Nunnally & Bernstein, 1994). Consistent with the analysis of Clement and Rooda (2000), principal components analysis of the 32 items yielded a six-factor solution accounting for 64.6% of the variance. The five items of the neutral acceptance subscale loaded on two separate factors. Due to the evidence that the neutral acceptance subscale measures more than one construct the subscale was not used in subsequent analyses.

3.2.2 Caregiving Self-Efficacy

Caregiving self-efficacy refers to a caregiver’s perceived confidence in performing and managing the behaviors associated with providing care for her or his loved one. In the present study, the RIS Eldercare Self-Efficacy Scale (Gottlieb & Rooney, 2003) was employed to measure caregiving self-efficacy. The RIS Eldercare
Self-Efficacy Scale is a self-report, paper-and-pencil administered instrument designed to assess three dimensions of caregiving self-efficacy among family caregivers of elderly dementia patients.

The three dimensions of caregiving self-efficacy are: (1) relational self-efficacy, beliefs about one’s ability to maintain a cooperative relationship with the care patient; (2) instrumental self-efficacy, beliefs about one’s ability to perform tasks associated with direct patient care; and (3) self-soothing self-efficacy, beliefs about one’s ability to maintain one’s physical, emotional, and social needs during the stressful experience of caregiving (Gottlieb & Rooney, 2003).

The scale was developed and validated using a sample of family caregivers of dementia patients residing in an urban area of Canada. The RIS Eldercare Self-Efficacy Scale consists of ten items. Three items are included in the instrumental self-efficacy subscale (e.g., “Improve/Solve caregiving problem”) and relational self-efficacy subscales (e.g., “Make time with relative enjoyable”), whereas the self-soothing self-efficacy subscale consists of the remaining four items (e.g., “Obtain help and support when wanted”). Participants rate their level of perceived self-efficacy for each item using a 5-point Likert-type scale ranging from 1 (“I’m certain I can’t do this”) to 5 (“I’m certain I can do this”). Higher scores indicate greater levels of caregiving self-efficacy.

Evidence of the reliability and validity of the RIS Eldercare Self-Efficacy Scale has been obtained with two separate samples of family caregivers (Gottlieb & Rooney, 2003, 2004). Gottlieb and Rooney (2003) provide information on the test-retest reliability and internal consistency reliability of the three RIS Eldercare Self-Efficacy subscales. To examine test-retest reliability, Gottlieb and Rooney asked participants to complete the
The construct validity of the three dimensions of self-efficacy has been examined with respect to health status, coping efficacy and effectiveness, personality traits, and perceived social support (Gottlieb & Rooney, 2003, 2004). Correlations of the three self-efficacy subscales with negative health outcomes were small to moderate and negative, while correlations with positive health outcomes were small to moderate and positive. The three dimensions of self-efficacy also related significantly and positively with measures of coping efficacy, and relational and instrumental self-efficacy related significantly and positively with coping effectiveness (Gottlieb & Rooney, 2004). Gottlieb and Rooney (2003) reported a moderate correlation between self-soothing self-efficacy and perceived social support. Finally, all three dimensions of caregiving self-efficacy related significantly to personality traits such as optimism, agreeableness, and conscientiousness. In sum, the RIS Eldercare Self-Efficacy Scale demonstrates adequate reliability for use in research, as well as initial evidence of construct validity with respect to behavioral and health outcomes, personality traits, and social support.

While the RIS Eldercare Self-Efficacy Scale demonstrates adequate psychometric properties for use in research, limitations of the two development and validation studies
(Gottlieb & Rooney, 2003, 2004) suggest using the scale with caution. First, the initial development sample (Gottlieb & Rooney, 2003) was primarily female (73%), identified largely as Jewish (nearly 90%), and of higher socioeconomic status as measured by yearly income (71% with incomes greater than $70,000 per year) and level of educational attainment (over 45% with or beyond a college or university degree). The sample of the second study (Gottlieb & Rooney, 2004) evidenced many of the same limitations. It is unclear if the second study heavily sampled particular ethnic or religious groups because the authors failed to report this information.

A second limitation is that the items sample only a limited and somewhat general array of possible caregiving behaviors. Bandura (1997) observes, “precision may be sacrificed for brevity by the use of general brief measures that skimp on the range of task demands for which self-efficacy is judged and that remove the contexts in which the activities are performed” (p. 50). An additional limitation of the RIS Eldercare Self-Efficacy Scale in the context of the present study is that the scale focuses on caregiving for relatives with dementia. While the present study proposes to control for the cognitive limitations and problematic behavior of care recipients, caregivers in the present study may or may not provide care for a relative with a diagnosis of dementia. However, given the greater ease of administration and more general nature of items, the author has elected to use the RIS Eldercare Self-Efficacy Scale in the present study. Interpretations of data will be made with care given the limitations addressed above.

3.2.3 Self-Esteem

Rosenberg’s (1965) Self-Esteem Scale (SES) originally was designed to assess global self-esteem among adolescents (Appendix G), but has been used regularly among
adult samples. Participants respond to each of the ten items on a four-point scale ranging from 1 (“strongly disagree”) to 4 (“strongly agree”). Sample items include “On the whole, I am satisfied with myself,” and “I certainly feel useless at times.” Negatively worded items are reverse-scored. Responses are summed, with higher scores indicating greater self-esteem. In their review of the SES, Blascovich and Tomaka (1991) report internal consistency reliability (Cronbach’s alpha) ranging from .77 to .88, and test-retest reliabilities after a two-week interval of .85 among a sample of 28 participants.

Rosenberg’s Self-Esteem Scale has demonstrated positive correlations with indicators of mental and physical health (Rosenberg, Schooler, Schoenbach, & Rosenberg, 1995), physical and psychosocial functioning (Forthofer, Janz, Dodge, & Clark, 2001), meaning in caregiving (Noonan & Tennstedt, 1997), and negative correlations with indicators of death anxiety (Cicirelli). Crespo, Lopez, and Zarit (2005) reported that low self-esteem among a sample of caregivers was a significant predictor of both self-reported depressive and anxiety symptoms. Internal consistency reliability for the present study was $\alpha = .92$.

3.2.4 General Health Status

Health status was assessed by the Medical Outcomes Study 12-item Short-Form Health Survey, version 2 (SF-12v2®; Ware, Kosinski, Turner-Bowker, & Gandek, 2002). The SF-12v2® is a shortened form of the SF-36®, a 36-item generic health survey tool used to assess health in the Medical Outcomes Study (Tarlov, Ware, Greenfield, Nelson, Perrin, & Zubkoff, 1989). The SF-12v2® was designed for self-administration, and takes approximately 2 to 3 minutes to complete. Both the SF-36® and SF-12v2® are recommended for studies where there is an interest in detecting small group differences.
The SF-12v2® has been selected for use in the current study for its shorter administration time that will limit the burden placed on participants. As stated above, the developers of the SF-12v2® and SF-36® have recommended administering their instruments first in a battery of tests in order to “be consistent with the standard followed when normative SF-36® data were gathered” (SF-36.org, accessed February 2005).

The SF-12v2® is a 12-item scale that assesses eight health concepts: (1) limitations in physical functioning; (2) limitations in social functioning; (3) limitations in mental health; (4) limitations in role activities due to physical health problems; (5) limitations in role activities due to mental health problems; (6) bodily pain; (7) vitality (energy and fatigue); and (8) perceptions of general health. The 12 items are grouped into seven sections with different response options. For example, two items assess limitations in activity level due to health with response options of “yes, limited a lot,” “yes, limited a little,” and “no, not limited at all.” Alternately, the response options for a single pain assessment item range from “not at all” to “extremely.”

In addition to the eight health concept scores, the SF-12v2® includes two summary scales: the Physical Component Summary (PCS) and the Mental Component Summary (MCS). Summary scores were used in the present study following the developers’ recommendation to use summary scores when limiting the number of outcomes and when a general effect in physical and mental functioning is expected (http://www.sf-36.org/faq/generalinfo.aspx?id=4). The present study utilized the four-week recall version due to the interest in chronic health status of family caregivers versus acute health status. Instructions for norm-based scoring of the SF-12v2® provided in the
user’s manual were followed herein (Ware, Kosinski, Turner-Bowker, & Gandek, 2002). Norm-based scores are standardized to a mean of 50 and standard deviation of 10.

Evidence of the reliability and validity of version 2 of the 12-Item Short Form Survey is provided in the user’s manual. Evaluations were conducted with data from the 1998 general U.S. population and Medical Outcomes Study. The authors used covariances among scale scores to estimate the reliability of the Physical Component Summary (PCS) and Mental Component Summary (MCS). Reliability estimates for the PCS was 0.89 (N = 6917) and for the MCS was 0.86 (N = 6924).

Evidence of the validity of the PCS and MCS was examined by way of the “four groups test” (Ware et al., 2002; p. 126), that is, the ability of the SF-12v2® to differentiate between patients in four mutually exclusive groups. Performance of the SF-12v2® was compared to that of the SF-36® and SF-12, version 1 (Ware, Kosinski, & Keller, 1996). Participants reported the number of chronic conditions they had from a list of 18 provided by the authors. Groups of participants were defined as follows: (1) “well” individuals reported none of the 18 chronic conditions; (2) “physical only” individuals reported one or more chronic condition, except depression; (3) “mental only” individuals reported depression and no other chronic condition; and (4) “physical and mental” individuals reported depression plus one or more of the other chronic conditions.

Analyses of variance were conducted to evaluate mean differences on the summary scales for the four groups. Results indicated that the SF-12v2® performed better than the original SF-12® on both the physical and mental health summary scores, but not as well as the physical and mental health summaries derived from the full SF-36®.
Caregivers’ health status has been assessed with various Short Form surveys by several authors. For instance, Bruce, Paley, Nichols, Roberts, Underwood, and Schaper (2005) used the SF-12v1® PCS and MCS to assess health status among a sample of Australian caregivers of dementia patients. Scores on the mental health summary score were lower than population norms, indicating that caregivers’ mental health was more impaired than among the general population. Furthermore, MCS scores were related to self-reported levels of stress and use of medications for a “nervous disorder.” Physical health summary scores were comparable to population norms, yet 30% of respondents reported severe disability. Caregivers’ PCS scores were correlated positively with age, self-reported physical health problems, and self-reported stress.

Among a Swedish sample of informal caregivers, low mental health summary scores on the SF-12v1® were predicted by caregivers’ adapting their own activities to fulfill caregiving duties, financial strain, keeping contact at least weekly with the care recipient, and caregivers’ own limitations in instrumental activities of daily living (Ekwall, Sivberg, & Hallberg, 2004). Low physical health summary scores in the Swedish sample were predicted by financial strain, providing assistance with care recipients’ instrumental activities of daily living, and caregivers’ own limitations in instrumental activities of daily living.

Finally, De Frias, Tuokko, and Rosenberg (2005) used the SF-36® in their study of mental and physical health predictors of reactions to caregiving. Better mental health among caregivers was related to less subjective burden and greater self-esteem, as well as to care recipient mental health. Furthermore, caregivers’ self-reported health status related to reporting fewer health problems as a result of caregiving.
3.2.5 Activities of Daily Living

The Index of Activities of Daily Living (ADL; Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) is a caregiver rated assessment of a frail elder’s ability to perform six functional activities of daily living (Appendix H). The six functional areas include bathing, dressing, feeding, toileting, transferring from bed or chair, and continence. Patients’ abilities are rated either as dependent (requiring full assistance) or independent (requiring no supervision, direction, or active assistance, except as specified). Definitions of independence differ depending upon the task being evaluated. For instance, independent bathing may include receiving assistance for bathing a single part of the body, whereas independent transferring specifically excludes assistance other than from mechanical supports (e.g., a brace or walker). Scores range from 0 to 6, where higher scores indicate greater impairment. Instructions for scoring are found in Appendix H.

3.2.6 Cognitive Status & Problematic Behavior

The Revised Memory and Behavior Problems Checklist (RMBPC; Teri, Truax, Logsdon, Uomoto, Zarit, & Vitaliano, 1992) is a 24-item, caregiver-report measure of observable memory disturbances and behavioral problems of care recipients with dementia (Appendix I). Caregivers rate the behavior’s frequency within the past week on a five-point Likert-type rating scale ranging from 0 (“never occurred”) to 4 (“daily or more often”). Higher scores indicate greater frequency of problematic behaviors. Caregivers also have the response option of “don’t know/not applicable.” Examples of items include: “losing or misplacing things,” “destroying property,” and “commenting about death of self or others (e.g., ‘Life isn’t worth living,’ ‘I’d be better off dead’).”
Additionally, the RMBPC assesses the burden of these behaviors on caregivers by asking caregivers to report how much each of the 24 behaviors have bothered or upset them during the past week. The caregiver reaction rating also is made on a five-point Likert-type scale ranging from 0 (“not at all”) to 4 (“extremely”). Higher scores indicate greater caregiver burden due to the problematic behaviors of the care recipient. Thus, the RMBPC provides a measure not only of care recipients’ cognitive status and problematic behaviors but also of the subjective burden experienced by caregivers.

While a three-factor solution to the RMBPC structure has been reported for both the frequency and reaction ratings (Johnson, Wackerbarth & Schmitt, 2000; Roth, Burgio, Gitlin, Gallagher-Thompson, Coon, Belle, Stevens, & Burns, 2003; and Teri et al, 1992), only total score for the frequency and reaction ratings were considered in the present study. It was determined that the addition of six rather than two subscales would place more restrictions on the power of statistical analyses than what was deemed acceptable. For the present study, scores were totaled separately for objective burden (frequency ratings) and subjective burden (reaction ratings). Internal consistency reliabilities for the two scales were $\alpha = .89$ (objective burden) and $\alpha = .91$ (subjective burden).

3.3 Data Analyses

Statistical analyses began with the calculation of means, standard deviations, and internal consistency reliability coefficients for each of the instruments described above. Multivariate analyses of variance (MANOVA) allowed for comparisons of mean scores based on gender and kin relationship for each of the instruments. Correlational analyses were employed to examine the interrelationships among the measures included in the
study. Correlations among the various measures were calculated separately for males and females as well as for adult child and spousal caregivers.

Hierarchical regression analyses were conducted to examine predictors of caregivers’ scores on coping with death and fear of death. Predictor variables were selected based upon previous research and consistent with Tomer and Eliason’s (1996, 2000a) comprehensive model of death anxiety. Tomer and Eliason’s model suggests that death attitudes (i.e., meaningfulness of death) are indirectly influenced by death salience through beliefs about self. Background characteristics such as caregivers’ age, gender, relationship to care recipient, and total time providing care were included in the first block of the regression analyses. Indicators of death salience and beliefs about self were added in the second and third blocks, respectively. Mediating effects of significant predictors from among the indicators of beliefs about self were examined to further test Tomer and Eliason’s model.

Several hypotheses were made with respect to relationships among study variables and coping with death. Age and total time providing care were expected to have positive relationships to coping with death. Negative influences on coping with death were anticipated for activities of daily living limitations, subjective burden and objective burden, while mental health and physical health were expected to have a positive effect on coping with death. Positive influences on coping with death were expected for the four beliefs about self factors (i.e., self-esteem, relational self-efficacy, instrumental self-efficacy, and self-soothing self-efficacy).

Hierarchical regression analyses also were conducted to examine predictors of death anxiety, as indicated by the fear of death subscale. In this second analysis, fear of
death was regressed on caregiver and care recipient background characteristics and indicators of death salience, beliefs about self, and positive death attitudes (e.g., coping with death, approach acceptance). Negative regression weights were expected for age and total time providing care. Additionally, positive death attitudes and beliefs about self were hypothesized to have negative relationships with fear of death. Among the indicators of death salience, mental health and physical health were expected to relate negatively to fear of death, while functional limitations and subjective and objective burden were expected to relate positively to fear of death.

In summary, analyses of the data encompassed several techniques. The present study evaluated mean scores and correlation coefficients among the instruments. A Multivariate Analysis of Variance was conducted to compare respondents’ mean scores for each measure based on kin relationship and gender. Finally, hierarchical regression analyses will be conducted to examine predictors of coping with death and fear of death intended to provide supportive evidence of two pathways of Tomer and Eliason’s (2000) comprehensive model of death anxiety.
CHAPTER 4

RESULTS

Table 1 presents the means and standard deviations for each of the manifest variables based upon all 203 participants’ responses. A mean of 3.75 on the Index of Activities of Daily Living Scale indicates limitations in at least bathing, dressing, and one additional function, which may include toileting, feeding, continence, or transferring to and from a chair. Mean scores on the measures of objective and subjective burden are consistent with those reported for the initial validation sample of caregivers of dementia patients (Teri, Truax, Logsdon, Uomoto, Zarit, & Vitaliano, 1992). Caregivers reported an average physical health summary score of 48.17 (SD = 11.84) and mental health summary score of 41.07 (SD = 7.78). Comparisons of the mean physical and mental health scores obtained from this sample were made with the norms for the general U.S. population in 1998 (physical health M = 49.63, SD = 9.91; mental health M = 49.37, SD = 9.75). An independent sample t-test (Glass & Hopkins, 1984) indicated that caregivers report less psychological well-being than that of a normative sample of nearly 7000 adults aged 18 and over (Ware, Kosinski, Turner-Bowker, & Gandek, 2002).
<table>
<thead>
<tr>
<th>Variable</th>
<th>Overall Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Death Salience</td>
<td></td>
</tr>
<tr>
<td>Activities of Daily Living</td>
<td>3.75 (2.18)</td>
</tr>
<tr>
<td>Objective Burden</td>
<td>33.89 (15.97)</td>
</tr>
<tr>
<td>Subjective Burden</td>
<td>20.69 (14.87)</td>
</tr>
<tr>
<td>Beliefs About Self</td>
<td></td>
</tr>
<tr>
<td>Mental Health</td>
<td>41.07 (7.78)</td>
</tr>
<tr>
<td>Physical Health</td>
<td>48.17 (11.84)</td>
</tr>
<tr>
<td>Self-Esteem</td>
<td>3.15 (.62)</td>
</tr>
<tr>
<td>Relational Self-Efficacy</td>
<td>3.89 (.97)</td>
</tr>
<tr>
<td>Instrumental Self-Efficacy</td>
<td>3.87 (1.02)</td>
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<tr>
<td>Self-Soothing Self-Efficacy</td>
<td>3.95 (.98)</td>
</tr>
<tr>
<td>Death Attitudes</td>
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<tr>
<td>Coping with Death</td>
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<td>Approach Acceptance</td>
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<td>Escape Acceptance</td>
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</tr>
<tr>
<td>Death Avoidance</td>
<td>3.15 (1.48)</td>
</tr>
</tbody>
</table>

Table 1: Overall Means and Standard Deviations for Indicators of Death Salience, Beliefs About Self, and Death Attitudes.
Participants’ average scores on the indicators of beliefs about self and death attitudes were compared with mean scores reported in the literature for samples comparable in age or caregiving-related experience. Caregiving self-efficacy subscale means for the present study are consistent with previous findings (Gottlieb & Rooney, 2004). Additionally, caregivers’ self-esteem ratings are consistent with mean self-esteem reported by two samples of older adults (Cicirelli, 2002; Forthofer, Janz, Dodge, & Clark, 2001). Caregivers’ mean Coping with Death score (M = 4.97, SD = 1.02) is consistent with scores reported by hospital volunteers and hospice volunteer trainees, yet is lower than that reported by hospice volunteers with two or more years of experience (Robbins, 1990-91, 1992).

Participants’ mean scores on four subscales of the Death Attitude Profile-Revised were compared with mean subscale scores in two age groups reported by Wong, Reker, and Gesser (1994). Ages of participants in the present study ranged from 27 to 95, where two caregivers reported an age less than 30. The current sample was divided into two age groups to be consistent with Wong and colleagues (1994): caregivers age 59 and under (N = 105) and caregivers age 60 and over (N = 94). Independent sample t-tests indicated that younger caregivers in the present study reported more approach acceptance than did middle-aged adult participants in Wong et al.’s study. Older caregivers in the present study reported more fear of death and death avoidance than did the participants over age 60 in the previous study.

Multivariate analysis of variance (MANOVA) was conducted to compare mean scale scores by gender and kin relationship. The omnibus F-test by gender was not significant with respect to indicators of death salience, beliefs about self, or death
attitudes. Univariate post hoc tests of the variables were not completed. Table 2 displays the results of MANOVA’s comparing mean scale scores by kin relationship. Means and standard deviations are listed for 96 adult child and 72 spousal caregivers, respectively. Thirty-one participants described their relationship with the care recipient under a catchall “other” category. Due to the small subsample size, “other” relatives have not been included in analyses related to differences by kinship status.

The omnibus F-test was significant with respect to analysis of the death salience (F = 3.65, p < .01) and beliefs about self variables (F = 3.17, p < .05), but not with respect to death attitudes (F = 1.45, p = .20). Univariate post hoc tests of the death salience variables showed significant differences by kin relationship with respect to activities of daily living (F = 4.67, p < .05) and physical health status (F = 13.95, p < .001). Caregivers of a spouse reported fewer functional limitations for their care recipient than did adult child caregivers (M = 4.21 vs. M = 3.49, respectively). The mean physical health score was 51.60 for adult children and 45.26 for spousal caregivers. Adult child and spousal caregivers also differed significantly with respect to self-esteem (M = 3.26 vs. M = 2.99, respectively), relational self-efficacy (M = 4.00 vs. M = 3.58, respectively), instrumental self-efficacy (M = 4.04 vs. M = 3.64, respectively), and self-soothing self-efficacy (M = 4.04 vs. M = 3.72, respectively).

Comparisons also were made on background characteristics such as care recipient age, care recipient living arrangement, and respite services used based upon gender and kin relationship. Male caregivers were significantly more likely to be older (M = 66.2 vs. M = 59.27). As expected, spousal caregivers were significantly more likely to be older (M = 70.42) than were adult child caregivers (M = 53.64). Adult children were
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* Wilks’ Lambda and multivariate F’s for the three subsets were as follows: Death Salience ($\lambda = .90; F = 3.65, p < .01$), Beliefs About Self ($\lambda = .93; F = 3.17, p < .05$), Death Attitudes ($\lambda = .95; F = 1.45, ns$).

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

Table 2: Means, Standard Deviations, and Comparisons by Kin Relationship for Indicators of Death Salience, Beliefs About Self, and Death Attitudes.
significantly more likely to have an older care recipient (M = 83.05 vs. M = 74.32) than did spousal caregivers. Additionally, adult children were significantly more likely to report using more hours of respite services, including adult day programs (M = 2.29 vs. M = 1.85, respectively). However, spousal caregivers were significantly more likely to report using religious support and support groups for respite.

Overall Pearson’s product-moment correlation coefficients among the measures of death salience, beliefs about self, and death attitudes are presented in Table 3. Activities of daily living were unrelated to all other latent variables. Among the measures of death salience, objective and subjective burden were correlated significantly and strongly (r = .67), while mental health was correlated significantly and moderately with objective burden (r = -.26) and subjective burden (r = -.32). Correlations among the indicators of beliefs about self ranged from a moderate r = .35 between self-esteem and instrumental self-efficacy to a strong r = .76 between relational self-efficacy and self-soothing self-efficacy. Correlations among the three types of caregiving self-efficacy were strong (range r = .56 to r = .76). The Coping with Death scale related moderately and significantly to fear of death (r = -.48) and death avoidance (r = -.36), and showed a small and significant correlation with approach acceptance (r = .19). Escape acceptance correlated significantly only with approach acceptance (r = .26) among the death attitudes indicators. Fear of death and death avoidance correlated significantly and strongly (r = .60). All other correlations among Death Attitude Profile-Revised (DAPR) subscales ranged from r = -.04 to r = -.27.

Statistically significant but small to moderate correlations were found between measures of death salience and beliefs about self. Correlations ranged from r = .16
## Table 3: Overall Correlation Coefficients Among Indicators of Death Salience, Beliefs About Self, and Death Attitudes.

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*Note: N = 203; Bold: p < .01; Underline: p < .05*
between mental health and instrumental self-efficacy and between physical health and self-soothing self-efficacy, to \( r = .44 \) between mental health and self-esteem and \( r = -.44 \) between subjective burden and relational self-efficacy. Small relationships were found between measures of death salience and death attitudes. Objective burden showed a small negative correlation with approach acceptance (\( r = -.17 \)). Subjective burden correlated significantly with coping with death (\( r = -.25 \)), fear of death (\( r = .19 \)), and approach acceptance (\( r = -.15 \)).

Statistically significant relationships between mental and physical health summary scores and indicators of death attitudes also were found. Mental health was related to coping with death (\( r = .29 \)) and fear of death (\( r = -.15 \)), while physical health was related to coping with death (\( r = .16 \)), fear of death (\( r = -.25 \)), and death avoidance (\( r = -.18 \)).

Statistically significant correlations among indicators of death attitudes and beliefs about self were in the small to moderate range (\( r = +/- .17 \) to \( r = .47 \)). Coping with death was moderately related to self-esteem (\( r = .47 \)) and showed small correlations with relational self-efficacy (\( r = .28 \)), instrumental self-efficacy (\( r = .19 \)), and self-soothing self-efficacy (\( r = .31 \)). Among the positive death attitude subscales of the Death Attitude Profile - Revised, escape acceptance correlated significantly only with self-esteem (\( r = -.20 \)). Additionally, approach acceptance correlated with relational self-efficacy (\( r = -.18 \)) and self-soothing self-efficacy (\( r = .23 \)). The fear of death subscale negatively correlated with self-esteem (\( r = -.35 \)), relational self-efficacy (\( r = -.17 \)), and self-soothing self-efficacy (\( r = -.27 \)). Death acceptance correlated negatively with self-esteem and self-soothing self-efficacy (\( r = -.22 \) and \( r = -.21 \), respectively).
Correlation coefficients are listed separately by gender and kin relationship in Tables 4 and 5, respectively. Table 4 lists the correlation coefficients among indicators of death salience, beliefs about self, and death attitudes for male (N = 41) and female (N = 159) caregivers. Comparisons of correlation values between males and females were conducted by way of Fisher’s Z-test for independent samples (Glass & Hopkins, 1984). Four differences were found. The correlation between objective and subjective burden was significantly greater for male caregivers (r = .82) than for female caregivers (r = .61). Male caregivers’ subjective burden was more strongly related to approach acceptance (r = -.43) than was female caregivers’ subjective burden (r = -.08). Additionally, males’ self-esteem was more strongly related to instrumental self-efficacy than was females’ self-esteem (r = .59 vs. r = .29, respectively). Finally, a stronger correlation existed between female caregivers’ relational self-efficacy and instrumental self-efficacy than what existed for male caregivers (r = .77 vs. r = .40, respectively).

Table 5 displays correlation coefficients for adult child caregivers (N = 96) and spousal caregivers (N = 72). Comparisons of correlation coefficients for the two subgroups indicated a few differences. The relationship between physical health and self-esteem was greater for adult children (r = .52) than for spouses (r = .06). Furthermore, patterns of relationships between approach acceptance and other death attitudes differed by kin relationship. Adult children’s approach acceptance correlated with fear of death (r = -.44) and death avoidance (r = -.40). Spousal caregivers’ approach acceptance was not significantly related to other death attitudes.

Table 6 displays the results of hierarchical regression analysis of coping with death scores on selected background characteristics, death salience indicators, and belief
### Table 4: Correlation Coefficients by Gender Among Indicators of Death Salience, Beliefs About Self, and Death Attitudes.

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*Note: N = 203; **Bold**: \( p < .01; \) **Underline**: \( p < .05 \)

Women (N = 159) above the diagonal & Men (N = 41) below the diagonal
Table 5: Correlation Coefficients by Kin Relationship Among Indicators of Death Salience, Beliefs About Self, and Death Attitudes.

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<td>4. Mental Health</td>
<td>-.09 -.26</td>
<td>-.36 .09</td>
<td>.53 .35 .27</td>
</tr>
<tr>
<td>5. Physical Health</td>
<td>-.18 -.05</td>
<td>-.36 .09</td>
<td>.52 .22 .25</td>
</tr>
<tr>
<td>6. Self-Esteem</td>
<td>-.03 -.06</td>
<td>-.12 .44</td>
<td>.36 .26 .51</td>
</tr>
<tr>
<td>7. Relational Self-Efficacy</td>
<td>-.06 -.20</td>
<td>-.34 .29</td>
<td>.42 .76 .80</td>
</tr>
<tr>
<td>8. Instrumental Self-Efficacy</td>
<td>-.10 -.21</td>
<td>-.31 .24 .31</td>
<td>.33 .70 .68</td>
</tr>
<tr>
<td>9. Self-Soothing Self-Efficacy</td>
<td>-.08 -.03</td>
<td>-.16 .40 -.10</td>
<td>.65 .72 .48</td>
</tr>
<tr>
<td>10. Coping with Death</td>
<td>.04 -.02</td>
<td>-.13 .37 .07</td>
<td>.38 .20 .03</td>
</tr>
<tr>
<td>11. Fear of Death</td>
<td>-.09 -.02</td>
<td>-.10 -.21 -.11</td>
<td>-.37 -.25 -.06</td>
</tr>
<tr>
<td>12. Death Avoidance</td>
<td>-.00 -.02</td>
<td>-.03 -.25 -.01</td>
<td>-.39 -.21 -.10</td>
</tr>
<tr>
<td>13. Approach Acceptance</td>
<td>.04 -.11</td>
<td>-.19 .15 -.32</td>
<td>-.03 -.10 -.20</td>
</tr>
<tr>
<td>14. Escape Acceptance</td>
<td>-.14 .21</td>
<td>-.03 -.04 -.21</td>
<td>-.17 -.08 -.18</td>
</tr>
</tbody>
</table>

Note: N = 203; Bold: p < .01; Underline: p < .05
Adult Children (N = 96) above the diagonal & Spouses (N = 72) below the diagonal
about self indicators. Background characteristics included in the model were caregivers’
age and gender, care recipients’ age, kin relationship, and number of years for which care
has been provided. The model tested is consistent with Tomer and Eliason’s (1996,
2000a) comprehensive model of death anxiety, where death salience and beliefs about
self are hypothesized to predict coping with death, an indicator of meaningfulness of
death (i.e., death attitudes). In the final model, caregivers’ total time providing care ($\beta = .14, t = 2.07$), mental health scores ($\beta = .21, t = 2.48$), and self-esteem ($\beta = .22, t = 2.29$) significantly predicted coping with death scores, such that more time providing care,
greater mental health and self-esteem were associated with higher coping with death
scores. These three factors combined to account for 21% of the variance in coping with
death scores.

When the indicators of beliefs about self were added to the model, the regression
coefficients of objective burden, subjective burden, and physical health were no longer
significant. Additional analyses were conducted to examine the mediating effect of self-
esteem on the relationship between individual death salience indicators and coping with
death scores. Results of the test of the mediating effect of self-esteem are discussed in the
following paragraphs and are not presented in the accompanying tables.

Procedures for testing the mediating effect of self-esteem were conducted in
accordance with procedures originally outlined by Kenny and colleagues (Baron &
Kenny, 1986; Kenny, Kashy, & Bolger, 1998) and presented in Frazier, Tix, & Baron
(2004). First, coping with death scores were regressed on each of the indicators of death
salience. Regression analyses indicated that Index of Activities of Daily Living scores ($\beta = .02, t = .56$) and objective burden ($\beta = -.01, t = -1.35$) were not significant predictors of
### Table 6: Hierarchical Regression Analyses Predicting Coping with Death from Background Characteristics and Indicators of Death Salience and Beliefs About Self.

<table>
<thead>
<tr>
<th>Order of Model Entry</th>
<th>Significant Predictors</th>
<th>Coping with Death</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>β</td>
</tr>
<tr>
<td>Block 1</td>
<td>Background Characteristics</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Caregiver’s Age</td>
<td>.08</td>
</tr>
<tr>
<td>2</td>
<td>Caregiver’s Gender</td>
<td>-.06</td>
</tr>
<tr>
<td>3</td>
<td>Kin Relationship</td>
<td>.08</td>
</tr>
<tr>
<td>4</td>
<td>Care Recipient’s Age</td>
<td>-.04</td>
</tr>
<tr>
<td>5</td>
<td>Total Time Providing Care</td>
<td>.14</td>
</tr>
<tr>
<td>Block 2</td>
<td>Death Salience</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Activities of Daily Living</td>
<td>.11</td>
</tr>
<tr>
<td>7</td>
<td>Objective Burden</td>
<td>.16</td>
</tr>
<tr>
<td>8</td>
<td>Subjective Burden</td>
<td>-.13</td>
</tr>
<tr>
<td>9</td>
<td>Physical Health</td>
<td>.11</td>
</tr>
<tr>
<td>10</td>
<td>Mental Health</td>
<td>.21</td>
</tr>
<tr>
<td>Block 3</td>
<td>Beliefs About Self</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Self-Esteem</td>
<td>.22</td>
</tr>
<tr>
<td>12</td>
<td>Relational Self-Efficacy</td>
<td>.19</td>
</tr>
<tr>
<td>13</td>
<td>Instrumental Self-Efficacy</td>
<td>-.15</td>
</tr>
<tr>
<td>14</td>
<td>Self-Soothing Self-Efficacy</td>
<td>.00</td>
</tr>
<tr>
<td>Full Model</td>
<td></td>
<td>.52</td>
</tr>
</tbody>
</table>

Note: The table presents results of the final model that included all three blocks listed above.

* $p < .05$

** $p < .01$

*** $p < .001$
coping with death scores. No further analyses with these two indicators were conducted. Subjective burden, mental health, and physical health were found to be significant predictors of coping with death. Therefore, the significance of the mediating effect of self-esteem on the relationship between subjective burden, mental health, and physical health was tested using the Freedman & Schatzkin (1992) difference in coefficients test as discussed and recommended by MacKinnon, Lockwood, Hoffman, West, and Sheets (2002). Self-esteem scores mediated the relationship between coping with death scores and subjective burden \( (t = -4.95, p < .001) \), mental health \( (t = 4.92, p < .001) \), and physical health \( (t = 5.86, p < .001) \). Effects of background variables such as total time providing care were not controlled for in the analysis of mediating effects and may, therefore, limit the results of these analyses.

A second hierarchical regression analysis was conducted to test another relationship hypothesized by Tomer and Eliason (1996, 2000a). Table 7 lists the standardized regression coefficients and their accompanying \( t \)-test values, and the \( R \)-value and adjusted \( R^2 \) for a model predicting fear of death scores from selected background characteristics and indicators of death salience, beliefs about self, and positive death attitudes. Significant predictors of caregivers’ death anxiety included the following: caregivers’ age \( (\beta = .20, t = 2.50) \), kin relationship \( (\beta = .18, t = 2.41) \), caregivers’ self-reported physical health \( (\beta = -.16, t = -2.15) \), instrumental self-efficacy \( (\beta = .22, t = 2.20) \), self-soothing self-efficacy \( (\beta = -.25, t = -2.20) \), and coping with death \( (\beta = -.42, t = -5.82) \). The final model accounted for 34% of the variance in caregivers’ fear of death scores.
### Table 7: Hierarchical Regression Analyses Predicting Fear of Death from Background Characteristics, Death Salience Indicators, Beliefs About Self Indicators, and Positive Death Attitudes.

<table>
<thead>
<tr>
<th>Order of Model Entry</th>
<th>Significant Predictors</th>
<th>β</th>
<th>t</th>
<th>R</th>
<th>R² adjusted</th>
</tr>
</thead>
<tbody>
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<td><strong>Block 1</strong>&lt;br&gt;Background Characteristics</td>
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<td></td>
<td></td>
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<td>Caregiver’s Age</td>
<td>.20</td>
<td>2.50*</td>
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<td></td>
</tr>
<tr>
<td>2</td>
<td>Caregiver’s Gender</td>
<td>.09</td>
<td>1.36</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Kin Relationship</td>
<td>.18</td>
<td>2.41*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Care Recipient’s Age</td>
<td>-.12</td>
<td>-1.89</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Total Time Providing Care</td>
<td>.04</td>
<td>.55</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Block 2</strong>&lt;br&gt;Death Salience Indicators</td>
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<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>6</td>
<td>Activities of Daily Living</td>
<td>.01</td>
<td>.21</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Objective Burden</td>
<td>.03</td>
<td>.40</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Subjective Burden</td>
<td>.06</td>
<td>.70</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Physical Health</td>
<td>-.16</td>
<td>-2.15*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Mental Health</td>
<td>.03</td>
<td>.39</td>
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<td></td>
</tr>
<tr>
<td><strong>Block 3</strong>&lt;br&gt;Beliefs About Self Indicators</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Self-Esteem</td>
<td>-.06</td>
<td>-.70</td>
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<tr>
<td>12</td>
<td>Relational Self-Efficacy</td>
<td>.07</td>
<td>.52</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Instrumental Self-Efficacy</td>
<td>.22</td>
<td>2.20*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Self-Soothing Self-Efficacy</td>
<td>-.25</td>
<td>-2.20*</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Block 4</strong>&lt;br&gt;Death Attitudes</td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Coping with Death</td>
<td>-.42</td>
<td>-5.82***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Approach Acceptance</td>
<td>-.08</td>
<td>-1.15</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Escape Acceptance</td>
<td>-.08</td>
<td>-1.22</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Full Model</strong></td>
<td></td>
<td>.63</td>
<td>.34***</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note: The table presents results of the final model that included all four blocks listed above.*

* p < .05  
** p < .01  
*** p < .001
5.1 Summary of Results

The present study was undertaken to extend the study of death attitudes to family caregivers of the elderly and to test hypotheses derived from a comprehensive model of death anxiety (Tomer & Eliason, 1996, 2000a). Death attitudes were defined herein as the positive and negative beliefs and feelings that one consciously attributes to death. For the present study, death attitudes included three indicators of positive death attitudes: (1) coping with death, caregivers’ judgment of the skills they have to cope the death of others and one’s self; (2) approach acceptance, accepting beliefs that death will lead to a happy afterlife; and (3) escape acceptance, acceptance of death because death leads to the end of pain and suffering. Additionally, death attitudes include death avoidance and death anxiety. Death avoidance refers to the degree to which an individual actively denies or avoids thoughts of death. Death anxiety refers to “a cluster of death attitudes characterized by fear, threat, unease, discomfort, and similar negative emotional reactions, as well as anxiety in the psychodynamic sense as a kind of diffuse fear that has no clear object (Neimeyer, Moser, & Wittkowski, 2003). Higher scores on measures of death attitudes indicate more of the respective attitude. For instance, higher scores on
Tomer and Eliason’s comprehensive model of death anxiety postulates three direct influences on death anxiety: meaningfulness of death (i.e., death attitudes), past-related regrets, and future-related regrets. The authors postulate that death attitudes are directly influenced by death salience, beliefs about the world, and beliefs about one’s self. Furthermore, coping processes moderate the effects of beliefs about world and self. The present study focused on the relationships among death anxiety, death attitudes, beliefs about self, and death salience. Beliefs about self refer to self-conceptualizations such as self-esteem and self-efficacy. Self-esteem is defined herein as an individual’s positive or negative attitude toward her or his self, while self-efficacy refers to an individual’s self-assessed level of confidence in her or his ability to perform a given behavior successfully. Higher scores on measures of self-esteem and self-efficacy indicate more of the respective quality. Death salience refers to the degree to which an individual is aware of or alert to his or her death. In the present study, health status indicated death salience. Higher scores on measures of physical and mental health indicated greater well-being in the respective domains, while scores on measures of functional status, objective burden, and subjective burden indicated greater impairment.

Studies of death attitudes have been conducted largely with samples of college students or healthcare professionals. Evidence indicates that healthcare professionals’ death attitudes can influence their attitudes toward patients, willingness to talk about death and dying, and even medical decision making, as well as their choice to avoid or
seek specialization in death exposure fields (Neimeyer & Van Brunt, 1995; Neimeyer, Wittkowski, & Moser, 2004; Schulz & Aderman, 1978-79). As Neimeyer and Van Brunt note, “these analyses of health care workers’ death attitudes leave unanswered the more critical question of how such personal concerns might influence their professional behavior” (p. 67). A similar question may well be asked of family caregivers: how do their experiences of caring for an elderly, frail, or terminally ill relative influence and are influenced by their death attitudes?

Participants in the present study were recruited through adult day programs affiliated with the Ohio Association of Adult Day Services. Caregivers provided information about their care recipients’ functional limitations, the caregivers’ physical and mental health status, subjective and objective burden, caregivers’ self-esteem, caregivers’ self-assessed caregiving self-efficacy beliefs, and positive and negative death attitudes. An instrument that assessed caregivers’ reactions to care recipients’ memory and behavior problems operationally defined subjective burden, while caregivers’ assessments of the frequency of care recipients’ memory and behavior problems operationally defined objective burden. Caregiving self-efficacy was defined herein as a caregiver’s judgment of her or his ability to perform caregiving behaviors. In the present study, three types of caregiving self-efficacy were evaluated: relational self-efficacy (i.e., confidence to facilitate a cooperative relationship with the care recipient), instrumental self-efficacy (i.e., confidence to provide for the care recipient’s physical needs and solve problems arising during caregiving), and self-soothing self-efficacy (i.e., confidence to manage the caregiver’s emotional reactions and needs). Information also was gathered on
caregivers’ and care recipients’ sociodemographic information, duration of caregiving, and use of respite services such as adult day programs and support groups.

The present study sought to accomplish three tasks. First, the study examined differences among caregivers on the primary study variables (e.g., indicators of death salience, beliefs about self, and positive and negative death attitudes) and key background characteristics (e.g., age, kin relationship, total time providing care, use of respite services) using multivariate analysis of variance and comparisons of correlation coefficients for independent samples. Second, evidence of the reliability and validity of two measures of death attitudes for a sample of family caregivers was reviewed. Coefficient alphas provided indicators of internal consistency reliability, while correlations between the death attitudes instruments and other study variables provided evidence of convergent and discriminant validity. Finally, the present study sought to test hypotheses derived from a comprehensive model of death anxiety (Tomer & Eliason, 1996, 2000a) among a sample of family caregivers of the elderly. Hierarchical regression analyses were employed to examine predictors of coping with death and fear of death, respectively.

5.2 Differences among Caregivers by Gender & Kin Relationship

Caregivers’ mean scores on indicators of death salience, beliefs about self, and death attitudes were compared with those reported in previous studies as well as by gender and kin relationship within the present sample using multivariate analysis of variance. Overall mean scores on functional limitations, physical health, subjective burden, objective burden, self-esteem, caregiving self-efficacy, coping with death, death avoidance, and escape acceptance for this sample were comparable to those reported for
other samples in the literature. Caregivers reported lower scores on the general measure of mental health than did a normative sample of nearly 7000 adults (Ware, Kosinski, Turner-Bowker, & Gandek, 2002), indicating less psychological well-being for participants in the present study. This finding is consistent with the multitude of studies indicating that caregiving is a stressful endeavor that can lead to impaired mental health for the caregiver (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Martire & Schulz, 2001).

Additionally, the present samples’ attitudes about coping with death were more similar to new hospice volunteers than to volunteers with two or more years of hospice experience (Robbins, 1990-91, 1992). Furthermore, older respondents in the present study reported more death anxiety than did respondents in a previous sample aged 60 and over, while younger participants (ages 27 to 59, inclusive) reported more approach acceptance than did similarly aged respondents in a previous study (Wong, Reker, & Gesser, 1994). Approach acceptance refers to an individual’s belief in the acceptance of death because it will lead to a happy afterlife. These two findings suggest that age and experience with death may be differently related to death attitudes among caregivers than among non-caregivers, paraprofessional and professional caregivers.

One factor that might mediate the relationship between experience with death and death attitudes is the type of relationship an individual has with a patient. Presumably, family caregivers will have a greater degree of emotional attachment to their patient than would a volunteer or physician. The intensity of the emotional attachment may hinder a
caregivers’ ability to manage either death fears or coping with the death of a loved one. Future studies would be needed to test these hypotheses and more directly compare the experiences of professional and family caregivers.

Multivariate analysis of variance examining gender differences on mean scores of the primary study instruments indicated no gender differences at the multivariate level. Previous studies of gender differences in death attitudes have been mixed. One limitation of the present analysis is the rather small number of male caregivers (N = 41) relative to the number of female caregivers (N = 159). Additional studies with larger samples of male caregivers would be necessary to more adequately compare male and female caregivers’ death attitudes.

Overall Pearson’s product-moment correlation coefficients for the full sample of caregivers were presented in Table 3. As will be discussed further below, the results of correlational analyses with the Coping with Death Scale and Death Attitude Profile – Revised provide support for the construct validity of these two instruments among a sample of family caregivers. Additionally, statistically significant and strong, positive correlations were found between subjective and objective burden as well as among the three types of caregiving self-efficacy. Moreover, caregivers’ mental health scores were negatively correlated with objective and subjective burden, indicating that as objective and subjective burden increase, psychological well-being decreases. Furthermore, subjective well-being was negatively related to all four indicators of beliefs about self. These findings are consistent with research documenting the negative effect of caregiving burden on caregivers’ mental health. Additionally, the findings suggest that greater subjective burden is associated with less confidence in successfully completing the tasks
of caregiving. Exploring the nature of the relationship between subjective burden and caregiving self-efficacy may facilitate the development of interventions for family caregivers to lessen the effects of burden or increase caregiving self-efficacy.

Correlation coefficients were compared for males and females by way of Fisher’s Z-test for independent samples (Glass & Hopkins, 1984). A stronger correlation existed between objective and subjective burden among male caregivers than among female caregivers suggesting that male caregivers’ subjective reactions to caregiving are more directly linked to their care recipients’ disruptive behaviors and memory problems. Male, but not female, caregivers’ approach acceptance scores were moderately and negatively correlated with subjective burden. This result suggests that as a male caregiver’s subjective burden increases he is more likely to endorse beliefs that death is acceptable because it will lead to a happy afterlife. Approach acceptance is the death acceptance believed to be most closely associated with religious beliefs. Activation of approach acceptance beliefs also is suggestive of a shift to a more externalized locus of control. As a loved one becomes more and more frail and impaired (i.e., as subjective burden increases), caregivers may begin to sense a loss of control over or influence on their patient’s well-being. It is conceivable that male caregivers may activate more approach acceptance beliefs in the face of subjective burden as an attempt to cope with a loss of perceived control by shifting the locus of control for their loved one’s well-being to an outside force (e.g., religious beliefs). Further research is needed to test this hypothesis.

Adult children and spouses differed with respect to their responses on the indicators of death salience and beliefs about self, but not on the measures of death attitudes. Spouses judged their care recipients’ functional limitations to be greater than
those of adult children’s care recipients. This finding is interesting in light of univariate analysis of variance testing the difference in mean care recipient age for adult children and spouses. Adult children’s care recipients’ average age was nearly 10 years greater than that of spousal caregivers’ care recipients. Health status tends to decline with chronological age. One would expect that the older group of care recipients would have more functional limitations. Consistent with the negative relationship between age and physical health, spousal caregivers reported less physical well-being than did adult child caregivers. Spousal caregivers’ mean age was 70.42 (SD = 10.51) compared to adult children’s mean age of 53.64 (SD = 7.76).

Mean scores of indicators of beliefs about self also differed by kin relationship. Adult children reported more self-esteem, relational self-efficacy, instrumental self-efficacy, and self-soothing self-efficacy than did spousal caregivers. The self-esteem difference is consistent with longitudinal data indicating that self-esteem tends to rise gradually during adulthood until roughly age 65, then begins to decline slightly (Robins & Trzesniewski, 2005). Self-esteem also was more highly correlated with physical health for adult children than it was for spouses. While this result may reflect differences by age, it may also be that physical health status has less influence on the self-esteem of a caregiving spouse as their partner’s health status also declines.

Adult children and spouses differed on the self-efficacy measures by roughly one-half of a standard deviation unit. Mean scores for both groups were above the midpoint of the range of potential responses (from 1 to 5), indicating that both groups felt they “probably” could accomplish the general caregiving tasks included in the instrument. Further examination of the differences in caregiving self-efficacy by kin relationship is
warranted. Understanding what sources of efficacy information differentially influence adult children and spousal caregivers’ self-efficacy beliefs may facilitate the development of interventions to target their different needs.

Among adult children, approach acceptance was correlated negatively with both fear of death and death avoidance. Spousal caregivers’ approach acceptance was unrelated to both fear of death and death avoidance. This finding suggests that as adult children activate acceptance beliefs that death is associated with the afterlife, their levels of death anxiety and desire to avoid death decrease. Alternately, as death anxiety and efforts to avoid death increase, adult children are less likely to be able to access their sense of the acceptability of death due to beliefs that death is related to a happy afterlife. As with male caregivers, approach acceptance beliefs among adult children may function as a strategy for coping with perceptions of a loss of agency in the caregiving role.

5.3 Reliability & Validity of the Coping with Death Scale and Death Attitudes Profile – Revised

An additional purpose of the present study was to examine evidence of the reliability and validity of two measures of death attitudes among a sample of family caregivers of the elderly. The Coping with Death Scale (CDS; Bugen, 1980-81) and Death Attitude Profile-Revised (DAPR; Wong, Reker, & Gesser, 1994) were selected for the present study because both scales capture a range of attitudes related to death, rather than being limited strictly to negative affective reactions to death (e.g., death anxiety). The Coping with Death Scale includes items that sample an array of cognitive, affective, and behavioral tasks associated with coping with the death of others and of one’s self. Higher scores indicate greater perceptions of effective coping skills. Similarly, the Death
Attitude Profile-Revised taps into several dimensions of death attitudes, including positive, acceptance-based beliefs and the more traditional dimensions of death fears and death avoidance. Higher scores on the acceptance subscales indicate greater acceptance of death, while higher score on the fear of death and death avoidance subscales indicate greater fear and avoidance tendencies. While the CDS had been administered to volunteer and professional caregivers, and the DAPR had been validated among adults ranging in age from 18 to 90, neither scale had been validated for use with family caregivers. While more research is needed, the present study provides initial evidence of the reliability and validity of the CDS and DAPR for use in research with family caregivers.

The CDS and four of the five DAPR subscales demonstrated adequate internal consistency reliability for research purposes as measured by Cronbach’s alpha (Nunnally & Bernstein, 1994). The neutral acceptance subscale of the DAPR had low internal consistency reliability in the present study. Neutral acceptance refers to an individual’s belief that death is a natural part of life. As discussed above, the finding of low internal consistency reliability of the neutral acceptance subscale is consistent with earlier reports (Clements & Rooda, 1999-2000; Wong, Reker, & Gesser, 1994). To replicate the analysis of Clements and Rooda, a principal components factor analysis was conducted to examine the factor structure of the DAPR. Similar to Clements and Rooda, a six-factor solution provided the best fit to the data. Items on the neutral acceptance subscale loaded on two separate factors. The neutral acceptance subscale was not included in subsequent analyses due to its questionable reliability. Conceptual clarification of the neutral acceptance construct and revisions to its measurement appear to be warranted.
Correlational and hierarchical regression analyses provide evidence for the construct validity of the CDS and four of the DAPR subscales. Theory and prior research on death anxiety suggest that fear of death is negatively correlated with global measures of physical health and mental health (Cicirelli, 2000; Fortner, Neimeyer, & Rybarczyk, 2000; Thorson & Powell, 2000); that is, more death anxiety is associated with poorer mental and physical health. Self-esteem has been shown to be negatively related to fear of death (Cicirelli, 2000; Miller, Davis, & Hayes, 1993), such that lower self-esteem is associated with more death anxiety. These hypotheses were supported in the present study.

Wong, Reker, and Gesser (1994) identified several hypothesized relationships between other DAPR subscales and measures of mental and physical health. Death avoidance and escape acceptance are postulated to have negative relationships to measures of psychological well-being, while approach acceptance is expected to have a positive relationship to mental health. In the present study, caregivers’ mental health status was unrelated to death avoidance, escape acceptance, or approach acceptance. Additionally, escape acceptance is hypothesized to have a negative relationship to physical health. This hypothesis was not supported in the present study. In fact, a small negative correlation was found between physical health and escape acceptance. Coping with death is hypothesized to have a positive relationship to measures of self-efficacy and experience with death, and negatively related to death fear and death avoidance. These hypotheses were supported by the data.

Overall, the Coping with Death Scale and Death Attitude Profile-Revised appear to have adequate reliability for use with caregivers of older adults. One exception, as
noted, is the neutral acceptance subscale of the DAPR, which would benefit from further clarification of the construct and its measurement. Evidence of the construct validity of the DAPR and CDS is mixed. The data from the present study provide evidence of convergent validity for the Coping with Death scale and the fear of death subscale of the Death Attitude Profile-Revised.

5.4 Predictors of Coping with Death and Fear of Death

The present study sought to test hypotheses derived from a comprehensive model of death anxiety (Tomer & Eliason, 1996, 2000a) among a sample of family caregivers whose elderly loved one participates in an adult day program. It was hypothesized that coping with death scores would be predicted by death salience and beliefs about self. Additionally, the role of beliefs about self as a mediator between death salience and coping with death would be examined. Moreover, death anxiety was expected to be influenced by indicators of death salience, beliefs about self, and coping with death. Hierarchical regression analyses were employed to test these hypotheses.

Results of regression analysis on coping with death provide support for Tomer and Eliason’s (1996, 2000a) model of death attitudes among family caregivers of the elderly. Indicators of death salience and beliefs about self influenced caregivers’ scores on coping with death, such that greater psychological well-being and self-esteem were associated with greater coping with death. Self-esteem was shown to mediate the relationship of subjective burden and physical health with coping with death, and to mediate partially the relationship between mental health and coping with death. These results suggest that subjective burden, physical health and mental health influence coping with death indirectly through self-esteem. Again, these results are consistent with the
model proposed by Tomer and Eliason (1996, 2000a), where beliefs about oneself mediate the relationship between death salience and death attitudes. Additionally, they suggest that interventions designed to increase caregivers’ beliefs about coping with their loved one’s death would be strengthened by efforts to improve caregivers’ self-esteem and general psychological well-being.

Additionally, the finding that total time providing care remains a significant predictor of coping with death scores is consistent with research by Robbins (1992). Robbins found that longer-term hospice volunteers reported greater coping with death than did non-volunteers and new volunteers. This finding suggests that self-assessment of coping with death increases as one’s experience with a chronically ill or functionally dependent patient increases.

Results of hierarchical regression analysis on fear of death also provide support for Tomer and Eliason’s (1996, 2000a) model. In this analysis, death anxiety was postulated to be directly influenced by death attitudes and indirectly influenced by background characteristics, death salience, and beliefs about self. Age, being an adult child caregiver, physical health status, instrumental self-efficacy, self-soothing self-efficacy, and coping with death were shown to be significant predictors of fear of death scores. Consistent with findings of Cicirelli (2002), while self-esteem was significantly correlated with fear of death in the present study, self-esteem was not a significant predictor of fear of death. The direction of the regression weights suggest that death anxiety increases as caregivers’ physical health declines, they lose confidence in their ability to manage their emotional reactions to caregiving successfully, and they believe they are unable to cope with their loved one’s death.
It is interesting that as caregivers’ confidence in their instrumental abilities increases their death fears should increase. This finding seems to run contrary to self-efficacy theory, which would suggest that increased confidence would lessen caregivers’ anxiety. It may be that as caregivers become more confident and secure in their abilities to meet the practical needs of their care recipients, they have more mental energy to devote to their own emotional responses, including fear of death. At that point, self-soothing efficacy beliefs may be enacted to decrease death anxiety. It may be that as caregivers progress through the caregiving career, different interventions may be needed to influence different types of caregiving self-efficacy. Initially, instrumental self-efficacy may be more important to bolster as caregivers adjust to the demands of their new role. As the caregiver becomes more confident about caregiving yet more anxious about death, interventions addressing self-soothing self-efficacy may increase in priority. Perhaps a reciprocal relationship between death attitudes and caregiving self-efficacy would better explain these results. Additional research examining the relationship between the different types of caregiving self-efficacy and death anxiety would be valuable, especially in light of the application of self-efficacy theory to treatment.

5.5 Qualitative Information

Several caregivers added comments directly to the questionnaires, on separate notes, or through phone contact. The comments revealed limitations of the design of the survey packet as well as the breadth of positive and negative reactions to the content of the questionnaire items. While every effort was made to ensure clarity of directions and response options, some participants added comments directly on the survey packet reflecting their confusion as to whether some questionnaires were asking about the
caregiver or the care recipient. When participants did indicate how they chose to respond to items (e.g., “I answered this based on my information, not my mother’s”), directions were followed as intended. Future studies assessing information about both caregivers and their care recipients would do well to ensure adequate pilot studies to examine the clarity of instructions, or conduct in-person interviews to minimize participant confusion.

Seventy-five caregivers wrote in responses to at least one item in the survey packet, mostly clarifying information requested about sociodemographic information. For example, some participants wrote in their kin relationship with the care recipient, such as “granddaughter” or “niece.” Other caregivers commented that caregiving had become a “24/7” undertaking. Sixteen participants commented on items on the death attitudes measures. These comments ranged from “yes!” to “This part of the test is crazy” to “I just don’t care anymore.” Handwritten notes accompanied two returned packets and provided explanations for missing data. Several calls were received from participants who indicated interest in obtaining results of the study, requests for counseling referrals, and one complaint about the study in general. Many of the comments were interesting in the way they revealed strong reactions to the caregiving experience and to experiences with death.

5.6 Limitations

The present study sought to begin to examine family caregivers’ death attitudes from the framework of Tomer and Eliason’s (1996, 2000a) comprehensive model of death anxiety. While support was found for the major hypotheses of the study, several factors would have increased the strength of the study. First, caregivers in the present study were recruited solely from adult day programs in Ohio. The likelihood of restricted
range increases with volunteer participants, rather than when using a random sample. Efforts to recruit more male caregivers would strengthen conclusions based upon gender comparisons. Additionally, comparisons between adult child and spousal caregivers introduces age as a confounding variable that needs to be better controlled for in future studies. Not only were participants volunteering, they were recruited from a non-random sample of adult day programs. Future studies involving participants from adult day programs should consider assessing characteristics of adult day programs, such as services provided and number of patients served, to examine more fully the effect of respite services on the caregiving experience. Furthermore, caregivers’ perceptions of the patient’s nearness to death may have been less than it would be for other samples of caregivers. Comparisons among caregivers at different stages in the caregiving career, including caregivers of patients designated as terminally ill or under hospice care, would strengthen conclusions drawn in the present study.

In addition to differences with respect to the sample, future studies may be focused on different ways of measuring study variables. For example, death salience was operationally defined by measures of caregiver and care recipient health status. However, duration and intensity of care recipients’ and caregivers’ physical health, including information about specific illnesses or symptoms, were not assessed in the present study. Assessments of caregivers’ perceptions of the care recipient’s nearness to death may provide another measure of death salience. Additionally, alternative measures of death attitudes or death anxiety could be used to assess other dimensions of death attitudes. For instance, the Collett-Lester Fear of Death Scale (Lester, 1994) includes dimensions of death and dying of self and other, which may be particularly relevant among family
The indicators of death attitudes used in the present study make it difficult to tease apart the effect of caregivers’ death attitudes related to thoughts of their own versus the care recipient’s death. Additionally, the study assessed conscious death anxiety, which limited the ability to test hypotheses derived from terror management theory. Terror management theory hypotheses apply to unconscious death anxiety.

Different research and statistical methods would strengthen future studies of caregivers’ death attitudes. The current study provides a cross-sectional analysis of caregivers’ death attitudes based upon self-report measures. Longitudinal studies would allow researchers to investigate the changes in death attitudes and death anxiety over the course of the caregiving career. The role of self-efficacy beliefs across the course of caregiving also would be best examined through a longitudinal study. The use of structural equation modeling would have improved the strength of conclusions drawn about the fit of the data to the theoretical model. Additionally, other theoretical models might better fit the data than did the comprehensive model of death anxiety. Alternatives include self-efficacy theory (Bandura, 1997) and the stress process model of caregiving (Pearlin, Mullan, Semple, & Skaff, 1990). Qualitative designs might also be valuable for exploring the role of death attitudes in the caregiving experience.

5.7 Conclusion

This study extended the literature on death attitudes to family caregivers of the elderly in three ways. Differences among caregivers by gender and kin relationship were examined with respect to background characteristics and indicators of death salience, beliefs about self, and death attitudes. Evidence of the reliability and validity of two measures of death attitudes provided support for the use of the Coping with Death Scale
and Death Attitude Profile-Revised with family caregivers. Finally, analysis of the predictors of coping with death and fear of death provided support for a theoretical model of death attitudes among family caregivers and identified several factors amenable to intervention that influence caregivers’ positive and negative death attitudes. Implications for interventions, suggestions for future research, and limitations to the present study were discussed.


APPENDIX A

LETTER TO OHIO ASSOCIATION OF ADULT DAY SERVICES BOARD

April 9, 2005

Ohio Association of Adult Day Services
3757 Indianola Avenue
Columbus, Ohio 43214

Dear OAADS Member:

The following letter provides a brief rationale and overview of a proposed study to be completed in partial fulfillment of the doctoral degree in psychology from the Department of Psychology at The Ohio State University. The faculty advisor for the study is Nancy E. Betz, Ph.D. (betz.3@osu.edu). Final approval of the study is pending a proposal meeting to be scheduled during Spring 2005, and review by the institutional review boards (IRBs) of The Ohio State University and Riverside Methodist Hospital anticipated for Summer 2005. Data collection is expected to begin during Autumn 2005.

The overall purpose of the study, detailed on the following page, is to add to knowledge of the psychological well-being of caregivers of elderly patients. In order to undertake this study we need to access these caregivers and are therefore requesting assistance from OAADS in recruiting family caregivers to participate in this study. We will provide participating OAADS member organizations with survey packets and postage-paid return envelopes for distribution to caregivers. Member organizations are asked to provide a cover letter indicating their support for the present study to be included with packets, as well as address labels for their individual members. A final report detailing results of the study will be made available to OAADS member organizations and caregivers upon completion of the study. We also welcome input from OAADS in identifying additional research questions that may be of interest to your members. Adjustments to the final design of the study may be made based upon your needs and interests.

Thank you for reviewing this proposal. If there are additional research questions related to the variables described that are of interest to you, please contact us. Moreover, we hope that you will lend your support to participant recruitment. It is our hope that this study will benefit your organization and family caregivers.
We would like to thank Michele Stokes for agreeing to present this proposal for your consideration and very much look forward to hearing from you.

Sincerely,
Sarah E. Reimer, M.A.
Doctoral Candidate, Counseling Psychology
The Ohio State University
reimer.14@osu.edu
614-886-9458

Study Rationale

It is hypothesized that caregivers with greater confidence in their ability to care for older relatives are more likely to persist longer in caregiving and to experience better physical and psychological well-being than family members with less caregiving self-efficacy (Zeiss, Gallagher-Thompson, Lovett, Rose, & McKibbin, 1999). Perceived caregiving self-efficacy has been shown to correlate with caregivers’ levels of depression, anger, anxiety, and beliefs about how well they are coping with their caregiving responsibilities (Gottlieb & Rooney, 2003, 2004; Steffan, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002; Zeiss, Gallagher-Thompson, Lovett, Rose, & McKibbin, 1999). Among a caregiver’s responsibilities are having an awareness of and ability to facilitate appropriate end-of-life treatments as well as to cope more generally with the death of the care recipient (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Robbins, 1990-91).

Adult day services are in a position to support caregivers with respite care and information to bolster caregivers’ efficacy in providing home-based care and to prepare for the loved one’s death. In the long run, adult day services may help caregivers postpone institutionalization of their older relative, protect caregivers’ physical and mental health, and promote an effective bereavement experience. While the long-term effects and benefits of adult day service utilization for family caregivers have yet to be systematically examined, the present study is intended to add to and expand the existing body of literature on adult day service outcomes, caregiver burden, caregiving self-efficacy, and death attitudes.

Overview

The present study proposes to examine the relationships among the following primary variables: caregiver health and perceived burden, attitudes about coping with death, and caregiving self-efficacy. Additionally, patterns of adult day service utilization and other caregiver coping strategies will be assessed. One of the unique features of the present study is the assessment of death attitudes among family caregivers of the elderly. Most research on death attitudes is conducted with samples of young adults or formal caregivers.

Completion of the paper-and-pencil survey by caregivers is expected to take between 20 and 40 minutes. Postage-paid return envelopes will be provided to participants. No adverse effects to the caregiver are expected. However, due to the potentially sensitive nature of caregiving experiences and attitudes about death, the investigator’s cover letter will provide caregivers with referral sources (e.g., Ohio Psychological Association’s referral program).

Further details of the proposed study will be made available upon request.
APPENDIX B

WRITTEN INSTRUCTIONS TO PARTICIPANTS
[Note: Provided for participants in writing on departmental letterhead.]

Dear Caregiver:

Thank you for taking time to consider participating in our study of the caregiving experience. We appreciate how valuable your time is, and hope you will be willing to assist us in gaining understanding of the caregiving experience. By doing so, you may provide valuable information to enable us to provide better services and support to other caregivers. If you elect to participate, we will ask you to read and sign the enclosed consent form to acknowledge your agreement to participate. Additionally, we will ask you to answer a series of questions related to your experience providing care to your loved one.

This study will be conducted using the enclosed paper-and-pencil questionnaires. Please read the directions for each questionnaire and indicate your response to each question as indicated in the instructions. It is important that you work through the statements and answer each one as honestly as possible. Don’t spend too much time thinking about your response. We want your first impression of how you think right now. We expect that it will take approximately 30 minutes to complete the questionnaires. If you must take a break, avoid doing so in the middle of a questionnaire.

Remember that your participation today is entirely voluntary. Your completion and submission of this survey indicates you consent to participate. If at any point you choose to discontinue your participation you are free to do so. Some of the questions may be challenging because they ask about your thoughts and feelings about you, about caregiving, and about issues related to caregiving. While it is not expected, if you experience any lingering distress after completing this questionnaire, please contact one or more of the resources listed on the last page of this packet.

You will not be asked to provide your name or any other identifying information on the questionnaires, so we cannot link your answers to you in any way. Return envelopes will be shredded upon receipt. Additionally, completed questionnaires will be stored in separate locked areas so your responses will not be connected to you in any way. This study has been designed to comply with standard research ethics and has been approved by the institutional review boards of The Ohio State University (protocol #: 000-00000) and Riverside Methodist Hospital (protocol #: 999-99999).
Once you complete the consent form and questionnaires, please return them to the researchers using the postage-paid return envelope enclosed with this packet. A debriefing sheet which will explain the study and give you some resources and names if you would like to pursue matters related to this research or would like more general counseling assistance is included at the end of the packet.

Thank you in advance for your participation.
Dear Caregiver:

Thank you for participating in our study. We are interested in how individuals caring for older family members experience caregiving, and how this may be related to beliefs and feelings about preparing for a loved one’s death. You have completed many questionnaires designed to tell us about these aspects of your life. Please note that your current responses do not necessarily mean that you will continue to feel this way or behave this way.

We hope to learn from you what factors influence a caregiver’s judgment of their confidence in providing care and in coping with death. We hope to use this information to improve understanding of the caregiving experience and to improve supportive services for caregivers. Therefore, our findings will be used to help other caregivers and their loved ones.

If in the course of this study you have developed concerns or uncertainties about your feelings or about yourself, or if you feel any type of distress related to your responses, you may wish to seek counseling. If you wish to do this, you might be able to find a counselor or therapist in your area by calling the Ohio Psychological Association at (614) 224-0034, toll-free at 800-783-1983, or using their on-line referral service at www.ohpsych.org. If you have any other questions about this study or would like additional counseling referrals, please contact Dr. Nancy Betz at 292-4166 or betz.3@osu.edu.

Again, thank you for assisting us with this research. We hope that it will eventually be used to help others like you.
### APPENDIX D

**COPING WITH DEATH SCALE**  
Bugen (1980-81)

**Instructions:** Please rate, on a scale from 1 to 7, how much you agree with each statement.

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1. Thinking about death is a waste of time.  
2. I have a good perspective on death and dying.  
3. Death is an area that can be dealt with safely.  
4. I am aware of the full array of services from funeral homes.  
5. I am aware of the variety of options for disposing of bodies.  
6. I am aware of the full array of emotions that characterize human grief.  
7. Knowing that I will surely die does not in any way affect the conduct of my life.  
8. I feel prepared to face my death.  
9. I feel prepared to face my dying process.  
10. I understand my death-related fears.  
11. I am familiar with funeral prearrangement.
12 Lately I find it O.K. to think about death. 1 2 3 4 5 6 7
13 My attitude about living has recently changed. 1 2 3 4 5 6 7
14 I can express my fears about dying. 1 2 3 4 5 6 7
15 I can put words to my gut-level feelings about death and dying. 1 2 3 4 5 6 7
16 I am making the best of my present life. 1 2 3 4 5 6 7
17 The quality of my life matters more than the length of it. 1 2 3 4 5 6 7
18 I can talk about my death with family and friends. 1 2 3 4 5 6 7
19 I know who to contact when death occurs. 1 2 3 4 5 6 7
20 I will be able to cope with future losses. 1 2 3 4 5 6 7
21 I feel able to handle the death of others close to me. 1 2 3 4 5 6 7
22 I know how to listen to others, including the terminally ill. 1 2 3 4 5 6 7
23 I know how to speak to children about death. 1 2 3 4 5 6 7
24 I may say the wrong thing when I am with someone mourning. 1 2 3 4 5 6 7
25 I am able to spend time with the dying if I need to. 1 2 3 4 5 6 7
26 I can help people with their thoughts and feelings about death and dying. 1 2 3 4 5 6 7
27 I would be able to talk to a friend or family member about his or her death. 1 2 3 4 5 6 7
28 I can lessen the anxiety of those around me when the topic is death and dying. 1 2 3 4 5 6 7
29 I can communicate with the dying. 1 2 3 4 5 6 7
30 I can tell people, before I or they die, how much I love them. 1 2 3 4 5 6 7

Scoring: Reverse score items 13 and 24, then total all items.
APPENDIX E

DEATH ATTITUDE PROFILE – REVISED
Wong, Reker, & Gesser (1994)

Instructions: This questionnaire contains a number of statements related to different attitudes toward death. Read each statement carefully, and then indicate the extent to which you agree or disagree. For example, an item might read: “Death is a friend.” Indicate how well you agree or disagree by circling one of the following: SA = strongly agree; A = agree; MA= moderately agree; U = undecided; MD = moderately disagree; D = disagree; SD = strongly disagree. Note that scales run both from strongly agree to strongly disagree and from strongly disagree to strongly agree.

If you strongly agreed with the statement, you would circle SA. If you strongly disagreed you would circle SD. If you are undecided, circle U. However, try to use the Undecided category sparingly.

It is important that you work through the statements and answer each one. Many of the statements will seem alike, but all are necessary to show slight differences in attitudes.

1. Death is no doubt a grim experience. SD D MD U MA A SA
2. The prospect of my own death arouses anxiety in me. SD D MD U MA A SA
3. I avoid death thoughts at all costs. SD D MD U MA A SA
4. I believe that I will be in heaven after I die. SD D MD U MA A SA
5. Death will bring an end to all my troubles. SD D MD U MA A SA
6. Death should be viewed as a natural, undeniable, and unavoidable event. SD D MD U MA A SA
7. I am disturbed by the finality of death. SD D MD U MA A SA
8 Death is an entrance to a place of ultimate satisfaction.
9 Death provides an escape from this terrible world.
10 Whenever the thought of death enters my mind, I try to push it away.
11 Death is deliverance from pain and suffering.
12 I always try not to think about death.
13 I believe that heaven will be a much better place than this world.
14 Death is a natural aspect of life.
15 Death is a union with God and eternal bliss.
16 Death brings a promise of a new and glorious life.
17 I would neither fear death nor welcome it.
18 I have an intense fear of death.
19 I avoid thinking about death altogether.
20 The subject of life after death troubles me greatly.
21 The fact that death will mean the end of everything as I know it frightens me.
22 I look forward to a reunion with my loved ones after I die.
23 I view death as a relief from earthly suffering.
24 Death is simply a part of the process of life.
25 I see death as a passage to an eternal and blessed place.
26 I try to have nothing to do with the subject of death.
27 Death offers a wonderful release of the soul.
28 One thing that gives me comfort in facing death is my belief in the afterlife.
29  I see death as a relief from the burden of this life.  SD  D  MD  U  MA  A  SA
30  Death is neither good nor bad.  SD  D  MD  U  MA  A  SA
31  I look forward to life after death.  SD  D  MD  U  MA  A  SA
32  The uncertainty of not knowing what happens after death worries me.  SD  D  MD  U  MA  A  SA

**Scoring:**

<table>
<thead>
<tr>
<th>Dimensions</th>
<th>Items</th>
</tr>
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<tbody>
<tr>
<td>Fear of Death (7 items)</td>
<td>1, 2, 7, 18, 20, 21, 32</td>
</tr>
<tr>
<td>Death Avoidance (5 items)</td>
<td>3, 10, 12, 19, 26</td>
</tr>
<tr>
<td>Neutral Acceptance (5 items)</td>
<td>6, 14, 17, 24, 30</td>
</tr>
<tr>
<td>Approach Acceptance (10 items)</td>
<td>4, 8, 13, 15, 16, 22, 25, 27, 28, 31</td>
</tr>
<tr>
<td>Escape Acceptance</td>
<td>5, 9, 11, 23, 29</td>
</tr>
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</table>

Score for all items are from 10 to 7 in the direction of *strongly disagree* (1) to *strongly agree* (7). For each dimension, a mean scale score can be computed by dividing the total scale score by the number of items forming each scale.
APPENDIX F

RIS ELDERCARE SELF-EFFICACY SCALE

*Instructions:* Read each item and indicate how confident you would be doing what it describes. Use the following scale for your responses.

1 = I’m certain I can’t do this.
2 = I probably can’t do this.
3 = Maybe I can and maybe I can’t do this.
4 = I probably can do this.
5 = I’m certain I can do this.

<table>
<thead>
<tr>
<th>Instrumental Self-Efficacy</th>
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<th>3</th>
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<th>5</th>
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<tbody>
<tr>
<td>I can do all the things that are needed to take care of my relative.</td>
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<td>2</td>
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<td>5</td>
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<tr>
<td>When I make caregiving plans, there are things I can do to make them work.</td>
<td>1</td>
<td>2</td>
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<tr>
<td>I can think of different things I can do to improve or solve problems related to caring for my relative.</td>
<td>1</td>
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*Self-Soothing Efficacy*

| 4 | There are things I can do to relax and calm myself. | 1 | 2 | 3 | 4 | 5 |
| 5 | There are things I can do to get pleasure out of life. | 1 | 2 | 3 | 4 | 5 |
| 6 | There are things I can do when I get worried or afraid about what the future will bring. | 1 | 2 | 3 | 4 | 5 |
| 7 | There are things I can do to get whatever help and support I want from other people. | 1 | 2 | 3 | 4 | 5 |

*Relational Self-Efficacy*

| 8 | There are things I can do to make the time I spend with my relative more enjoyable. | 1 | 2 | 3 | 4 | 5 |
9 There are things I can do to get my relative to cooperate with me.

10 There are things I can do to avoid or reduce conflict with my relative.

Scoring: Sum item responses. Higher scores indicate greater caregiver self-efficacy.
APPENDIX G

ROSENBERG’S SELF-ESTEEM SCALE
Rosenberg (1965)

Instructions: Please circle the appropriate number for each statement depending on whether you strongly agree, agree, disagree, or strongly disagree with it.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>1</td>
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</table>

1  On the whole, I am satisfied with myself. 1 2 3 4
2  At times I think I am no good at all. 1 2 3 4
3  I feel that I have a number of good qualities. 1 2 3 4
4  I am able to do things as well as most other people. 1 2 3 4
5  I feel I do not have much to be proud of. 1 2 3 4
6  I certainly feel useless at times. 1 2 3 4
7  I feel that I’m a person of worth, at least on an equal plane with others. 1 2 3 4
8  I wish I could have more respect for myself. 1 2 3 4
9  All in all, I am inclined to feel that I am a failure. 1 2 3 4
10 I take a positive attitude toward myself. 1 2 3 4
Scoring: Reverse score items 2, 5, 6, 8, and 9, then total all items. Scores range from 10 to 40, with higher scores indicating higher self-esteem.
**APPENDIX H**

**INDEX OF INDEPENDENCE IN DAILY LIVING ACTIVITIES**  
Katz, Ford, Moskowitz, Jackson, and Jaffe (1963)

*Instructions:* For each area of functioning listed below, circle the number corresponding to the description that applies to your care recipient. (The word “assistance” means supervision, direction, or active assistance). Base your evaluation upon your relative’s actual status and not on ability. The care recipient who refuses to perform a function is considered as not performing the function even though he or she is deemed able.

**Bathing** – either sponge bath, tub bath, or shower

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<tbody>
<tr>
<td>1</td>
<td>Receives no assistance (gets in and out of tub by self if tub is usual means of bathing)</td>
<td>2</td>
</tr>
</tbody>
</table>

**Dressing** – gets clothes from closets and drawers – including underclothes, outer garments and using fasteners (including braces if worn)

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</thead>
<tbody>
<tr>
<td>1</td>
<td>Gets clothes and gets completely dressed without assistance</td>
<td>2</td>
</tr>
</tbody>
</table>
**Toileting** – going to the “toilet room” for bowel and urine elimination; cleaning self after elimination, and arranging clothes

1. Goes to “toilet room,” cleans self, and arranges clothes without assistance (may use object for support such as cane, walker, or wheelchair and may manage night bedpan or commode, emptying same in morning)
2. Receives assistance in going to “toilet room” or in cleansing self or in arranging clothes after elimination or in use of night bedpan or commode
3. Doesn’t go to room termed “toilet” for the elimination process

**Transfer** –

1. Moves in and out of bed as well as in and out of chair without assistance (may be using object for support such as cane or walker)
2. Moves in or out of bed or chair with assistance
3. Doesn’t get out of bed

**Continence** –

1. Controls urination and bowel movement completely by self
2. Has occasional “accidents”
3. Supervision helps keep urine or bowel control; catheter is used, or is incontinent

**Feeding** –

1. Feeds self without assistance
2. Feeds self except for getting assistance in cutting meat or buttering bread
3. Receives assistance in feeding or is fed partly or completely by using tubes or intravenous fluids
Scoring: Functional independence is based on the above evaluation and is graded according to the following index:

0 = Independent in feeding, continence, transferring, going to toilet, dressing, and bathing.
1 = Independent in all but one of these functions.
2 = Independent in all but bathing and one additional function.
3 = Independent in all but bathing, dressing, and one additional function.
4 = Independent in all but bathing, dressing, going to toilet, and an additional function.
5 = Independent in all but bathing, dressing, going to toilet, transferring, and one additional function.
6 = Dependent in all six functions.
Other = Dependent in at least two functions, but not classifiable as 2, 3, 4, or 5.

Higher scores indicate greater functional dependence.
Instructions: The following is a list of problems patients sometimes have. Please indicate if any of these problems have occurred during the past week. If so, how much has this bothered or upset you when it happened? Use the following scales for the frequency of the problem and your reaction to it. Please read the description of the ratings carefully.

FREQUENCY RATINGS:  
0 = never occurred  
1 = not in the past week  
2 = 1 to 2 times in the past week  
3 = 3 to 6 times in the past week  
4 = daily or more often  
9 = don’t know/not applicable

REACTION RATINGS:  
0 = not at all  
1 = a little  
2 = moderately  
3 = very much  
4 = extremely  
9 = don’t know/not applicable

Please answer all the questions below. Please circle a number from 0-9 for both frequency and reaction.

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Reaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Asking the same question over and over.</td>
<td>0 1 2 3 4 9</td>
</tr>
<tr>
<td>2</td>
<td>Trouble remembering recent events (e.g., items in the newspaper or on TV)</td>
<td>0 1 2 3 4 9</td>
</tr>
<tr>
<td>3</td>
<td>Trouble remembering significant past events.</td>
<td>0 1 2 3 4 9</td>
</tr>
<tr>
<td>4</td>
<td>Losing or misplacing things.</td>
<td>0 1 2 3 4 9</td>
</tr>
<tr>
<td>5</td>
<td>Forgetting what day it is.</td>
<td>0 1 2 3 4 9</td>
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<td></td>
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<tr>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Starting, but not finishing, things.</td>
<td>0 1 2 3 4 9</td>
</tr>
<tr>
<td>7</td>
<td>Difficulty concentrating on a task.</td>
<td>0 1 2 3 4 9</td>
</tr>
<tr>
<td>8</td>
<td>Destroying property.</td>
<td>0 1 2 3 4 9</td>
</tr>
<tr>
<td>9</td>
<td>Doing things that embarrass you.</td>
<td>0 1 2 3 4 9</td>
</tr>
<tr>
<td>10</td>
<td>Waking you or other family members up at night.</td>
<td>0 1 2 3 4 9</td>
</tr>
<tr>
<td>11</td>
<td>Talking loudly and rapidly.</td>
<td>0 1 2 3 4 9</td>
</tr>
<tr>
<td>12</td>
<td>Appears anxious or worried.</td>
<td>0 1 2 3 4 9</td>
</tr>
<tr>
<td>13</td>
<td>Engaging in behavior that is potentially dangerous to self or others.</td>
<td>0 1 2 3 4 9</td>
</tr>
<tr>
<td>14</td>
<td>Threats to hurt oneself.</td>
<td>0 1 2 3 4 9</td>
</tr>
<tr>
<td>15</td>
<td>Threats to hurt others.</td>
<td>0 1 2 3 4 9</td>
</tr>
<tr>
<td>16</td>
<td>Aggressive to others verbally.</td>
<td>0 1 2 3 4 9</td>
</tr>
<tr>
<td>17</td>
<td>Appears sad or depressed.</td>
<td>0 1 2 3 4 9</td>
</tr>
<tr>
<td>18</td>
<td>Expressing feelings of hopelessness or sadness about the future (e.g., “Nothing worthwhile ever happens,” “I never do anything right”).</td>
<td>0 1 2 3 4 9</td>
</tr>
<tr>
<td>19</td>
<td>Crying and tearfulness.</td>
<td>0 1 2 3 4 9</td>
</tr>
<tr>
<td>20</td>
<td>Commenting about death of self or others (e.g., “Life isn’t worth living,” “I’d be better off dead”).</td>
<td>0 1 2 3 4 9</td>
</tr>
<tr>
<td>21</td>
<td>Talking about feeling lonely.</td>
<td>0 1 2 3 4 9</td>
</tr>
<tr>
<td>22</td>
<td>Comments about feeling worthless or being a burden to others.</td>
<td>0 1 2 3 4 9</td>
</tr>
</tbody>
</table>
23 Comments about feeling like a failure or about not having any worthwhile accomplishments in life.

24 Arguing, irritability, and/or complaining.

**Scoring:** The circled scores are summed for each scale. Higher scores indicate greater limitations of cognitive status.

**Subscales:**
- **Memory-Related Problems:** Items 1, 2, 3, 4, 5, 6, and 7.
- **Disruption Problems:** Items 8, 9, 10, 11, 13, 15, 16, and 24.
- **Depression-Related Problems:** Items 12, 14, 17, 18, 19, 20, 21, 22, and 23.
APPENDIX J

DEMOGRAPHIC QUESTIONNAIRE
Caregivers

Instructions: Please provide the following information.

Your Age _____

Your Gender _____ Male
_____ Female

Your Race/Ethnicity _____ African American
_____ Arab American
_____ Asian American/Pacific Islander
_____ European American/White
_____ Latino/a
_____ Native American
_____ Biracial/Multiracial
_____ Other

Your Relationship to Care Recipient _____ Spouse
_____ Adult Child
Other, please specify: ______________________

Your Education _____ Less than high school graduation
_____ High school graduation
_____ Some college or associate’s degree
_____ Bachelor’s degree
_____ Master’s degree
_____ Doctoral degree or Professional degree
<table>
<thead>
<tr>
<th>Your Income</th>
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<tbody>
<tr>
<td>_____ Less than $19,999</td>
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<tr>
<td>_____ $20,000 to $39,999</td>
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<tr>
<td>_____ $40,000 to $59,999</td>
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<tr>
<td>_____ $60,000 to $79,999</td>
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<tr>
<td>_____ $80,000 to $99,999</td>
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<tr>
<td>_____ More than $100,000</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Your Residence</th>
</tr>
</thead>
<tbody>
<tr>
<td>_____ Urban or Medium City</td>
</tr>
<tr>
<td>_____ Suburban or Small City</td>
</tr>
<tr>
<td>_____ Small Town</td>
</tr>
<tr>
<td>_____ Rural</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Your Occupational Status</th>
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</thead>
<tbody>
<tr>
<td>_____ Part Time</td>
</tr>
<tr>
<td>_____ Full Time</td>
</tr>
<tr>
<td>_____ Full-Time Homemaker</td>
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<tr>
<td>_____ Retired</td>
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<tr>
<td>_____ Unemployed</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Estimated Time Providing Care Per Week</th>
</tr>
</thead>
<tbody>
<tr>
<td>_____ 0 to 15 hours per week</td>
</tr>
<tr>
<td>_____ 15 to 30 hours per week</td>
</tr>
<tr>
<td>_____ 30 to 40 hours per week</td>
</tr>
<tr>
<td>_____ More than 40 hours per week</td>
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</table>

<table>
<thead>
<tr>
<th>Estimated Time Using Respite Services (e.g., Adult day program, relatives or other respite caregivers)</th>
</tr>
</thead>
<tbody>
<tr>
<td>_____ 0 to 5 hours per week</td>
</tr>
<tr>
<td>_____ 6 to 10 hours per week</td>
</tr>
<tr>
<td>_____ 11 to 15 hours per week</td>
</tr>
<tr>
<td>_____ 16 to 20 hours per week</td>
</tr>
<tr>
<td>_____ 21 to 25 hours per week</td>
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<tr>
<td>_____ 26 to 30 hours per week</td>
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<tr>
<td>_____ More than 30 hours per week</td>
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<thead>
<tr>
<th>Total Time Providing Care</th>
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<tbody>
<tr>
<td>_____ 0 to 1 year</td>
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<tr>
<td>_____ 1 year</td>
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<td>_____ 2 years</td>
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<tr>
<td>_____ 3 years</td>
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<tr>
<td>_____ 4 years</td>
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<tr>
<td>_____ 5 years</td>
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<tr>
<td>_____ More than 5 years, please specify</td>
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</tbody>
</table>
Care Recipient

Instructions: Please provide the following information about your care recipient.

Age _____

Gender _____ Male
_____ Female

Race/Ethnicity _____ African American
_____ Arab American
_____ Asian American/Pacific Islander
_____ European American/White
_____ Latino/a
_____ Native American
_____ Biracial/Multiracial
_____ Other

Education _____ Less than high school graduation
_____ High school graduation
_____ Some college or associate’s degree
_____ Bachelor’s degree
_____ Master’s degree
_____ Doctoral degree or Professional degree

Living Arrangement _____ With Caregiver
_____ Without Caregiver
_____ Care Recipient’s Home
_____ Assisted Living
_____ Nursing Home
_____ Other arrangement

Residence _____ Urban
_____ Suburban or Small City
_____ Small Town
_____ Rural
<table>
<thead>
<tr>
<th>Estimated Time Per Week at Adult Day Program</th>
<th>0 to 5 hours per week</th>
<th>6 to 10 hours per week</th>
<th>11 to 15 hours per week</th>
<th>16 to 20 hours per week</th>
<th>21 to 25 hours per week</th>
<th>26 to 30 hours per week</th>
<th>More than 30 hours per week</th>
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