

## ABSTRACT

Title of Thesis:       WHAT IT MEANS TO CARE: A MEANING-FOCUSED  
EXPRESSIVE WRITING INTERVENTION FOR FAMILY  
CAREGIVERS

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Over 67 million adults in the U.S. provide informal or unpaid care to a loved one facing a health challenge, but caregivers often feel underprepared and isolated in this challenging role. There is a dearth of interventions to improve quality of life for caregivers. One hundred caregivers wrote three expressive writing essays about their experience in one of three randomly-assigned conditions: caregiver time-management, emotional expression, and meaning of caregiving. This study had two primary aims: 1) to investigate effects of writing among the three writing conditions on outcomes of depression, caregiver burden, intrusiveness, satisfaction with life, worldview violation, and meaning in life and 2) to assess whether meaning in life serves as a mediator for outcomes. Results indicated that some positive effects of expressive writing can be explained by the discovery of, but not

simply the search for, meaning. Implications about understanding of the psychological experience of caregivers are discussed.

WHAT IT MEANS TO CARE: A MEANING-FOCUSED EXPRESSIVE WRITING  
INTERVENTION FOR FAMILY CAREGIVERS

by

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Thesis submitted to the Faculty of the Graduate School of the  
University of Maryland, College Park in partial fulfillment  
of the requirements for the degree of  
Master of Arts  
2015

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## Introduction

People tend to believe that the world is coherent, fair or just (Furnham, 2003; Lerner, 1980), and that there are predictable, ordered, and meaningful qualities to their lives (Epstein, 1991; Janoff-Bulman, 1989). The onset of trauma or a significant stressful event that leads to becoming a caregiver, typically violates these kinds of beliefs (Holland & Reznik, 2005; Janoff-Bulman & Frantz, 1997). Violation of long held beliefs or life goals can lead to distress, and this distress can last for days, weeks, months, or years depending on one's coping abilities and resources. Faced with the chronic need to cope that comes with the uncertain trajectory of illness, family members of persons with a serious health challenge often grapple with the coherence, fairness, and meaning of their partner's disease.

There are more than 65 million caregivers in the United States, nearly all of whom struggle with the emotional, physical, and financial stresses of caring for a loved one with a health challenge (National Alliance for Caregiving, 2009). This distress – effecting 1 in 5 people – can lead to years filled with attempts to make sense of changing circumstances and relationships. For caregivers of persons with a debilitating condition, the experience of providing care can be especially volatile – filled with the ups and downs of treatment, recovery, and the possibilities of recurrence and decline – and lead to a chronic need to make sense of the caregiving experience.

To understand how caregivers manage the stress of caregiving, it is useful to examine the psychological literature on coping. Much of the coping literature has focused on the management of distress or psychological deficits associated with negative events (Haan, 1977; Lazarus & Folkman, 1984; Moos & Schaefer, 1993). However, there is an

emerging literature illustrating that there are positive aspects of coping with stress and trauma that may occur as well (Folkman, 1997; Lazarus et al., 1980).

When distress is experienced, negative emotions can also be accompanied by positive emotions (Folkman, 1997; Lazarus et al., 1980). Lazarus and colleagues (1980) characterized the experience of positive emotion as a “breather” or distraction from distress, as a “sustainer” that bolsters self-esteem and self-efficacy, and as a “restorer” that builds connection and care with others. Fredrickson (2001) proposed the broaden-and-build theory, asserting that experiencing positive emotion broadens one’s ability to build enduring physical, intellectual, social, and psychological resources that can buffer the effects of distress.

A longitudinal study of caregiver partners of men with AIDS was among the first to suggest that people often report positive psychological states amidst high levels of persistent distress (Folkman, 1997). Although the focus of Folkman’s study was to explore caregiver hassles, burdens, and the most stressful events of their caregiving experience, she also asked participants to describe something that was meaningful to them related to caregiving and that helped them get through the day. Nearly 100 % of caregivers discussed positive events in their caregiving experience. Folkman identified four types of coping associated with the positive caregiving experiences of these caregivers of AIDS patients: positive reappraisal, goal-directed problem-focused coping, spiritual beliefs and practices, and the infusion of ordinary events with positive meaning. Folkman concluded that searching for and finding meaning was the common theme that binds all four of these coping strategies, and further concluded that meaning can be created in the face of stressful circumstances.

Lazarus and Folkman (1984) initially proposed that people continuously appraise their interactions with their environment, and stressful appraisals such as threats, challenges, or harms, require coping to regulate distress. Coping then leads to an outcome such as favorable resolution, unfavorable resolution, or no resolution (Lazarus & Folkman, 1984). This original model posited that emotion is generated throughout the coping process, whereby favorable resolutions are likely to lead to positive emotion and unfavorable or no resolutions are likely to lead to distress. However, as a result of her study with AIDS caregivers, Folkman proposed that positive psychological states be integrated into the model in three pathways (Folkman, 1997). The first pathway involves positive emotion resulting from meaning-based coping, such as finding meaning regarding beliefs and values through appraisal of the situation, revising one's goals or sense of purpose, or finding spiritual beliefs that lead to existential meaning. The second pathway suggests coping as a response to distress rather than a response to the conditions that initiated the distress. In other words, positive emotion may offer relief from negative psychological states. Finally, the third pathway posited a link between positive emotion and appraisal and coping, in which positive emotions serve as a sustaining force for coping processes.

This understanding of the role of positive emotion in coping – particularly the thematic function of meaning – led to the development of a model to capture the role of making meaning as a way to cope with stressful life events (Park & Folkman, 1997). For example, when a problematic event, such as a cancer diagnosis, occurs, individuals engage in meaning-making to protect wellbeing in the face of threats (Hoffman, Lent, & Raque-Bogdan, 2013). Meaning-making is viewed as a coping mechanism that is

initiated when a major event is at odds with a person's personal beliefs and goals (Park, 2010). Finding meaning has been the focus of a number of studies examining coping with chronic stress and loss (Baumeister, 1991; Frankl, 1963; Klinger, 1977; Park & Folkman, 1997; Silver & Wortman, 1980), and efforts to further understand the role of meaning in coping has spurred the creation and refinement of a meaning-making model (Park & Folkman, 1997; Park, 2010). This leads to the first purpose of the study which was to examine whether the expressive writing paradigm developed by Pennebaker (Pennebaker & Beall, 1986) might be one way that caregivers might make meaning of their caregiving experience.

According to Park's model (2010), the meaning-making process is initiated when people encounter situations that have the potential to challenge ways in which they view themselves and the world (global meaning). When a person's appraised meaning of a situation is discrepant with their global meaning, distress occurs. Through efforts to make meaning, individuals attempt to reduce the discrepancy and distress experienced. When the meaning-making process leads to an outcome, meaning made, people demonstrate better adjustment to the stressful event (Park & Folkman, 1997). Moreover, Park (2010) asserts that it is not the *attempt* to make meaning that is adaptive, but rather *achieving* meaning (meaning made). Folkman (1997) asserted that positive emotion and adaptive coping comes from the ability to identify meaning rather than asking the question, "What does this mean?" In fact, just thinking about or searching for meaning without the outcome of having made meaning can lead to rumination and increased distress (Nolen-Hoeksema & Larson, 1999). Thus, helping people to access the adaptive outcomes of the

meaning-making process provides promise for interventions for persons dealing with chronic stressors such as informal caregivers.

Dozens of studies have examined meaning-focused interventions in myriad distressed populations, from bereaved parents to survivors of incest. However, many studies have examined only attempts to make meaning or products of the process (meaning made). There have been more than 30 studies that examine both meaning-making and meaning made, which more fully captures the theoretical constructs associated with coping and adjustment. Interventions focused on participants' search for and discovery of meaning have found a number of improvements, including lower levels of distress, more positive mood, lower levels of cancer-specific distress, and less rapid decline in T cell levels in persons with AIDS.

Expressive writing, which has been identified as a possible mechanism for meaning-making (Park, 2010), is a brief psychological intervention focused on disclosure of thoughts and emotions (Pennebaker & Beall, 1986). This paradigm involves writing about emotional or traumatic experiences to help participants explore thoughts and feelings around a stressful event (Pennebaker, 1997). Expressive writing helps people to organize their narratives and is posited to increase the acceptance of negative events (Pennebaker, 1993). Extensive research has found that expressive writing produces improvements in self-reported health, psychological well-being, physiological functioning, and general functioning (Frattaroli, 2006; Frisina et al., 2004; Smyth, 1998). Effect sizes have generally been small and vary depending on the sample, setting, and specific prompt instructions (Frattaroli, 2006, Frisina et al., 2004; Smyth, 1998). In addition, immediately after writing about trauma, participants generally report increased

negative affect which can last for several weeks (Gillis et al., 2006; Smyth, 1998). Findings such as this have prompted researchers to develop variations of the traditional paradigm that instruct participants to focus on positive constructs such as gratitude when writing about their experiences and to explore the underlying mechanisms that can highlight the positive effects of the intervention. In contrast to the traditional paradigm, in which participants are asked to write about upsetting events (Pennebaker & Beall, 1986), positive writing interventions have been found to immediately increase positive affect and produce the same benefits several months later as writing about trauma (Burton & King, 2004; King, 2001). Thus there was interest in examining an intervention utilizing a positive writing condition because of its potential to provide more immediate benefits as compared to the traditional expressive writing paradigm about trauma.

Research on expressive writing and meaning making has been equivocal, with some research suggesting that making meaning may be a mechanism underlying positive effects in expressive writing (Boals & Klein, 2005; Pennebaker, 1997; Park, 2010), while others assert that expressive writing leads to making meaning (Cordova, Cunningham, Carlson, & Andrykowski, 2001; Creswell et al., 2007; Graybeal, Sexton, & Pennebaker, 2002; and Low, Stanton, & Danoff-Burg, 2006). Expressive writing studies have examined making meaning through a focus on the use of words such as because, think, or realize. Studies have revealed that participants for whom meaning making increases across the intervention are the most likely to benefit from the expressive writing paradigm (Owen et al., 2005; Pennebaker, Mayne, & Francis, 1997; Rivkin, Gustafson, Weingarten, & Chin, 2006; and Schwartz & Drotar, 2004). Expressive writing has also increased meaning made, (Smyth, Hockemeyer, & Tulloch, 2008; Ulrich & Lutgendorf,

2002). However, several studies, however, have failed to support the idea that expressive writing leads to meaning making or that making meaning mediates positive effects of the intervention (Cordova, Cunningham, Carlson, & Andrykowski, 2001; Creswell et al., 2007; Graybeal, Sexton, & Pennebaker, 2002; and Low, Stanton, & Danoff-Burg, 2006). Other studies highlight moderating differences within expressive writing. Boals (2012) operationalized meaning making in expressive writing through the use of judges' ratings and the use of cognitive words and found that participants who wrote about highly distressing events were more likely to have increases in meaning making and decreases in intrusive thoughts. However, for participants who wrote about less distressing events, increases in meaning making – as rated by judges – were linked with increases in intrusive thoughts. A significant gap in the literature on expressive writing was the paucity of studies that ask participants to write about meaning they attribute to a specific identified stressor. Explicitly testing the fundamental components of the meaning-making model, such as examining changes in global or situational meaning – or the discrepancy between them – can provide valuable information about making meaning through expressive writing. This was another purpose of the proposed study. Additionally, very few expressive writing studies have intervened with participants in the midst of chronic stress, and instead, have assessed meaning making only through retrospective participant self-report. The proposed study addressed the need to more accurately examine the role of making meaning in expressive writing by examining the effects of a meaning-focused expressive writing in a sample of family caregivers of people undergoing treatment for a health condition.

Prior to the current study, four expressive writing interventions had been

conducted with various samples of informal caregivers, including caregivers of those with early psychosis (Barton & Jackson, 2008), caregivers of older adults (Mackenzie, Wiprzycka, Hasher, & Goldstein, 2007, 2008), caregivers of children and adolescents with chronic illness (Schwartz & Drotar, 2004), and a sample comprised of various types of caregivers (Ashley, O'Connor, & Jones, 2011). Little to no effects of the expressive writing intervention were found on outcomes of interest, such as mood, physical symptoms, caregiver burden, and depression and anxiety. Three out of the four studies asked participants to write about thoughts and feelings related to negative events, including care recipient's first episode of psychosis (Barton & Jackson, 2008), caregiver stress and burden (Mackenzie, Wiprzycka, Hasher, & Goldstein, 2007), and the most traumatic and upsetting experiences of their entire life (Schwartz & Drotar, 2004). Only one study with caregivers (Ashley, O'Connor, & Jones, 2011) examined the efficacy of writing about positive life events (e.g., being in love, becoming a parent), despite evidence that writing about topics other than stress can have benefits (Burton & King, 2004, 2008; Wing, Schutte, & Byrne, 2006). Mackenzie and colleagues (2008) have suggested that when studying caregivers, given the potential for expressive writing to increase rumination and negative affect, expressive writing should focus on prompts that are positive, optimistic, and future-oriented to have positive outcomes.

The purposes of the present study were a) to assess the effectiveness of a brief, online meaning-making intervention for informal, spousal or partner caregivers of persons with cancer; b) to compare the effectiveness of an explicitly meaning-focused intervention with a traditional expressive writing intervention; c) and to examine whether meaning made mediates the relationship between the intervention and positive outcomes.

The first purpose of the study was inspired by the emergence of a national health priority to develop research that identifies ways to support caregivers (U.S. Department of Health and Human Services, 2010). Moreover, identifying psychosocial interventions that can be easily implemented, as in the case of the present online intervention, had the potential to provide support that addresses the multidimensional impact of caregiving. In addition, the use of positive psychology interventions for those managing chronic medical diseases represented a relatively unexplored area.

The second purpose of the study was to address the call within the expressive writing literature to determine for whom the intervention is most effective (McNulty & Fincham, 2012; Pennebaker, 2004). The very limited body of research utilizing the traditional or standard expressive writing paradigm with caregiver samples had not found positive results. However, this study assessed the effectiveness of writing prompts that had been shown to be effective with other vulnerable and distressed samples but that had not yet been assessed with caregivers. A meaning-focused prompt was proposed help to explore whether making meaning through writing mediates the relationship between the intervention and emotional outcomes.

The third purpose of the study was to examine whether there are emotional benefits of meaning exploration for caregivers (Park, 2010; Folkman, 1997). Research is needed to test the application of the concepts in the meaning-making model to determine if this way of coping is linked to more positive adaptation.

The final purpose of the proposed study was to improve upon previous research, which typically had assessed meaning making attempts indirectly through post-hoc analyses, such as the use of insight words, rather than through deliberate direction to

write about meaning within the prompt. In contrast, the current study examined whether instructing participants to write about meaning in their current caregiving experience would increase participants' reports of meaning making and other positive outcomes.

## **Review of the Literature**

This literature review is divided into two main sections: research on informal caregivers with an emphasis on those caring for someone with cancer and research on the expressive writing paradigm. In the first section on caregivers, I describe the characteristics and roles of caregivers. Next I outline research on the psychological impact of caregiving. I discuss interventions aimed at providing support to caregivers, with a focus on psychological interventions and outcomes. This section also presents research related to making meaning of caregiver experiences as a way of coping, focusing on the benefits of meaning-focused interventions for caregivers.

In the second section, I review the literature related to the expressive writing paradigm developed by Pennebaker. First, meta-analyses regarding the general effectiveness of the expressive writing intervention will be discussed. Then, the research from the limited studies that have used the expressive writing paradigm with caregivers will be examined. Finally, I will discuss potential moderators within the expressive writing paradigm that are relevant to this study.

### **Caregiving.**

While there is a vast literature on caregiving and the physical, psychological, financial, and social toll of the caregiving experience, much of the existing research has been conducted by nurses and other medical professionals. Nurse researchers have focused inquiry and intervention on the caregiver-care recipient dyad, considering the pair and not the individual as “the unit of care.” However, caregivers are chronically engaged with the care recipient, and interventions that focus specifically on those who provide care may offer therapeutic effects simply by focusing on the individual needs of

the caregiver.

**Description.**

There are more than 65 million caregivers in the United States providing physical, emotional, and financial support to those facing chronic conditions and illness (National Alliance for Caregiving, 2009). This section describes the characteristics of informal caregivers. According to the Family Caregiver Alliance (2011), informal caregivers are untrained, unpaid friends or relatives providing assistance to a person with a chronic or disabling condition. In 2009, one in three American households reported that at least one person served as an unpaid family caregiver (Family Caregiver Alliance, 2011).

Family caregivers are also referred to as informal caregivers and are typically women – often the partner or daughter of the care recipient (National Alliance for Caregiving & AARP, 2009). The majority of caregivers report providing from 20 to 39 hours of caregiving per week, with one-third of caregivers having provided such care for more than five years (National Alliance for Caregiving & AARP, 2009). Informal caregivers report having been in that role for an average of 4.6 years (National Alliance for Caregiving & AARP, 2009). In addition to daily activities, such as helping with activities of daily living such as getting in and out of bed, paying bills, and filling medicine prescriptions, some caregivers must now conduct activities once provided by professionals (e.g., changing an IV) without adequate training or preparation (Given, Given & Kozachik, 2001).

Care recipients are on average 69 years of age and rely on caregivers to help with at least one activity for daily living (e.g. bathing, getting dressed), with the majority requiring the assistance to manage four essential activities (e.g. taking medication,

managing finances) (National Alliance for Caregiving & AARP, 2009). Nearly three-fourths of care recipients have one or more medical conditions defined as chronic (National Alliance for Caregiving & AARP, 2009), or diseases that are long-lasting with slow progression (World Health Organization, 2013).

### **Physical and Financial Effects.**

Emerging evidence suggests that caregiving takes a toll on multiple aspects of well-being. For example, 17% of caregivers report that their health has gotten worse due to providing care (National Alliance for Caregiving & AARP, 2009). Caregivers may experience negative health effects as a result of their role, including cardiovascular diseases (Lee et al., 2003; von Kanel et al., 2008), decreased immune functioning (Kiecolt-Glaser et al., 1987; Rohleder et al., 2009), cognitive decline (Lee, Kawachi, & Grodstein, 2004), poor sleep quality (Cho et al., 2006), and increased rates of mortality (Schulz & Beach, 1999; Christakis & Allison, 2006). Research has also suggested that spousal caregivers often do not seek medical care for themselves when ill due to time demands of caregiving (Burton et al., 1997; Carter, 2002). Research on physical effects specific to cancer caregivers include fatigue, pain, sleep disturbance, and loss of appetite (Carter, 2002; Stenberg et al., 2010). While cancer caregivers initially report levels of health similar to non-caregiving populations, caregivers report decreased physical functioning (e.g., sleep disturbance, impaired cognitive functioning) over time (Bishop et al., 2007).

Financial burdens also have a negative impact on caregiver quality of life (Clavarino et al., 2002; Yun et al., 2005). These burdens include workplace difficulties such as missing work (Scharlach & Boyd, 1989). Caregivers are often employed,

especially because of the need for income and insurance benefits, but these caregivers report lost hours from work when they must assist the care recipient more with activities of daily living (Sherwood et al., 2008). In addition, caregivers report more lost hours with each increasing month from the date of the care recipient's diagnosis as caregiving demands increase (Sherwood et al., 2008). Two-thirds of caregivers reporting they have gone into work late, left early, or used personal or vacation leave to address caregiving concerns (National Alliance for Caregiving & AARP, 2009). Cancer caregivers attempting to balance the demands of career and personal responsibilities may be particularly vulnerable to stress and other negative outcomes (Gaugler et al., 2008; Kim et al., 2006), such as higher levels of depressive symptoms (Given et al., 2004). Yet, employment often provides a kind of respite for caregivers who need a break from the strain of caregiving and who need social support and economic stability (Gysels & Higginson, 2009; Kim et al., 2006; Swanberg, 2006).

### **Psychological Effects.**

Many caregivers provide such assistance for years, leading to long periods of emotional, physical, and financial stress. Family caregivers often report levels of emotional distress, anxiety, and depression similar to the patients for whom they provide care (Bishop et al., 2007; Cliff & MacDonagh, 2000; Given et al., 1993; Kornblith et al., 1994). For cancer caregivers, advanced stages of disease is especially difficult, with some caregivers reporting higher levels of depression than do patients (Braun et al., 2007). As the health of those for whom they provide care improves, worsens, or remains the same, caregivers often must make sense of their changing circumstances and relationships. Despite these challenges, caregivers often do not utilize mental health services to address

their emotional needs (Bishop et al., 2007; Vanderwerker et al., 2005), and therefore psychological distress can persist for as long as or longer than the treatment for the cancer patient.

Caregivers report increased and clinical levels of depression and anxiety when compared with non-caregivers (Aschbacher et al., 2008; Bandeira et al., 2007; Dura, Stukenberg, & Kiecolt-Glaser, 1991; Haley et al., 1995; Shaw et al., 1999). Up to half of caregivers of older adults and persons with dementia experience depressive symptoms consistent with levels of clinical depression (Butler et al., 2005; Covinsky et al., 2003). Depression may result from concerns about the care receiver's illness or eventual death (Lindemann, 1994; Walker & Pomeroy, 1996). Informal caregivers have also been found to experience significantly high levels of stress (Vitaliano et al., 1991), lower well-being (Rose-Rego, Strauss, & Smyth, 1998), more feelings of burden (Dunkin & Anderson-Hanley, 1998), and decline in physical health (Loomis & Booth, 1995; Rose-Rego et al., 1998) when compared with non-caregiver populations.

Cancer caregivers represents one of the largest groups of those providing care as more than 11 million Americans are currently living with cancer (American Cancer Society, 2010). Cancer caregivers comprise about 7 percent of adult caregivers (NAC & AARP, 2005) report some of the most negative effects of caregiving, including the highest levels of responsibility, demand, and depression (NAC & AARP, 2005). Despite evidence that cancer caregivers experience some of the highest levels of distress such as burden and depression (NAC & AARP, 2005), even meta-analyses (e.g., Northouse et al., 2010) that examine interventions for cancer caregivers rely on information about the experience of the general population of caregivers. As advances in medicine continue to

increase rates of cancer survivorship, interventions that more specifically target cancer caregivers will be needed to assist the growing number of these caregivers as they help loved ones face ongoing challenges to independent function and mental health. While this growing population has led to the creation of a new national health priority to support caregivers (U.S. Department of Health and Human Services, 2010), further research is needed to identify effective interventions that decrease depression and anxiety and increase subjective well-being.

Despite the negative effects of caregiving discussed so far in this review, many caregivers report positive outcomes as well such as positive affect, sense of mastery, and improvement in relationship between caregiver and care recipient (Beach, Schulz, Yee, & Jackson, 2000). For example, caregivers report that caregiving makes them feel good about themselves, feel as if they are needed, feel there is meaning in their lives, and help them to learn new skills (Schulz et al., 1997). Caregivers may also report that they have grown because of their caregiving experiences, but they may also simultaneously report a loss of role identity (Skaff & Pearlin, 1992). Stage of caregiving may also have different effects on caregivers. Some studies have reported that caregivers may not experience negative effects during the early stages of caregiving (Burton et al., 2003; Hirst, 2005), though this may not be true for cancer caregivers, who experience the abrupt onset of responsibility with a variable trajectory and greater intensity because of possible mortality (Kim & Schulz, 2008). Despite evidence from Folkman's landmark study that positive emotions and meaning may play a central role in coping for caregivers (Folkman, 1997), relatively few studies have examined interventions to see if this is the case.

### **Research on interventions to assist caregivers.**

The prolonged period of distress experienced by caregivers calls for interventions that bolster coping and maintain levels of psychological and physical health for caregivers. Furthermore, it appears that most psychosocial services that address cancer survivorship are provided for the survivor and not the caregiver.

A number of interventions have been developed to decrease negative physical and psychological effects for caregivers helping those with illness, disability, and other health conditions. These efforts have had mixed results (Sorensen, Pinquart, & Duberstein, 2002; Northouse et al., 2010), and the need for effective interventions will increase as the number of informal caregivers is projected to rise by 85 percent in the coming years due to decreases in hospital stays, changes in insurance reimbursement, and an aging population (Aldrich, 2011).

Two meta-analyses have investigated the effectiveness of interventions for caregivers (Sorensen, Pinquart, & Duberstein, 2002; Northouse et al., 2010). Sorensen, Pinquart, and Duberstein (2002) conducted a meta-analysis of interventions for caregivers of older adults with various conditions. The 78 studies selected for the analysis included care recipients with a mean or median age of 60 years or older; had at least one intervention and one control condition; examined outcomes of either caregiver burden, depression, measures of psychological well-being (e.g., life satisfaction, morale, self-esteem, happiness), uplifts of caregiving, caregiver knowledge, caregiver coping abilities, and care receiver symptoms; contained effect size statistics; were written in English, German, French, or Russian; and were published in peer-reviewed journals. The meta-analysis examined these studies on six outcome variables (caregiver burden, depression,

subjective well-being, perceived caregiver satisfaction, ability/knowledge, and care receiver symptoms) and included six different types of interventions (psychoeducational, supportive, respite/adult day care, psychotherapy, care receiver competence, and multicomponent interventions). This meta-analysis concluded that the most consistent short-term effects on outcome measures came from psychoeducational ( $g = -.43 - .53$ ) and psychotherapeutic ( $g = -.29 - .37$ ) interventions. Sorensen et al. concluded that effect sizes were larger for increasing the ability/knowledge of caregivers ( $g = .41$ ) than for decreasing burden ( $g = -.15$ ) and decreasing depression ( $g = -.14$ ). A number of caregiver characteristics were also examined. Caregivers of persons suffering from dementia reported smaller improvements on outcomes than those for other groups. Observed moderators of effects were: number of intervention sessions, intervention setting, care receiver age, caregiver age, gender, relation to care recipient (spouse vs. child), and initial burden.

The Sorensen et al (2002) meta-analysis found that caregiver interventions produced a mean weighted effect size of between 0.14 and 0.41 across outcomes. Effects immediately following interventions were greater for ability/knowledge interventions than for those measuring burden, depression, uplifts of caregiving, and symptoms of care receiver. Immediate effects on subjective well-being were greater than those on burden and depression. At follow-up (an average of 7 months post intervention), significant effects were reported for burden ( $g = -.12$ ), depression ( $g = -.15$ ), subjective well-being ( $g = .23$ ), and ability/knowledge ( $g = .46$ ), but not for care recipient symptoms ( $g = -.09$ ). Overall, individual interventions were more effective than group interventions in terms of improving caregiver outcomes, which was consistent with previous findings

(Knight et al., 1993; Whitlatch et al., 1991).

Northouse and colleagues (2010) examined the effectiveness of 29 randomized clinical trials offered to family caregivers of cancer patients to determine the effect of the interventions on various outcomes, such as caregiver burden, caregiver benefit, information needs, coping strategies, self-efficacy, physical functioning, distress and anxiety, depression, marital-family relationships, and social functioning. Studies published from 1983 to 2009 were selected if they involved family caregivers or the caregiver care recipient dyad, if the intervention was psychosocially, cognitively, or behaviorally oriented, if participants were randomly assigned to intervention or control conditions, and if they were published in peer reviewed journals. Three types of interventions were identified: psychoeducational interventions (57 %) that sought to provide information regarding aspects of patient care, psychosocial needs of patients, caregivers, and family relationships; skills training (26 %), which focused on the development of coping, communication, and problem-solving involving behavior change; and therapeutic counseling (17%), aimed at developing a therapeutic relationship to address concerns related to cancer or caregiving. The majority of interventions were aimed at the caregiver/recipient dyad, or offered jointly to family caregivers and the cancer patient (63 %), were face-to-face visits (69 %), provided in the clinical setting (66 %). In more than half of cases, interventions were delivered by nurses, with only 14 % of interventions delivered by psychologists.

Small to medium effect sizes were found across interventions and outcomes. Better outcomes were reported for burden ( $g = -.04$  to  $.34$ ), benefit ( $g = -.53$  to  $1.49$ ), information needs ( $g = .92$  to  $1.77$ ), coping strategies ( $g = .02$  to  $.78$ ), self-efficacy ( $g =$

.03 to .56), physical functioning ( $g = -.05$  to .49), distress and anxiety ( $g = .03$  to .51), marital-family relationships ( $g = -.38$  to .38), and social functioning ( $g = -.34$  to .74). Results indicated that interventions did not decrease caregiver depression ( $g = -.38$  to .33), which may have been due to low baseline levels of depression and high attrition among depressed caregivers across samples. Of importance for the present study, this meta-analysis found that studies that promoted active coping or reduction of avoidance or denial coping enhanced caregiver coping and therefore better outcomes. Additionally, interventions for caregivers only resulted in more caregiver benefit, perhaps because they typically focused on the specific needs of the caregiver. Northouse and colleagues (2010) note that these interventions gave caregivers "...the opportunity to better reflect on the meaning and the importance of, as well as their confidence in, their caregiving role."

These meta analyses show that interventions for caregivers yield consistently small to medium effect sizes. Most interventions for caregivers have been psychoeducational in nature, and interventions designed for the caregiver and not the caregiver/care recipient dyad have yielded better results. There have been mixed results in decreasing caregiver depression, but caregiver burden seems to decrease through various kind of intervention.

While research has yet to explain the mechanisms through which caregiver interventions are successful, researchers agree that many interventions have been too time consuming for caregivers, who have significant burdens related to time to themselves and finances available for assistance (Wiles, 2003; Yantzi, Rosenberg, & McKeever, 2006). Wiles (2003) analyzed 30 interviews with self-identified family caregivers and observed that these caregivers sometimes sought care services for formal sources such as medical

or community organizations, but often carried the majority of the time and financial burden for the care of their loved one. In a series of semi-structured interviews with mothers of children with long term care needs, Yantzi, Rosenberg, and McKeever (2006) reported that mothers reported restricted employment opportunities because they needed to be available to take care of their children. Interventions that are time-limited, inexpensive, and based in the home may be the most appropriate. Another qualitative study investigating the experiences of cancer caregivers found that the onset of the caregiving experience was “life-changing” (Williams & Bakitas, 2012). Through analysis of 135 interviews of caregivers for those with colon or lung cancer, Williams & Bakitas (2012) reported a need for interventions that support caregivers through reinforcement of positive aspects of caregiving, cultivate open communication, and acknowledge the experiences and social factors that are supportive and burdensome. These studies seem sort of tacked on as the meta-analyses are pretty comprehensive- think about framing this paragraph so it flows from the previous one and offers something new or adds to the previous ones

### **Meaning making in the context of caregiving.**

People tend to believe that that the world is coherent and fair or just (Furnham, 2003; Lerner, 1980) and that there are predictable, ordered, and meaningful qualities to their lives (Epstein, 1991; Janoff-Bulman, 1989). The onset of trauma or significant stressful event, such as the need to become a caregiver, typically violates these kinds of beliefs (Holland & Reznik, 2005; Janoff-Bulman & Frantz, 1997). Violation of beliefs leads to immediate distress that can last for days, weeks, months, or years depending on the coping efficacy of the caregiver.

Building on Folkman's cognitive theory of stress and coping, the way that caregivers appraise the stressful situation of caregiving will influence their responses to the chronic stress (Folkman, 2008). Many have described caregiving as challenging, but some may experience it as more threatening to well-being. If something is appraised to be more of a challenge than a threat, the appraiser will experience less stress related to the situation (Nolan et al., 1996). This suggests that identifying positive aspects of providing care and encouraging positive appraisal of caregiving experiences could result in less stress and other negative outcomes.

Caregivers can positively appraise their caregiver experiences in many ways. One such way is to find meaning in caregiving. Finding meaning consists of making sense, order, and coherence of one's existence (Reker, Peacock, & Wong, 1987). Researchers have proposed that the degree to which caregivers can find meaning in their caregiving can reinforce the desire to provide care (Quinn et al., 2010).

An existing model of meaning-making helps to understand this coping mechanism (Park & Folkman, 1997; Park, 2010). According to the model, the meaning-making process is initiated when people encounter situations that have the potential to challenge ways in which they view themselves and the world (global meaning). When a person's appraised meaning of a situation (situational meaning) is discrepant with their global meaning, distress occurs. The level of distress is determined by the magnitude of the discrepancy (Park, 2010). Through efforts to make meaning, individuals attempt to reduce the distress experienced and the discrepancy between situational and global meaning. This process may be automatic or deliberate, an assimilation or accommodation, a search for comprehensibility or significance, and be a cognitive or

emotional process. The model posits that when meaning is discovered or made, people demonstrate better adjustment (e.g., less distress) related to the stressful event. Moreover, Park (2010) asserts that it is not the attempt to make meaning that is adaptive, but rather coming to an outcome, or meaning made. While meaning making as a *process* is widely considered to be essential for adjusting to stressful events (Gillies & Neimeyer, 2006), many believe that meaning making only leads to adjustment to the extent that some product is achieved (meaning made) (Park & Folkman, 1997). Reductions in distress are necessarily dependent on the reduction of discrepancy between appraised and global meaning. When meaning making is present, it does not mean that adjustment is taking place, but rather that a person is attempting to reduce discrepancy.

Dozens of studies have examined the meaning-making process in myriad distressed populations, like caregivers (Park, 2010). In a study to examine the factors that predict finding meaning in caregiving, Quinn, Clare, and Woods (2012) examined a population of dementia caregivers and found that higher levels of meaning was significantly predicted by high competence, religiosity, intrinsic motivations, and low role captivity (the extent to which caregivers felt trapped in their role). Identifying factors like these are important in understanding the origins and function of meaning for caregivers. The findings suggest that caregivers find and make meaning from a variety of perspectives and based on different individual characteristics. The study also underscores the importance of creating interventions that allow for the experience of both positive and negative aspects of caregiving.

While researchers contend that helping people to access the adaptive outcomes of the meaning-making process provides promise for interventions for chronically distressed

populations like caregivers (Park, 2010), few have empirically tested the model of meaning-making or its components. Moreover, most studies have not examined meaning-making using the theoretical framework espoused by Park (2010), but rather measure one or two aspects of the model or do not differentiate between key aspects of the model such as the process and outcome of the process (Park & George, in press). Additionally, studies that aim to capture the process of meaning making often do not use measurements that are consistent with these conceptual components.

Park (2010) suggests that the process of meaning-making may be a mechanism underlying expressive writing. However, based on personal communication with Park (July 26, 2013), the current study conceptualizes meaning-making as a process and outcome within expressive writing, and aims to test the effectiveness of the writing paradigm using components of the model rather than testing the comprehensive components of the meaning-making model. The compatibility of meaning-making and expressive writing will be described in more detail in the following section.

### **Expressive Writing Paradigm**

There are emotional and cognitive components of meaning making (Hunt, Schloss, Moonat, Poulos, & Wieland, 2007; Sloan, Marx, Epstein, & Lexington, 2007; Ulrich & Lutgendorf, 2002), and both of these processes are highlighted in the expressive writing paradigm developed by Pennebaker (1997). During times of distress, such as a loved one struggling with illness, the act of written disclosure can be a powerful tool to facilitate acknowledgment of thoughts, emotions, and experiences and to integrate these into personal narratives (Pennebaker, 1997). This goal to integrate and make congruent

personal narratives is in line with the theory of meaning-making in which discrepancy between beliefs/goals and experience is reduced.

Expressive writing is a brief, cost-effective intervention that could have numerous benefits for caregivers, including the ability to make sense of experiences. While outcome research of talk therapy supports verbal disclosure as an agent of change, Pennebaker developed expressive writing to explore the psychological and physical benefits of writing about emotional experiences (Pennebaker & Beall, 1986). In more than two decades since the development of expressive writing, myriad of studies with various populations have produced findings that suggest that the paradigm is effective in improving people's lives (Frattaroli, 2006). The paradigm typically involves writing for three sessions of about 15 to 20 minutes, and has proven effective when administered online (Lange et al., 2003). Following evidence that expressive writing is effective, studies have continued to investigate the properties that make the intervention successful and for whom the paradigm works best.

### **Empirical support for expressive writing.**

There are several competing models regarding the theoretical function of the expressive writing paradigm. The first suggested model was emotional inhibition, in which it was hypothesized that disclosing thoughts and feelings related to traumatic experiences would reduce inhibition and lead to improvements in health and well-being (Pennebaker, 1986). The second framework is cognitive adaptation, which posits that the resolution of trauma includes assimilation and accommodation of traumatic events with pre-existing schemas (Janoff-Bulman, 1992). Finally, exposure or emotional processing assumes that writing allows negative stimuli to be re-experiences and therefore negative

associations to be extinguished through repetition.

The current study is most closely aligned with the cognitive adaptation or cognitive processing model. Expressive writing studies in which participants write in a narrative manner compared with a fragmented manner benefitted more from the intervention (Smyth et al., 2001). This narrative-building approach has also been supported by an analysis of expressive writing studies in which results indicated that those who used more insight and causal words, which have been markers of attempts to make meaning of experiences, benefitted more from the intervention (Pennebaker & Seagall, 2006).

Smyth and Pennebaker (2008) note that expressive writing has drawn enough meta-analytic attention “to conduct a meta-meta-analysis.” These meta-analyses have been conducted to explore if the intervention is effective, how effective it is, for whom it works, and when it works (Smyth, 1998; Frisina et al., 2004; Frattaroli, 2006). Smyth’s meta-analysis (1998) examined 13 experimental studies, which relied heavily on samples of healthy college students. Results of the analysis indicated a small mean effect size ( $r = .23$ ) across all studies and outcomes. Written disclosure across the sample of 13 studies found medium effect sizes for psychological well-being ( $d=.66$ ) and physiological functioning ( $d=.68$ ), and found small effect sizes for reported health ( $d =.42$ ) and general functioning ( $d=.33$ ) when compared to the control groups. No significant improvements were found for health behaviors ( $d=.02$ ).

Another meta-analysis explored the effects of expressive writing on health outcomes for psychiatric or physical disorders (Frisina et al., 2004). The study examined nine experimental studies, five of which focused on medial illnesses (e.g. breast cancer,

prostate cancer, renal cancer, asthma, and rheumatoid arthritis). Analysis found a mean weighted effect size across all studies and outcomes that was smaller than the Smyth meta-analysis ( $r = .10$ ). This significant but smaller finding indicated that effects were larger for studies of healthy people. In the cases included in this study, expressive writing demonstrated a larger impact on physical health outcomes (e.g., health care utilization, somatic symptoms;  $d = .21$ ) than psychological outcomes (e.g., positive and negative affect;  $d = .07, p = .17$ ). The effect size for psychological outcomes was not significant in this analysis, but researchers found a positive impact on individual psychological symptoms like depression, mood, anxiety, and quality of sleep.

Both the Smyth (1998) and Frisina et al. (2004) meta-analysis present evidence that expressive writing interventions produce significant improvements. However, these studies have several noteworthy limitations. Both meta-analyses employed a fixed effects approach to determine the significance of the overall mean effect size. While this is an appropriate method for analyzing a small number of studies, it limits the ability to generalize the findings because the results and conclusions cannot be generalized to participants in studies not chosen for or included in the analysis (Hedges, 1994). According to Raudenbush (1994), a random effects approach allows researchers to extrapolate the findings to similar studies not included in the analysis since the study, instead of the participants, is the unit of analysis. A random effects approach allows for a larger number of studies in the analysis and increases the scope of generalizability. A second limitation of these previous meta-analyses is that many current expressive writing studies were not included in the analyses. In the span of time captured by these studies, the number of experimental studies and the types of methodologies of these studies

expanded. Including studies with different types and disclosure and writing instructions would have provided a more complete understanding and the effectiveness of the paradigm.

Frattaroli (2006) attempted to address these limitations in a more recent meta-analysis. This analysis employed a random effects approach and broadened the scope of inclusion criteria (4 % of studies were verbal disclosure) to examine studies with varying definitions of disclosure. They termed this inclusive group of studies experimental disclosure. The analysis included 146 experimental studies and examined effect sizes and tests of moderators not included in previous meta-analyses. Frattaroli (2006) found a small, significant mean weighted effect size across outcomes ( $r = .08$ ). Expressive writing significantly improved psychological health, including an increase in positive function and a reduction in distress, depression, anger, and anxiety. For physiological functioning, expressive writing demonstrated significant improvement in immune parameters, however, there was no significant improvement found on other types of functioning (e.g., joint condition, strength). In terms of reported health, expressive writing demonstrated significant improvement related to specific disease outcomes (e.g., HIV symptoms) and illness behaviors (e.g., medication use). Findings related to general functioning showed significant improvement on work-related outcomes (e.g., absenteeism), social relationships (e.g., forgiveness) and cognitive functioning (e.g., working memory). Frattaroli (2006) also assessed participants' feelings about completing the expressive writing and found that they felt more positive about the intervention, having attempted to make sense of the event significantly more often than the control group.

With the large number of studies included in the meta-analysis, Frattaroli (2006) explored several moderator variables of expressive writing, including setting, participant, methodological variables, and treatment variables. The study concluded that the conditions under which the expressive writing paradigm had the largest effect were: studies that included only participants with physical health problems, paid participants, and participants that engaged in disclosure at home or in a private setting. Examination of moderators also found that having at least three sessions of disclosure (lasting for at least 15 minutes), asking for participants to write about more recent events, giving participants direct questions or specific examples of disclosure, and having follow-up periods of less than one month demonstrated larger effect sizes. Examination of studies with these optimal characteristics showed an average effect size of  $r = .20$ . Several factors did not effect on outcomes, including participant factors like age, ethnicity, and education level. Other factors with no significant effects on outcomes included the time interval between disclosure sessions, valence of disclosure topic, and mode of disclosure (typing, talking, hand writing).

Each of these three meta-analyses provides an overall sense of the effectiveness of the expressive writing paradigm, providing guidelines about the ideal conditions under which to implement the intervention. Still, these studies examined a wide array of participants, outcomes, and methodologies, making it difficult to draw conclusions about the general properties and specific factors that would make expressive writing effective with caregiver populations. To address this issue, the next section examines the limited studies that have used expressive writing with participants who identify as caregivers.

**Expressive Writing Studies With caregivers.** Many interventions have been too time consuming for caregivers, who have significant burdens related to time to themselves and finances available for assistance (Wiles, 2003; Yantzi, Rosenberg, & McKeever, 2006). Interventions that are time-limited, inexpensive, based in the home, and focused on the emotional experience of caregivers may be the most appropriate. The expressive writing paradigm proposed in this study fits these criteria.

Expressive writing has been reported to be more helpful for those at lower levels of psychopathology (Sloan & Marx, 2004), and the majority of caregivers have subclinical levels of distress (Schulz et al., 2002). To date, four expressive writing interventions have been conducted with caregivers (Schwartz & Drotar, 2004; Mackenzie, Wiprzycka, Hasher, & Goldstein, 2007, 2008; Barton & Jackson, 2008; Ashley, O'Connor, & Jones, 2011).

The first study to use expressive writing with caregivers explored written emotional disclosure utilizing caregivers of children and adolescents with chronic illness, looking specifically at its effects on mood, physical symptoms, health-related quality of life, distress, and caregiver appraisal of stress and efficacy (Schwartz & Drotar, 2004). In a hospital setting, participants wrote about trauma or stressors following the traditional expressive writing format or they were assigned to write about summer activities in the control condition. Results indicated that participants in the traditional expressive writing condition experienced less positive affect and more negative affect and physical symptoms immediately after writing when compared with the control group. Participants in the control group reported more vitality, as measured by the Health Related Quality of Life scale, than the experimental group at 4-month follow-up.

The findings of this study are difficult to interpret when drawing conclusions about the effectiveness of expressive writing with caregivers for several reasons. First, only about half of participants who began the study completed it, raising questions about the characteristics of caregivers who chose to participate in the study. Researchers reported that those who dropped out of the study did not differ in mood from those who remained in the study, however, researchers did not provide information about dropout by condition. Interestingly, researchers found significant differences between the experimental and control groups, wherein more participants in the experimental group reporting having written (journalled) prior to the study. Additionally, this study assesses several outcomes, but did not assess appraisal, coping, or problem solving. As expressive writing is aimed at new or changed appraisal related to life events, it is possible that this research failed to capture changes in these processes and therefore did not find effects of written disclosure on the major outcomes. Finally, this study varied significantly from standard and recommended procedures of the expressive writing paradigm (Pennebaker, 1994) in that participants conducted writing while surrounded by the stressors (e.g., hospital environment, near or in the presence of the sick child) and were susceptible to distractions. Pennebaker (1994) recommends that participants write in a quiet and setting removed from the stressors associated with their stressful event and, in which they can get in touch with their deepest thoughts and feelings.

Another study examined the effect of expressive writing on caregiver burden and health among family caregivers of physically frail and cognitively-impaired older adults (Mackenzie, Wiprzycka, Hasher, & Goldstein, 2007). Participants were randomly assigned to traditional expressive writing, time management, or history-writing

conditions and completed four writings over a two-week period. Researchers did not find significant differences between the traditional expressive writing and the history writing interventions across outcomes. However, results indicated that participants in the time-management condition experienced significant improvements in mental and physical health following the intervention ( $d = 0.89$ ). These results must be interpreted with caution since time-management participants exhibited poorer ratings of health prior to the intervention, and therefore the magnitude of their improvement might represent intervention-related improvement, regression to the mean, or a combination of both.

The findings of Mackenzie and colleagues (2007) suggest that writing about emotional and stressful experiences of caregiving and writing about objective historical events did not relate to improvements in caregiver physical and mental health outcomes. Consistent with previous expressive writing studies, participants experienced slight short-term distress following the intervention. Despite the small sample, researchers concluded that a larger sample would have only underscored the lack of benefits for this intervention. Mackenzie and colleagues (2007) suggested that caregivers may benefit from expressive writing that is positively focused rather than focused on aspects so closely linked with chronic stress.

Because they did not find improvements in caregiver health and well-being through expressive writing, Mackenzie and colleagues conducted further analyses of participants' writings to explore characteristics linked with outcome improvement (Mackenzie et al., 2008). Though they hypothesized that narrative development would predict improvement, they found that the use of insight words did not predict positive outcomes. Participants who wrote with increasing complexity and honesty over the

course of the writings showed significant improvement in psychological distress. Still, the strongest evidence for positive improvement was observed among participants who wrote optimistically about their experiences. Mackenzie and colleagues (2008) concluded that for caregivers, expressive writing interventions should prompt participants to write in a manner that is positive, optimistic, and future-oriented to promote outcome improvement.

Barton and Jackson (2008) aimed to establish whether caregivers of persons with psychosis who wrote retrospectively about the first episode of psychosis would experience improvement in trauma-related symptoms, such as post-traumatic stress, anxiety, depression, somatic symptoms, and caregiver burden, through writing about their experiences. Thirty-seven caregivers participated in the study which found that those who wrote about their thoughts and emotions related to the first episode of the care recipient psychosis were significantly less likely to report avoiding their feelings about the event at follow-up (8 weeks after intervention) compared with the control group (writing about time management). Participants in the experimental group also reported greater reductions in trauma severity, as measured by improvements on the IES-R.

Finally, Ashley, O'Connor and Jones (2011) explored the effects of two types of writing interventions with caregivers on levels of depression and anxiety: writing about the stress of being a caregiver and writing about positive life experiences, such as being in love. While these researchers did not find main effects for writing condition on the outcome measures, further analysis of alexithymia (a deficit in processing emotions) as a moderator indicated that those with lower alexithymia who wrote about positive experiences reported less anxiety and depression on three follow-up measures (2 weeks, 2

months, and 6 months). Caregivers with lower scores on alexithymia in the control group also reported less anxiety at 2-week and 6-month follow-ups. This finding lends support for efforts to identify individual characteristics that align with desired outcomes.

The very few expressive writing studies done with caregivers to date have shown little to no effects on mood and physical symptoms (Schwartz & Drotar, 2004), post-traumatic symptoms (Mackenzie et al., 2007), somatic symptoms (Barton & Jackson, 2008), caregiver burden (Mackenzie et al., 2007; Barton & Jackson, 2008), depression and anxiety (Ashley, O'Connor, & Jones, 2011) and psychological well-being (Barton & Jackson, 2008; Mackenzie, Wiprzycka, Hasher, & Goldstein, 2007; Schwartz & Drotar, 2004). But these studies have employed only the traditional expressive writing prompt that asks caregivers to write about their deepest thoughts and feelings about caregiving. Only one study examined the efficacy of alternative writing prompts despite evidence that writing about topics other than stressors, such as meaning, can have benefits (Burton & King, 2004, 2008; Wing, Schutte, & Byrne, 2006). Further, the study that asked some participants to write about positive life events (Ashley, O'Connor, & Jones, 2011) did not ask them to write specifically about the caregiving experience in a positive manner. Positive disclosure about negative events has been linked to several health outcomes (e.g., fewer health complaints, fewer health center visits) and increased mood and life satisfaction (Burton & King, 2004, 2008; Wing et al., 2006). When writing about stressful events, expressive writing benefitted caregivers who used language considered positive, optimistic, and future-focused (Mackenzie et al., 2008). The researchers suggested that future expressive writing studies with caregivers should be positive, optimistic, and future-oriented to have positive outcomes. Yet to date, no expressive

writing studies have instructed caregivers to write positively about their caregiving experience. The proposed study will direct participants to do this through the meaning-focused prompt.

### **Moderators and Mediators.**

Based on the large number of studies on expressive writing and the mixed findings, Pennebaker (2004) has called for further investigation to determine when and for whom expressive writing interventions are most effective. Frattaroli (2006) found that effect sizes in expressive writing studies tended to be larger when studies included participants who had physical health problems, a history of trauma or stress, were non-college students, wrote at home or in a private setting, were paid, had at least three sessions of disclosure, had sessions lasting at least 15 minutes, wrote about previously undisclosed aspects of topics, wrote about positive topics, did not have their writings collected by the experimenter at the end, and had follow-up within one month of the intervention.

To address the effectiveness of variations of the traditional expressive writing paradigm, researchers have begun to develop expressive writing prompts with a positive focus. The traditional expressive writing paradigm asks participants to disclose thoughts and feelings about a traumatic event. Some more recent variations on the paradigm ask participants to write from a positive approach, such as the possible benefits of the traumatic or negative event (King & Miner, 2000) or their “best possible self” (King, 2001). Positive-focused writing interventions have been found to be as beneficial as traditional expressive writing interventions in terms of health benefits (Cameron & Nicholls, 1998) including reducing doctor visits (King, 2001; King & Miner, 2000).

Beyond the benefits of the traditional paradigm, writing interventions with a positive focus may produce additional benefits. In traditional expressive writing interventions, participants typically experience increased negative affect that can last for several weeks (Gillis et al., 2006; Smyth, 1998). Positive writing interventions, in contrast, have been found to immediately increase positive affect (Burton & King, 2004; King, 2001). One study asked participants to write about one's life as if all one's goals were met and everything went right. Participants showed improved psychological wellbeing whereas participants in the traditional expressive writing condition did not (King, 2001).

Mounting evidence begs the question about whether invoking negative emotions is necessary on the pathway to improvement. Instead, using positive writing conditions may lead to more benefits, both immediately and in the long term. While empirical support is building about when and for whom expressive writing is effective. However, there is no agreed upon theory of why the intervention works (Pennebaker, 2004). Pennebaker theorized that the writing process allows people to label emotions linked with negative events and therefore assign meaning to the event. Assigning meaning to the event allows one to blend the event and its meaning into existing cognitive schemas in such a way that lessens distress (Pennebaker & Seagal, 1999; Pennebaker & Chung, 2007).

Studies have begun to seek further understanding about the underlying psychological mechanisms that explain positive effects of expressive writing. In a sample of early-stage breast cancer survivors, Creswell et al. (2007) assessed three constructs as possible mediators of the effects of expressive writing on physical health: self-affirmation, cognitive processing, and discovery of meaning. Researchers found that self-affirmation was a full mediator in both emotional expression and benefit-finding writing

conditions. Cognitive processing and discovery of meaning were not associated with physical health outcomes. However, the combination of cognitive processing and discovery of meaning were associated with beneficial outcomes, predicting less distress immediately after writing. This suggests that thinking about a particular event, such as cancer, and finding meaning in it may buffer distress. Several important limitations should be noted about these findings. First, mediating factors (self-affirmation, cognitive processing, and discovery of meaning) were not manipulated or directly assessed. Rather, these mediators were assessed through content analysis of participants' essays. This kind of approach limits the ability to make causal statements. Still, the naturalistic observation of these characteristics supports the notion of their existence across writing prompts. Additionally, researchers coded participant statements, sometimes assigning more than one code to the same statement. This limited their ability to consider these mediators as mutually exclusive categories. Therefore, it is difficult to interpret the correlations of these mediators or to assess their unique contributions as orthogonal constructs.

Several researchers have advocated that making meaning of a stressor is a mechanism underlying positive effects in expressive writing (Boals & Klein, 2005; Pennebaker, 1997). Writing down thoughts and feelings related to a stressor is a form of making meaning, and expressive writing studies that have examined aspects of the meaning-making model add to knowledge about meaning and adjustment (Park, 2010). Expressive writing studies have examined meaning make through a focus on the use of words such as because, think, or realize. Studies have revealed that participants for whom meaning making increases across the intervention are the most likely to benefit from the expressive writing paradigm (Owen et al., 2005; Pennebaker, Mayne, & Francis, 1997;

Rivkin, Gustafson, Weingarten, & Chin, 2006; and Schwartz & Drotar, 2004). Expressive writing has also increased meaning made, (Smyth, Hockemeyer, & Tulloch, 2008; Ulrich & Lutgendorf, 2002). Specifically, in a sample of persons with PTSD, results from the writing intervention suggested that participants experienced an increased sense of the possibilities in their life, personal strength, and appreciation for life (Smyth, Hockemeyer, & Tulloch, 2008). These findings imply that written disclosure like expressive writing may help to repair disrupted views of the world or incongruent schemas (Janoff-Bulman, 2004).

Several studies, however, have failed to support the idea that expressive writing leads to meaning making or that making meaning mediates positive effects of the intervention (Cordova, Cunningham, Carlson, & Andrykowski, 2001; Creswell et al., 2007; Graybeal, Sexton, & Pennebaker, 2002; and Low, Stanton, & Danoff-Burg, 2006). However, a significant gap in research on expressive writing is the lack of studies asking participants to write about meaning related to the identified stressor. Prior to the present study, no expressive writing study had asked participants directly to write about the meaning of a negative event. Explicitly testing the fundamental components of the meaning-making model, such as examining changes in global or situational meaning – or the discrepancy between them – provides valuable information about making meaning through expressive writing. Additionally, very few expressive writing studies had studied participants in the midst of chronic stress, and instead, assessed meaning making only through retrospective participant self-report. The current study addressed the need to more accurately examine the role of meaning in expressive writing by testing the effects of meaning-focused expressive writing in a sample of informal caregivers of cancer

patients. Specifically, this study hypothesized that successful engagement in the meaning making process would mediate the relationship between expressive writing and positive outcomes.

### **Conclusion.**

Expressive writing continues to serve as a promising, brief, and cost-effective intervention capable of reaching a large number of participants to improve psychological and physical functioning (Frattaroli, 2006). Expressive writing can serve as a complement to interventions provided in traditional health care and community facilities, for which participants would typically have to travel or spend additional resources. Mixed findings in expressive writing studies highlight the need to design research that consider when and for whom these interventions are effective. Some participants may not be ready to disclose emotions related to negative or traumatic events, and may need a less threatening way to explore feelings (Lumley, Smith & Longo, 2002). Understanding individual differences as moderators of the effectiveness of expressive writing interventions and identifying variations on writing prompts may fulfill these needs for less threatening forms of the paradigm.

Meaning-focused writing interventions align with the movement toward positive expressive writing while serving as a less-threatening form of the paradigm for vulnerable individuals, such as caregivers. Meaning had not be adequately explored as a potential mediator, but had the potential to provide valuable information about the mechanisms that result in successful outcomes in expressive writing interventions (Park, 2010). A meaning-focused expressive writing intervention promised particular benefits for caregivers, who are faced with making sense of challenging and changing

circumstances. This study employed three conditions (traditional expressive writing, meaning-focused writing, and time-management writing), each of which was meant to provide some benefit as opposed to previous studies that used an irrelevant control condition (such as writing about the contents of one's closet), since such a control condition lacks face validity (Norman et al., 2004).

### **Statement of the Problem**

Many interventions have been developed to reduce negative physical and psychological effects for the estimated 65.7 million informal caregivers helping those with illness, disability, and other health conditions in the United States (National Alliance for Caregiving, 2009). These efforts have had mixed results (Sorensen, Pinquart, & Duberstein, 2002), and the demand for effective interventions will increase as the number of informal caregivers is projected to rise by 85 percent in the coming years due to decreases in hospital stays, changes in insurance reimbursement, and an aging population (Aldrich, 2011).

As advances in medicine continue to increase rates of survivorship from health challenges such as cancer, more specifically-targeted interventions will be needed to assist the growing number of caregivers as they help loved ones face ongoing barriers to independent function and mental health. While this growing population has led to the creation of a new national health priority to support caregivers (U.S. Department of Health and Human Services, 2010), further research was needed to identify effective interventions that decrease depression, caregiver burden, and impact of events and increase productive meaning-making and satisfaction with life.

Psychoeducational and psychotherapeutic interventions for caregivers have had the most consistent short-term effects on outcome measures, compared with supportive, respite care, care receiver competence, and multicomponent interventions, (Sorensen, Pinquart, & Duberstein, 2002), but research had yet to explain the mechanisms through which these interventions are successful. In addition, many interventions had been too time consuming for caregivers, who experience significant burdens related to time to

themselves and finances available for assistance (Wiles, 2003; Yantzi, Rosenberg, & McKeever, 2006). Interventions that are time-limited, inexpensive, and based in the home were the most appropriate. The expressive writing paradigm proposed in this study fit those criteria.

Pennebaker and Beall (1986) developed the expressive writing paradigm with the idea that acknowledging and making sense of distressing experiences through writing will have both psychological and physical benefits. Since the development of expressive writing interventions, research has demonstrated the paradigm a cost-effective way to improve psychological and other health outcomes (Frattaroli, 2006). In addition, expressive writing interventions have been linked with more attempts to process or make sense of events than control groups (Frattaroli, 2006).

Prior to this study, four expressive writing interventions conducted with caregivers were reported in the literature (Barton & Jackson, 2008; Mackenzie, Wiprzycka, Hasher, & Goldstein, 2007, 2008; Schwartz & Drotar, 2004; Ashley, O'Connor, & Jones, 2011). Little to no effects were found for disclosure on mood and physical symptoms (Schwartz & Drotar, 2004), post-traumatic symptoms (Mackenzie et al., 2007), somatic symptoms (Barton & Jackson, 2008), caregiver burden (Mackenzie et al., 2007; Barton & Jackson, 2008), depression and anxiety (Ashley, O'Connor, & Jones, 2011) and psychological well-being (Barton & Jackson, 2008; Mackenzie, Wiprzycka, Hasher, & Goldstein, 2007; Schwartz & Drotar, 2004). But these studies employed only the traditional expressive writing prompt that asks caregivers to write about their deepest thoughts and feelings about various negative events, including caregiving experiences. Only one study examined the efficacy of alternative writing prompts despite evidence

that writing about topics other than stress can have benefits (Burton & King, 2004, 2008; Wing, Schutte, & Byrne, 2006). While Ashley, O'Connor, and Jones (2011) asked a group of participants to write about positive life events, such as being in love, (Ashley, O'Connor, & Jones, 2011) the positive prompt did not directly examine writing about the caregiving experience. Participants in an emotional disclosures condition were asked to write about their caregiver experiences, but no main effects were found on depression and anxiety when caregivers in this study wrote about either positive life events or caregiving experiences (Ashley, O'Connor, & Jones, 2011). Positive disclosure about negative events has been linked to several health outcomes and increased mood and life satisfaction (Burton & King, 2004, 2008; Wing et al., 2006). When writing about the stress and burden of caregiving, expressive writing benefitted caregivers who used language considered positive, optimistic, and future-focused (Mackenzie et al., 2008). Caregiver interventions have shown immediate positive effects for caregiver burden, depression, satisfaction with life, and distress. Still, the researchers suggested that future expressive writing studies with caregivers should be positive, optimistic, and future-oriented to have positive outcomes. Yet, prior to the current study, no expressive writing studies had instructed caregivers to write positively about their caregiving experience.

In order to examine the effectiveness of a writing intervention that directs caregivers to explore the positive aspects of caregiving, the proposed study examined the effect of a meaning-focused writing intervention on caregiver stress, depression, caregiver burden, meaning in life, and satisfaction with life. Making meaning is a positive coping process and the present intervention was aligned with theorists' assertions that

making meaning is adaptive, especially during chronic stress (Folkman, 1997). Thus, it was hypothesized that:

**Hypothesis 1: Caregivers who write about the meaning(s) of their caregiving experiences will report better outcomes than caregivers in the traditional and time-management expressive writing conditions, such that:**

**Hypothesis 1a: Caregivers in the meaning condition will report greater pre-post decreases in depression at three-week follow-up, compared to those in the traditional and time-management writing conditions.**

**Hypothesis 1b: Caregivers in the meaning condition will report greater pre-post decreases in caregiver burden at three-week follow-up, compared to those in the traditional and time-management writing conditions.**

**Hypothesis 1c: Caregivers in the meaning condition will report greater pre-post increases of satisfaction with life at three-week follow-up, compared to those in the traditional writing and time-management conditions.**

**Hypothesis 1d: Caregivers in the meaning condition will report greater pre-post decreases in impact of event scale at three-week follow-up, compared to those in the traditional and time-management writing conditions.**

**Hypothesis 1e: Caregivers in the meaning condition will report greater pre-post increases in search for meaning (as measured by the Meaning in Life Questionnaire Search for Meaning subscale) compared to those in the traditional and time-management writing conditions.**

Another aim of this study was to examine the mediating role of the meaning-making process on the relationship between expressive writing and the dependent

variables of depression and impact of events. Northouse and colleagues (2010) found that interventions with caregivers targeted depression and caregiver burden frequently. Making meaning of distressing events leads to adjustment to the stressful event (Park & Folkman, 1997) and can lead to reductions in depression and domain-specific improvements such as caregiver burden. Previous expressive writing studies had examined the presence of the meaning-making process in writing samples, but had not directly asked participants to make meaning or examined the effect of successfully having made meaning on outcomes. Because continued attempts to make meaning without meaning made have been associated with increased levels of distress (Nolen-Hoeksema & Larson, 1999), it was important to find ways to promote successful meaning making processes for chronically stressed populations like caregivers. Pennebaker (1986) asserted that the expressive writing paradigm helps people to adjust to stress and trauma through the construction more coherent narratives. In the present study, caregivers who discovered or expressed made meaning through writing would engage in the construction of more coherent narratives about their experiences. Thus, it was hypothesized that:

**Hypothesis 2: Having made meaning (as measured by decreases in worldview violation or search for meaning from pre-intervention to post-intervention) will mediate the relation between treatment and outcomes such that participants who wrote expressively in both the meaning-focused and traditional writing condition who make meaning during their writing will have better outcomes on depression than participants in the time management condition.**

Research has indicated that participants in positive expressive writing conditions have experienced increased positive affect immediately following intervention compared to those in neutral or traditional expressive writing conditions (Burton & King, 2004; King, 2001). Given this, it may be that there were differences in mood between participants in the traditional expressive writing condition and participants in the more positive prompt, the meaning-focused condition.

**Research Question 1: How did the affect scores (positive and negative affect as measured by the PANAS) differ after each writing sessions between participants in the three conditions?**

## Method

### Design

The current study was designed as an experimental field study. Participants were randomized to one of three conditions: meaning-focused writing, traditional expressive writing, and time-management writing. Participants completed baseline measures of depression, caregiver burden, intrusiveness, satisfaction with life, meaning in life (search for and presence of meaning), and worldview violation (violation of goals and violation of beliefs) prior to beginning the intervention. Participants were asked to write about the topic of their randomized condition (meaning, emotional expression, time-management) related to their caregiver experience for one 20-minute session once a week for three consecutive weeks. Participants were instructed to choose a date for the first writing that was within one week of their completion of baseline measures. This study followed meta-analytic recommendations about length of and timing of writing sessions associated with effective expressive writing interventions (Fratraroli, 2006). Participants completed a measure of positive and negative affect directly before and directly after each of the three writing sessions. Three weeks after the final writing, participants were asked to complete the same outcome measures completed at baseline. Participants could complete the entire study online through the Qualtrics platform at the University of Maryland. The link to the initial Qualtrics survey was present on recruitment materials and could be emailed to support group leaders for distribution. The researcher then sent participants a link to the measures and writing on the scheduled writing days. Reminder emails were sent if participants did not complete the measures and writing within 24 hours of the scheduled time, again after three days, and again after five days.

## **Participants**

Participants needed to meet the following eligibility criteria: 1) at least 18 years old, 2) able to read and write in English, 3) currently providing care for a family member. Participants who completed the eligibility survey and indicated interest in participation included 182 individuals. Of these, 37 participants did not begin the writing intervention. The reason for this drop-out was not readily available since participants were all anonymous. An additional 43 participants did not complete all three writing sessions, leaving a total final sample of 102 caregivers. Participants included individuals who identified as unpaid/informal caregivers for a family member. Participants ranged in age from 20 to 79 (mean age 56.5) and provided an average of 10.6 hours per day of care (range 1 to 24) for an average of 6.4 years to date. Caregivers provided care for a range of conditions, including Parkinson's, Alzheimer's, ALS, dementia, bipolar disorder, brain injury, cardiovascular disease, cerebellar hemorrhage, concussion, lupus, diabetes, stroke, chronic pain, spinal fracture, seizure disorder, autism, mesothelioma, multiple sclerosis, muscular dystrophy, oral cancer, panic disorder, PTSD, and vascular disease. More than half of participants (57.8 %) were providing care to a spouse or partner, followed by those caring for a child (12.7%), parent (11.8 %), and other relative (6 %). About 12 % of participants provided care to two or more relatives.

## **Procedures**

Participants were recruited from a University of Maryland faculty/staff listserv, online caregiver forums, caregiver support group listservs, caregiver support groups, and organizations serving caregivers across the United States. Participants were assigned a four-digit number which was used to track responses to measures and the writing

intervention. After completing the informed consent, participants filled out the dependent measures so that baseline scores could be obtained. Participants were randomized to one of three conditions: a traditional expressive writing condition, a meaning-focused writing condition, and a caregiving time management control condition. Participants were asked to write for at least 15 minutes about their caregiving experience related to emotion, meaning, or time management once a week for three consecutive weeks. The writing instructions were the same for each of the three writing sessions within conditions, but participants were informed that they could write different or similar accounts of their caregiving experiences each time. Directly before and after each of the three writing sessions, participants completed the PANAS-short form. After completing the writing intervention, participants also completed a subjective evaluation of writing by answering several questions to evaluate their beliefs about the writing intervention. These questions were used to determine how participants experienced the intervention as other expressive writing studies have (Frattaroli, 2006; Pennebaker & Beall, 1986). Participants were emailed the link to the writing session on the day of the week they were expected to write. The first writing session took place within one week after the completion of the initial measures. Approximately three weeks after the final writing session, participants completed all dependent measures again. All portions of the study, including the writing intervention, were conducted online through Qualtrics. After participants completed the entire study, they were emailed the option to receive an electronic \$10 gift certificate to either Amazon.com or Starbucks in exchange for their participation. Of the 102 participants, 10 chose not to accept the gift certificate and 2 participants ask that the money be donated to charity.

**Traditional expressive writing condition.** The traditional expressive writing intervention was based on the empirically-supported paradigm which asks participants to write about their deepest thoughts and emotions about a stressful topic (Pennebaker & Beall, 1986) such as providing unpaid care to a sick family member. Participants were asked to write about their deepest emotions and thoughts about the most upsetting experiences of caregiving. This included writing about relationships with others, impact of caregiving on career, other effects of serving as a caregiver, and their feelings about those experiences. The intervention encouraged participants to really explore their deepest emotions and thoughts about their experiences as a caregiver. Writing instructions for this prompt were as follows:

Before you begin this exercise, please do your best to be sure you will likely have the next 20 minutes to yourself. It is best if you are able to complete this writing session from start to finish uninterrupted. It may help to use some sort of timer such as <http://www.online-stopwatch.com/> so that you do not need to be concerned about the time as you write.

For the three writing sessions, I would like you to write about your experiences as a caregiver. Write about your deepest emotions and thoughts about the most upsetting experiences of caregiving. Really let go and explore your feelings and thoughts about it. In your writing, you might tie this experience to your childhood, your relationship with your parents, people you have loved or love now, or even your career. You can write about the same issue each time, or different issues. Whatever you choose to write about, however, it is critical that you really let go and explore your very deepest emotions and thoughts about your experiences as a caregiver.

As you write for this first writing session, do not worry about grammar, spelling, or style. Don't worry about deleting. The only rule is that once you begin writing, please continue to write until the 20 minutes has passed. If you run out of things to say, just repeat what you have already written. Your writing will be kept confidential and only members of the research team will review the writing.

**Meaning-focused writing condition.** The meaning-focused writing instructions were written to mirror the traditional expressive writing instructions in length and format and were based on Park & Folkman's (1997) concept of making meaning of experience

to integrate it into one's concept of self and of the world. Participants were asked to explore what being a caregiver means to them and for their life. They were asked to think and write about how they understand the changes that they have experienced due to providing care and to express what they need to better understand their experiences as a caregiver, including how they might view these experiences when they are no longer in the caregiver role. Writing instructions for this prompt were as follows:

Before you begin this exercise, please do your best to be sure you will likely have the next 20 minutes to yourself. It is best if you are able to complete this writing session from start to finish uninterrupted. It may help to use some sort of timer such as <http://www.online-stopwatch.com/> so that you do not need to be concerned about the time as you write.

For the three writing sessions, I would like you to write about what your experience as a caregiver means to you and for your life. You might write about how serving as a caregiver affects your relationship with your loved one, your career, your other relationships, and your feelings about those experiences. I realize that having a loved one who is sick can change many things about your life and your hopes and expectations for it. I want you write about how you understand these changes. Try to think about how you will view your experiences as a caregiver in the future when you are no longer in that role. I would like you to write whatever comes to you, but make sure that this exercise provides you with what you need to better understand your experiences as a caregiver. You can write about different experiences or understandings each time or similar ones for all three writing sessions.

As you write, do not worry about grammar, spelling, or style. Don't worry about deleting. The only rule is that once you begin writing, please continue to write until the 20 minutes has passed. If you run out of things to say, just repeat what you have already written. Your writing will be kept confidential and only members of the research team will review the writing.

**Time-management writing condition.** The time-management writing instructions were written to mirror the traditional expressive writing and meaning-focused writing instructions in length and format and were based on instructions used in previous caregiver studies linked with positive outcomes (Mackenzie et al., 2007).

Participants were asked to write objectively about how they spend their time, including

their routine of work (career) time, time as a caregiver, and leisure time. Writing instructions for this prompt were as follows:

Before you begin this exercise, please do your best to be sure you will likely have the next 20 minutes to yourself. It is best if you are able to complete this writing session from start to finish uninterrupted. It may help to use some sort of timer such as <http://www.online-stopwatch.com/> so that you do not need to be concerned about the time as you write.

For the three writing sessions, I would like you to write objectively about how you spend your time. For example, you can describe what your typical day is like, including describing your routine in the morning, afternoon, and evening. You can write about how long you spend doing each activity and can include information about work (career) time, time as a caregiver, or leisure time. You can write about different thing(s) for all three writing sessions.

As you write, do not worry about grammar, spelling, or style. Don't worry about deleting. The only rule is that once you begin writing, please continue to write until the 20 minutes has passed. If you run out of things to say, just repeat what you have already written. Your writing will be kept confidential and only members of the research team will review the writing.

## Measures

**Demographic.** The demographic questionnaire asked participants for their age, sex, country of residence, state of residence (if applicable), relationship status, ethnicity, level of education, household income, employment status, number of care recipients, relationship to care recipient(s), diagnosis(es) of care recipient(s), other health problems of care recipient(s), personal health diagnoses, average number of hours spent in caregiver role per day, length of caregiving experience to date, and expected duration of caregiver role from beginning to end.

**The Center for Epidemiological Studies - Depression Scales.** The Center for Epidemiological Studies - Depression Scales (CES-D; Radloff, 1977) was used in this study to evaluate depressive symptoms. The 20-item scale was administered at baseline and at follow-up. This scale assesses the frequency of depressive symptoms over the past

week on a 4-point scale (0=less than one day, 3=5-7 days). A literature review identified the CES-D as a psychometrically sound, clinically-useful assessment instrument for caregivers. This scale has demonstrated internal consistency around Cronbach's alpha = .85, in line with recommendations for high internal consistency (Cole et al., 2004). In this study, the Cronbach's alpha was .92 for the pretest and .93 for the posttest.

**The Satisfaction with Life Scale.** The 5-item Satisfaction with Life Scale (SWLS; Diener, Emmons, Larsen, & Griffin, 1985) represents a reliable and valid measure of global life satisfaction. The SWLS has been validated in chronically stressed populations, where it was found to demonstrate high internal consistency (Dezutter, Robertson, Luyckx, & Hutsebaut, 2010; Walker, Esterhuyse, & Van Lill, 2010) and validity (Cohen, Patel, Khetpal, Peterson, & Kimmel, 2007; Walker et al., 2010). The scale was administered at baseline and at follow-up. In the present study, the Cronbach's alpha for the SWLS was .90 for the pretest and .91 for the posttest.

**Positive and Negative Affect Schedule.** The 20-item Positive and Negative Affect Schedule (PANAS) was used to measure of individual differences in positive and negative affective levels (Kercher, 1992). The PANAS includes ten positive emotions (e.g., alert, inspired, excited, and determined) and ten negative emotions (e.g., afraid, upset, nervous and distressed). The PANAS has demonstrated good internal consistency and validity in a multitude of clinical and healthy populations (e.g., Davis, Zautra, & Reich, 2001; Kercher, 1992; Mackinnon et al., 1999; Zautra et al., 2005). In a highly-stressed population, high internal consistency has been found (.88 for positive affect and .84 for negative affect; Zautra et al., 2005). In the current study, the average Cronbach's alphas for the PANAS Positive Affect was .92 for the three pre-writing

scores and .94 for the post-writing scores; the Cronbach's alphas for Negative Affect averaged .87 for the pre-writing and .88 for the post-writing scores.

**Caregiver Strain Index.** The Caregiver Strain Index (CSI; Robinson, 1983) is a 13-item measure of strain or burden related to providing care. This measure was used to examine the experience of caregiver burden. The measure asks caregivers if 13 items apply to them in a "Yes" or "No" format related to employment, financial, physical, social and time burdens. Yes responses across the 13 items are summed for a total score, where a score of 7 or higher yes responses indicates high level of burden. The scale was administered at baseline and at follow-up. Internal consistency is high with a Cronbach's alpha coefficient of 0.86, and the scale has correlated with measures of caregiver physical and emotional health and with subjective views of the caregiving situation at levels that indicate construct validity. In the present study, Cronbach's alpha coefficients were .70 for pre-intervention and .80 for post-intervention.

**Impact of Event Scale-Revised.** The 22-item Impact of Events Scale- Revised (IES-R; Weiss & Marmar, 1997) is a commonly used measure for symptoms of distress related to trauma or stressful life experiences. This use of this scale was conceptualized as an appropriate assessment of the process of meaning-making coping (Park & George, in press) as a way to assess individuals' attempts to integrate the stressful situation with their cognitive schemas (Greenberg, 1995). The scale was administered at baseline and at follow-up. The IES-R includes six items measuring hyperarousal (e.g., arousal related to the experience), eight items measuring intrusion, and eight items measuring avoidance. This three-factor structure (hyperarousal, intrusion, and avoidance) has been supported through EFA and CFA analyses (Beck et al., 2008; Weiss & Marmar, 1997). The

instructions ask respondents to indicate how distressing each thought has been within the last seven days. Items are rated on a 5-point scale (0 = Not at all; 4 = Extremely) and summed to create subscales and a total score ranging from 0 to 88. For this study, total score of the IES-R will be used, with higher scores indicating greater distress related to stressful events or experiences. The scale was administered at baseline and at follow-up. Scores on the IES-R have exhibited high internal consistency with coefficient alphas ranging from .87 to .94 for intrusion, .84 to .87 for avoidance, .79 to .91 for hyperarousal, and .95 to .96 for the total scale (Beck et al., 2008; Creamer et al., 2003; Weiss & Marmar, 1997). In addition, test–retest correlations revealed a moderate to high level of stability across time (Cronbach’s alphas = .51 to .94; Weiss & Marmar, 1997). Stehl and colleagues (2009) found high internal consistency using this measure with parental caregivers (Cronbach’s alpha = .93). Each of the IES-R subscales have been found to correlate with measures of depression, anxiety and PTSD (Beck et al., 2008). In the present study, the total scale score was used, and Cronbach’s alpha at baseline was .95 and .94 at follow-up.

**Meaning in Life Questionnaire.** This 10-item scale (MLQ; Steger et al., 2006) is a self-report measure assessing a person’s sense of meaning in their life. This scale was conceptualized in this study as a measure of both the search for and the presence of meaning in life for participants. Factor analysis has indicated two subscales (Steger et al., 2006): Presence of Meaning (MLQ-P; e.g., “I have discovered a satisfying life purpose”) and Search for Meaning (MLQ-S, e.g.; “I am seeking a purpose or mission in life”). Items are rated on a 7-point scale (1 = Absolutely Untrue; 7 = Absolutely True). Small to medium correlations have been reported between the Search for Meaning subscale and

measures of negative affect and depression (Meyersburg & McNally, 2011). The Presence of Meaning subscale has been found to correlate positively with measures of well-being and religiosity (Meyersburg & McNally, 2011). These correlations support the validity of the scales, and adequate internal consistency (.84 and .81, respectively) and test–retest reliability coefficients over one month (.73 and .70, respectively) have also been found. In the current study, Cronbach’s alphas were calculated for both the presence of meaning and search for meaning subscales. The search for meaning subscale had internal consistency of .87 prior to the intervention and .91 after the intervention. Presence of meaning Cronbach’s alphas were .91 at baseline and .92 at follow-up.

**Worldview Violation.** This scale (Park, 2008) is intended to measure the extent to which global meaning (both beliefs and goals) are violated through appraisal of discrepancies between global and situational meaning. The 17-item measure has two subscales, one to measure violation of beliefs (5 items) and one to measure violation of goals (12 items). There is preliminary evidence of reliability and validity (Park & George, in press), though this is the first formal application of the scale in applied psychological research. Cronbach’s alpha for the belief subscale has been reported at .63, and Cronbach’s alpha for the goals subscale has been reported at .94 (Park, Mills, & Edmondson, 2012). This scale was administered before the intervention and at three-week follow-up to assess the degree to which the discrepancy between global and situational meaning changes as a result of the intervention. The degree to which the discrepancy decreases is an indicator of participants having made meaning. In the present study, violation of goals subscale had internal consistency of .90 prior to the intervention and .89 after the intervention. Violation of beliefs Cronbach’s alphas were .82 at baseline

and .83 at follow-up.

**Subjective Evaluation of Writing Task.** The Subjective Evaluation of Writing Task scale is a widely used measure in expressive writing studies that assesses participants' perceptions of their writing experience. The items used in this study were adapted from the original expressive writing study (Pennebaker & Beall, 1986) as well as more recent expressive writing research (Earnhardt, Martz, Ballard, & Curtin, 2002). Participants used a Likert-type scale ranging from "not at all" (1) to "to a great deal" (7), to assess the following aspects of their writing: (a) How personal were your essays? (b) To what degree did you reveal your emotions in your essays? (c) Do you believe that writing about this topic has affected how you think about this topic? (d) Do you believe facing this topic in your writing has improved the way you feel about it? (e) To what degree did writing about this topic make you feel understood and more accepting of your pain? and (f) To what degree did writing about this topic make you feel more confident about managing your pain? The last two items were added to reflect the specific directions in the self-compassion and the self-efficacy writing intervention, respectively.

## Results

The results chapter includes preliminary analyses of the hypotheses, manipulation checks, analysis of the research question, and some additional analyses.

### Preliminary Analyses

The analyses were completed using the statistical package software IBM SPSS Version 22. Each variable was checked for normality, internal consistency, and univariate outliers. No variable displayed skewness, as indicated by values greater than 1. In addition the following scales displayed some kurtosis, as indicated by values greater than 1: the pretest scores of Worldview Violation Scale - Goals Subscale and the posttest scores of Satisfaction with Life Scale. All other univariate distributions were close to normal for the other variables. The multivariate normality assumptions were met for the ANOVA and linear regression analyses and therefore, none of the variables were transformed. All of the scales yielded acceptable internal consistency as indicated by Cronbach's alphas ranging from .70 to .95. Reliability estimates, range, means, and standard deviations of all of the scales are presented in Table 2. There were no missing item values since participants could not continue unless they provided an answer to each question. Each variable was assessed for outliers by converting raw scores to standardized scores (i.e., z-scores) and assessing for data points that deviated from the mean of all cases. Values that were two or more standard deviations away from the mean were considered outliers and eliminated from subsequent analyses as recommended by Lomax (2007). The number of outliers per scale ranged from zero to eight. There was only one participant who had outlier scores on multiple (three or greater) scales, which

may reflect response style. All analyses were run with and without the outliers, and the outliers were found to unduly influence the results. The outliers were removed on the scale level rather than the subject level in order to retain as much data as possible.

Between-groups comparisons were made regarding demographic variables using ANOVAs and chi-square analyses. Baseline differences were also assessed for between-group differences on all outcome variables. There was a significant difference between groups in marital status, where participants randomized to the self-compassion condition were more likely to be divorced than those randomized to the traditional writing condition ( $\chi^2=16.2, p=.40$ ). Therefore, marital status was controlled for in subsequent analyses. There was also a significant difference in baseline scores of search for meaning ( $F(1,96)=3.94, p=.02$ ).

Two-way mixed ANCOVAs were used to test Hypotheses 1, with marital status and time 1 scores of search for meaning as covariates. This type of analysis was chosen so that the main effects of pre- and post-intervention changes, regardless of writing condition, could be assessed in addition to the interaction between writing condition and pre-post changes in the dependent variables. The assumptions of mixed ANCOVA analyses were assessed, and steps were taken to address any violations that occurred as noted under these sections. All of the assumptions of the ANCOVA analyses, including normality, linearity, and homogeneity of variance, were met. A correlation matrix of Pearson's  $r$  correlation coefficients was created to capture information about the relationships among all interval variables (see Tables 2 and 3). All of the correlations were in the expected direction.

Table 1. Reliability estimates, means, and standard deviations for outcome variables

<i>Measure</i>	<i>Possible Range</i>	<i>Scoring</i>	<i>Alpha</i>	<i>Time Management (TM) Mean</i>	<i>TM SD</i>	<i>Traditional Writing (TW) Mean</i>	<i>TW SD</i>	<i>Meaning Focused (MF) Mean</i>	<i>MF SD</i>
SWLS-Pre	5 - 35	Scale 1-7 (higher=higher satisfaction)	.90	17.5	8.57	18.5	8.99	16.5	7.30
SWLS-Post	5 - 35	Scale 1-7 (higher=higher satisfaction)	.91	18.9	8.92	18.2	9.21	17.0	7.76
CESD-Pre	0-60	Scale 0-3 (higher=greater depression)	.92	22.4	13.93	20.95	12.45	20.95	12.31
CESD-Post	0-60	Scale 0-3 (higher=greater depression)	.93	19.0	13.38	20.86	13.12	23.88	12.74
IES-R-Pre	0-88	Scale 0-4 (higher=higher intrusiveness)	.95	29.2	19.88	32.3	20.25	30.3	21.68
IES-R-Post	0-88	Scale 0-4 (higher=higher intrusiveness)	.94	27.4	20.38	25.1	14.93	28.5	17.24
CSI-Pre	0-13	Scale 0-1 (higher=higher stress/burden)	.70	9.1	3.11	9.7	2.55	9.0	3.06
MLQ_P-Pre	5-35	Scale 1-7 (higher=higher presence)	.91	24.2	6.75	24.2	8.57	24.1	6.65
MLQ_P-Post	5-35	Scale 1-7 (higher=higher presence)	.92	24.1	7.44	24.5	7.24	24.4	6.69
MLQ_S-Pre	5-35	Scale 1-7 (higher=higher search)	.87	15.6	5.94	20.2	8.37	21.3	6.94
MLQ_S-Post	5-35	Scale 1-7 (higher=higher search)	.91	21.0	7.85	16.4	5.53	21.4	7.97
WVS_B-Pre	5-25	Scale 1-5 (higher=greater violation)	.82	12.9	4.12	14.2	5.79	14.7	5.91
WVS_B-Post	5-25	Scale 1-5 (higher=greater violation)	.83	15.6	5.40	14.0	4.12	15.2	5.77
WVS_G-Pre	12-60	Scale 1-5 (higher=higher violation)	.90	33.9	10.66	35.8	11.77	35.5	13.2
WVS_G-Post	12-60	Scale 1-5 (higher=higher violation)	.89	38.5	11.47	34.2	12.26	37.0	10.35
PANAS-PA-Pre	10-50	Scale 1-5 (higher=greater pos emotion)	.92	27.8	7.92	26.3	8.55	26.2	6.45
PANAS-PA-Post	10-50	Scale 1-5 (higher=greater pos emotion)	.94	27.5	8.7	25.1	9.35	27.5	8.89
PANAS-NA-Pre	10-50	Scale 1-5 (higher=greater neg emotion)	.87	18.1	6.94	19.3	9.33	17.6	5.17
PANAS-NA-Post	10-50	Scale 1-5 (higher=greater neg emotion)	.88	20.3	10.12	20.4	9.88	17.9	5.28

*Note.* SWLS=Satisfaction with Life Scale; CESD=Center for Epidemiological Studies - Depression Scales; IES-R=The Impact of Events Scale - Revised; CSI=Caregiver Strain Index; MLQ\_P=Meaning In Life Questionnaire Presence of Meaning subscale; MLQ\_S=Meaning in Life Questionnaire Search for Meaning subscale; WVS\_B=Worldview Violation Scale Beliefs subscale; WVS\_G= Worldview Violation Scale Goals subscale.

Table 2. *Correlations among the outcome variables*

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1. SWLS-Pre	-															
2. SWLS-Post	.86**	-														
3. CESD-Pre	-.66**	-.36**	-													
4. CESD-Post	-.50**	-.34**	.70**	-												
5. IES-R-Pre	-.46**	-.42**	.78**	.51**	-											
6. IES-R -Post	-.31**	-.36**	.65**	.79**	.69**	-										
7. CSI-Pre	-.39**	-.41**	.51**	.36**	.52**	.45**	-									
8. CSI-Post	.32**	-.41**	.38**	.45**	.47**	.52**	.79**	-								
9. MLQ_P-Pre	.68**	-.59**	-.61**	-.44*	-.37**	-.34**	-.30**	-.23**	-							
10. MLQ_P-Post	-.62**	.62**	-.54**	-.55**	-.38**	-.40**	-.25*	-.25*	.83**	-						
11. MLQ_S-Pre	-.23*	-.17	.40**	.30**	.23*	.28**	.15	.11	-.29**	.68**	-					
12. MLQ_S-Post	-.33**	-.31**	.31**	.34**	.20*	.30**	.14	.21*	-.43**	-.53**	.68**	-				
13. WVS_B-Pre	-.42**	-.45**	.51**	.46**	-.45**	.46**	.43**	.43**	-.45**	-.47*	.29**	.38**	-			
14. WVS_B-Post	-.47**	-.53**	.29**	.40**	.41**	.31**	.23*	.24*	-.43**	-.44**	.29**	.35**	.67**	-		
15. WVS_G-Pre	-.57**	-.56**	.64**	.62**	.57**	.51**	.50**	.51**	-.44**	-.47**	.29**	.38**	.49**	.56**	-	
16. WVS_G-Post	-.50**	-.62**	.52**	.71**	.42**	.51**	.47**	.52**	-.42**	-.50**	.27**	.39**	.40**	.58**	.79**	-

Note. SWLS=Satisfaction with Life Scale; CESD=Center for Epidemiological Studies - Depression Scales; IES-R=The Impact of Events Scale - Revised; CSI=Caregiver Strain Index; MLQ\_P=Meaning In Life Questionnaire Presence of Meaning subscale; MLQ\_S=Meaning in Life Questionnaire Search for Meaning subscale; WVS\_B=Worldview Violation Scale Beliefs subscale; WVS\_G= Worldview Violation Scale Goals subscale.

\*  $p < .05$     \*\*  $p < .01$

Table 3. *Correlations among the PANAS and outcome variables*

	PANAS-PA-Pre	PANAS-PA-Post	PANAS-NA-Pre	PANAS-NA-Post
SWLS-Pre	.38**	.41**	-.36**	-.37**
SWLS-Post	.38**	.40**	-.36**	-.41**
CESD-Pre	-.41**	-.45**	.58**	.63**
CESD-Post	-.39**	-.34**	.64**	.69**
IES-R-Pre	-.23*	-.24*	.64**	.67**
IES-R -Post	-.20*	-.16	.63**	.62**
CSI-Pre	-.21*	-.27**	.29**	.28**
CSI-Post	-.33**	-.29**	.32**	.31**
WVS_B-Pre	-.19	-.21*	.30**	.36**
WVS_B -Post	-.34**	-.29**	.33**	.36**
WVS_G -Pre	-.35**	-.33**	.45**	.47**
WVS_G-Post	-.42**	-.36**	.52**	.53**
MLQ_P-Pre	.45**	.47**	-.39**	-.37**
MLQ_P -Post	.46**	.48**	-.39**	-.42**
MLQ_S-Pre	-.02	-.08	.16	.16
MLQ_S-Post	-.19	-.23*	.21*	.19
PANAS-PA-Pre	1	.90**	-.38**	-.17
PANAS-PA-Post	.85**	1	-.35**	-.41**
PANAS-NA-Pre	-.38**	-.35**	1	.87**
PANAS-NA-Post	-.35**	-.41**	.87**	1

*Note.* SWLS=Satisfaction with Life Scale; CESD=Center for Epidemiological Studies - Depression Scales; IES-R=The Impact of Events Scale - Revised; CSI=Caregiver Strain Index; MLQ\_P=Meaning In Life Questionnaire Presence of Meaning subscale; MLQ\_S=Meaning in Life Questionnaire Search for Meaning subscale; WVS\_B=Worldview Violation Scale Beliefs subscale; WVS\_G= Worldview Violation Scale Goals subscale, PANAS-PA=Positive and Negative Affect Schedule-Positive Affect subscale (avg across 3 writing sessions); PANAS-NA=Positive and Negative Affect Schedule-Negative Affect subscale (avg across 3 writing sessions).

\* p<.05 \*\*p<.01

### **Adherence Check**

All writing sessions were checked to see if participants closely adhered to the 20 minute writing time and the seven days in between writing sessions. A time stamp was collected when participants entered the writing session website and when they exited the website. Therefore, the time stamps can only provide a rough estimate for the amount of time spent writing, since participants may have may not have started writing directly after entering the website or may not have exited directly after completing the writing. In general, the average length of time between when participants entered and exited the writing website ranged from 27 to 33 minutes across writing sessions. Therefore, it

appears that most participants adhered to the 20 minutes of actual writing. The average number of days in between writing sessions ranged from 7 to 9 days, indicating that most participants completed their writing sessions approximately one week apart.

### **General Analytic Strategy**

Hypothesis 1: Caregivers who write about the meaning(s) of their caregiving experiences will report better outcomes than caregivers in the traditional and time-management expressive writing conditions, such that:

Hypothesis 1a: Caregivers in the meaning condition will report greater pre-post decreases in depression at three-week follow-up, compared to those in the traditional and time-management writing conditions.

A two-way mixed ANCOVA was conducted with depression as the outcome variable. The pre- and post- measurement time points served as the repeated measures variable and the three writing conditions served as the between-groups variable. There were no significant main effects for time or writing condition, but there was a significant interaction between time and condition ( $F(1,96)=4.10, p=.02$ ) The partial eta squared of .08 indicates that this was a medium effect. Results indicate that depression scores decreased very slightly for the traditional writing condition (mean pre-score=20.95; mean post-score=20.86), decreased for the time-management condition (mean pre-score=22.42; mean post-score=19.00), and increased for the meaning-focused condition (mean pre-score=20.95; mean post-score=23.88).

Hypothesis 1b: Caregivers in the meaning condition will report greater pre-post decreases in caregiver burden at three-week follow-up, compared to those in the traditional and time-management writing conditions.

A two-way mixed ANCOVA was conducted with caregiver burden (as measured by the Caregiver Strain Index; CSI) as the outcome variable. The pre- and post-measurement time points served as the repeated measures variable and the three writing conditions served as the between-groups variable. There were no significant main effects for time ( $F(1,96)=.02, p=.88$ ) or writing condition ( $F(1,96)=.40, p=.67$ ) and no significant interaction ( $F(1,96)=.48, p=.62$ ). While changes across conditions were not significant, results indicated that burden scores slightly increased on average from pre to post intervention across conditions.

Hypothesis 1c: Caregivers in the meaning condition will report greater pre-post increases of satisfaction with life at three-week follow-up, compared to those in the traditional writing and time-management conditions.

A two-way mixed ANCOVA was conducted with satisfaction with life as the outcome variable. The pre- and post-measurement time points served as the repeated measures variable and the three writing conditions served as the between-groups variable. While Satisfaction with Life Scores increased slightly from pre to post intervention across conditions, there was no main effect for time (or writing condition) because these changes were not significant. There was no significant interaction between time and writing condition.

Hypothesis 1d: Caregivers in the meaning condition will report greater pre-post decreases in impact of event scale at three-week follow-up, compared to those in the traditional and time-management writing conditions.

A two-way mixed ANCOVA was conducted with average intrusiveness as the outcome variable. The pre- and post-measurement time points served as the repeated

measures variable and the three writing conditions served as the between-groups variable. There was no significant main effect for time ( $F(1,96)=.25, p=.62$ ), no significant main effect for writing condition ( $F(1,96)=.27, p=.76$ ), and no significant interaction between time and writing condition ( $F(1,96)=.01, p=.99$ ). Results indicate that the average participant reported experiencing a non-significant decrease in intrusiveness after the intervention.

Hypothesis 1e: Caregivers in the meaning condition will report greater pre-post increases in search for meaning (as measured by the Meaning In Life Questionnaire Search for Meaning subscale) compared to those in the traditional and time-management writing conditions.

A two-way mixed ANCOVA was conducted with average search for meaning as the outcome variable. The pre- and post- measurement time points served as the repeated measures variable and the three writing conditions served as the between-groups variable. There was no significant main effect for time. There was a significant main effect for writing condition ( $F(1,94)=3.64, p=.03$ ). Results indicate that the average search for meaning that participants reported experiencing increased after the interventions for participants in the traditional writing condition (avg pre-score=20.22; avg post-score=20.97), decreased slightly for participants in the meaning-focused condition (avg pre-score=20.89; avg post-score=20.76), and increased for participants in the time-management condition (avg pre-score=15.63; avg post-score=16.42). There was no significant interaction between time and writing condition ( $F(1,96)=.55, p=.58$ ). This was a medium effect, as indicated by a partial eta squared of .08.

Hypothesis 2: Having made meaning (as measured by decreases in worldview

violation or search for meaning from pre-intervention to post-intervention) will mediate the relation between treatment and outcomes such that participants who wrote expressively in both the meaning-focused and traditional writing condition who make meaning during their writing will have better outcomes on depression than participants in the time management condition.

The process of making meaning and the outcome of having made meaning were assessed through pre-post examination of the MLQ Search and Presence subscales and the Worldview Violation Scale Beliefs and Goals subscales. The mediating effect of meaning made in this study was analyzed using the change in Worldview Violation of Beliefs and Goals score. Mediation was examined using the multiple regression method suggested by Frazier, Tix, & Barron (2004). This method requires tests of four equations. First, the outcome variable (depression) is regressed on the predictor (writing condition) to establish an effect that would be mediated. Next, the mediator, or meaning made, is regressed on the predictor to establish the mediation path. Then, the outcome variable is regressed on the predictor and mediator to test whether the mediator is related to the outcome and is an estimate of the relation between the predictor and the outcome when controlling for the mediator. Complete mediation is indicated by a relation of 0 between the predictor and the outcome when controlling for the mediator. When the predictor and the outcome have a significantly smaller relation when the mediator is not in the equation, partial mediation is suggested. To test the significance of the effect, an assessment of the significance of the product of paths a and b will be conducted by dividing the product by a standard error term, yielding a z score of the mediated effect. If the score is larger than 1.96 (Kenney et al., 1998), the effect is significant at the .05 level.

Using the two meaning measures in a test of mediation between expressive writing and the outcomes of depression and caregiver burden will require four separate regressions as described above.

Due to small sample size, bootstrapping was used to increase ability to detect effects. A test of the equation in which writing condition, where this variable represented treatment versus control, was regressed on change in depression showed statistical significance ( $\beta = .615, p = .02$ ). The second regression equation was then tested. This analysis revealed a significant effect, with treatment as a predictor of change in presence of meaning ( $\beta = -.349, p = .049$ ). Next, a test of the equation in which change in presence of meaning was regressed on change in depression scores revealed a significant effect ( $\beta = -.572, p = .001$ ). Finally, the outcome variable (change in depression) was regressed on the predictor (treatment) and the mediator (change in presence of meaning) to establish full or partial mediation. Analysis revealed change in presence of meaning to be a full mediator between the relationship of expressive writing and change in depression since this regression analysis indicated that the mediator retained significant predictive value ( $\beta = -.536, p = .004$ ) when controlling for treatment ( $\beta = .395, p = .052$ ). Plainly stated, analyses showed that the changes in depression scores were fully mediated by participants' gains in meaning.

Research Question 1: How will the affect scores (positive and negative affect as measured by the PANAS) differ after each writing sessions between participants in the three conditions?

Positive affect and negative affect scores were collected for each participant before and after the three writing sessions. These pre and post writing scores for positive

and negative affect were averaged to create four scores representing pre writing scores for positive affect, pre writing scores for negative affect, post writing scores for positive affect, and post writing scores for negative affect. Two-way mixed ANCOVAs were conducted with positive and negative affect as the outcome variables. The pre- and post-measurement time points served as the repeated measures variable and the three writing conditions served as the between-groups variable.

Negative affect analyses indicated that within participants, there no significant effect for time and no significant interaction between time and condition. Between participants, there was no significant main effect for condition. Participants in all three conditions experienced a slight, but non-significant average increase in negative affect from pre-to-post writing. This is in line with previous expressive writing research, which has indicated that disclosing thoughts and feelings tends to increase negative affect.

For positive affect, there was no significant effect for time. There was no main effect for condition. There was a significant interaction between time and condition ( $F=4.19, p=.02$ ). Results indicate that participants in the traditional writing condition experienced a decrease in positive affect from before writing to after writing (mean pre-score: 26.30; mean post-score 25.13). Participants in the meaning-focused condition experienced an increase in positive affect from pre to post writing (mean pre-score: 26.24; mean post-score 27.45). Participants in the time-management condition experienced about the same positive affect before and after each writing on average (mean pre-score 27.75; mean post-score 27.47).

### **Additional Analyses**

Primary analyses indicated little difference between conditions and pointed to the possibility that individual differences may be more important to outcomes when studying a highly distressed sample. Examination of levels of participant distress (e.g., depression and strain) compared with other samples of caregivers across research areas indicated that the participants in this study are highly distressed. The mean level of depression at baseline for this sample was 21.23, which is about 1/2 standard deviation above the clinically depressed cutoff score of 16 for the CES-D. Original norm scores for the CES-D indicated a mean of 8.17 and a standard deviation of 8.23 (Radloff, 1977). About 68 % of the sample in this study reported levels of clinical depression at baseline, which is well above established norms of 19 % for the general population (Radloff, 1977) and well above the overall normative mean for the CES-D. It is important to note that norms scores were based on a sample of men and women, while the sample in this study was comprised of mostly women. Men tend to have lower reported levels of clinical depression (Radloff, 1977), which could have affected the normative mean scores and the mean scores of this sample. This average score was also higher when compared with average levels of depression among other caregiver samples ( $X = 13.28$ , Gaugler et al., 2009;  $X = 16.44$ , Haley et al., 1995;  $X = 20.35$ , Papastavrou, Charalambous, & Tsangari, 2009) and community samples of adults ( $X = 6.14$  Bishop et al., 2007;  $X = 10.24$ , Crawford et al., 2011;  $X = 11.21$ , Haley et al., 1995). Because of the high levels of depression found in this sample, further investigation was conducted into distress levels of participants and into the percentage of clinically-depressed participants (at baseline) who may have benefitted from the interventions by reporting lower (subclinical) levels of depression at the time of follow-up.

Previous studies have investigated changes in depression scores to identify those who may have benefitted from intervention looking at how many in the sample reported clinical levels of depression at baseline (CES-D scores 16 or greater), but scores below clinical depression at follow-up (CES-D scores 15 or below). While 68% ( $n = 96$ ) of participants reported levels of clinical depression at baseline, change-score analyses indicated that 13 of these participants ( $13.5\%$ ;  $n=96$ ) had post-intervention depression scores below 16 and indicative of non-clinical depression. The average decrease for these participants was 12.46 points ( $SD=5.35$ ) on the CES-D depression scale. The clinically significant change was found for participants across conditions, with clinically significant decreases in depression coming for five of those in the time management condition, five coming from the meaning-focused condition, and three coming from the traditional writing condition. The 46 other participants whose baselines scores indicated clinical depression but who still had follow-up CES-D scores at 16 or above a non-clinically-significant change reported a mean change of .043 ( $SD = 8.11$ ). Thirty-eight participants reported baseline scores of depression below clinical levels ( $X=8.86$ ,  $SD=4.84$ ). These participants had a mean change in depression score of 4.76 ( $SD=9.98$ ) from pre to post intervention.

To further understand the factors associated with changes in depression scores from pre to post intervention, two moderating factors were examined because of their significance in the caregiver literature: relation to care recipient (e.g., spouse) and type of condition of care recipient (e.g., Alzheimer's). Spousal caregivers may have higher rates of depression due to disruption in their most significant relationship, while caregivers of those with a cognitive condition (e.g., Alzheimer's, Parkinson's, dementia) have had

more negative outcomes than caregivers for those with other conditions (e.g., cancer; Ory et al., 1999). Spousal caregivers reported baseline depression scores that were slightly higher (21.6) than caregivers of other relatives (20.5) and slightly higher depression scores (22.4) than other caregivers (20.6) post-intervention. These differences were not significant in a test of within and between subject effects. However, when testing differences of time 1 and time 2 depression scores, there was a significant interaction between relation to care recipient and condition of care recipient ( $F=7.85$ ,  $p=.006$ ). Spouses caring for a person with a cognitive condition had baseline and follow-up depression scores below those of non-spouses caring for a person with a cognitive condition (mean pre-score 18.21 vs. 24.94; mean post-score 19.89 vs. 25.06).

### **Cluster Analysis**

The distress levels of this sample as evidenced by high depression scores, high impact of event scores, and high levels of negative affect may have obscured our ability to detect effects of the three interventions and for expressive writing in general for a subgroup of the sample. Fifty-two percent of the sample in this study reported levels of intrusiveness consistent with suggested cut-off for clinically significant reactions (Horowitz et al., 1979). Forty-two percent of the sample had a score of 33 or higher, consistent with clinical levels of with post-traumatic stress disorder (Creamer, Bell, & Failla, 2003). In another expressive writing study with caregivers of persons with psychosis, 35% of the sample reported symptoms of traumatic stress as defined by this cutoff (Barton & Jackson, 2008). While normative data from a non-clinical population indicated positive affect scores of 31.31 ( $SD=7.65$ ) and negative affect scores of 16.00

(SD=5.90; Crawford & Henry, 2004), the mean scores for this sample were 26.56 (SD=9.02) for positive affect and 19.34 (SD=8.33) for negative affect.

The variation of caregiver distress could be informative in highlighting characteristics that distinguish highly distressed caregivers from those with lower levels of distress. To assess these varying levels of distress and their associated characteristics, a cluster analysis was conducted. Cluster analyses group cases together so that they are more similar to each other than to cases in other groups. A k-means cluster analysis was used to minimize within-cluster variance. In order to maximize interpretability of cluster groups, three clusters were chosen a priori in line with the theoretical existence of distress level groupings (high, mid, and low) in this sample. Distress variables used for clustering included caregiver strain, depression, intrusiveness, violation of goals, violation of beliefs, negative affect, and positive affect). The final 3-cluster solution included 89 cases. Clusters differed significantly between groups on six of seven variables (only positive affect was not significantly different). Cluster 3 most resembled a highly distressed group comprised of 22 cases. Cluster 2 had characteristics of mid-level distress and was comprised of 37 cases. Cluster 1 had characteristics of low-level distress and was comprised of 30 cases. Table 6 illustrates cluster means on the seven outcomes and Table 7 illustrates statistical differences. Post-hoc analyses indicated that across group comparisons were significantly different for 5 of 7 variables used to cluster cases (only violation of beliefs and positive affect had one non-significant group comparison). No significant distress cluster group differences emerged for moderating variables (e.g., gender, marital status, number of care recipients, expected duration of care, relationship to care recipient, and condition of care recipient).

Table 4. Cluster groupings and means

<b>Final Cluster Centers</b>			
	Cluster		
	1 (n=30)	2 (n=37)	3 (n=22)
Depression*	9.13	23.73	38.95
Caregiver Strain*	8.93	10.32	11.95
Worldview Violation of Beliefs*	10.93	16.81	17.95
Worldview Violation of Goals*	27.83	38.84	48.73
Intrusiveness of Caregiving event*	13.60	27.08	52.50
Positive Affect**	31.98	23.30	23.88
Negative Affect*	13.84	19.32	28.71

\*High scores indicate more distress

\*\*High scores indicate more positive affect

Table 5. Pearson Chi-Square statistics for cluster analysis

	<i>N</i>	$\chi^2$	<i>P</i>
Strain	89	44.28	.000
Depression	89	114.35	.001
Intrusiveness	89	119.87	.050
Violation of Goals	89	108.29	.001
Violation of Beliefs	89	71.46	.002
Negative Affect	89	126.71	.014
Positive Affect	89	129.05	.129

## **Influence of Affect**

Previous research has indicated that expressive writing has an effect on positive and negative affect. Research has also supported the notion that participants' affect influences the tone of their writing, and ultimately, the outcome of the intervention. In this study correlational analyses indicated that both positive and negative affect scores were significantly correlated with almost every variable at pre and post intervention. Effect sizes of these correlations are presented in Table 4. Most correlations of both positive and negative affect indicated medium to large effects, suggesting that affect may account for notable variance in participant scores across outcome variables.

Negative affect was highly correlated with distress variables, and specifically displayed a large effect related to scores of depression ( $r=.69$ ), intrusiveness ( $r=.62$ ), and violation of goals ( $r=.53$ ). Medium effects were present for other distress indicators such as caregiver strain ( $r=.31$ ), violation of beliefs ( $r=.36$ ), satisfaction with life ( $r=-.41$ ), and presence of meaning ( $r=-.42$ ).

Positive affect was highly correlated with protective factors, demonstrated medium to large effects related to scores on satisfaction with life ( $r=.40$ ) and presence of meaning ( $r=.48$ ). Similarly, positive affect was negatively correlated with distress variables such as depression ( $r=-.34$ ), strain ( $r=-.29$ ), violation of beliefs ( $r=-.29$ ), and violation of goals ( $r=-.36$ ). The effects of affect on this and future interventions are discussed further in the next chapter.

The main effect analyses for positive and negative affect indicate that there was an interaction between time and condition for positive affect. However, these analyses used average pre and post scores, which may have minimized ability to understand how

participants' affect changed throughout the course of the intervention across the six distinct measurements of affect (pre and post writing for three writing sessions). An examination of mean scores of negative affect at these six time points illustrates trends that differ by condition (See Figure ##). Participants in the meaning-focused condition reported overall decreases in negative affect from beginning to completion of the intervention, while participants in the traditional writing and time-management conditions had relatively stable levels of negative affect from pre to post intervention. Participants in all three conditions reported increases in negative affect after each writing session. Investigation of the pattern of affect scores for positive affect (See Figure ##) indicates a decreasing trend from the first to final measurement for the traditional writing and time-management conditions. In contrast, participants in the meaning-focused condition reported a higher level of positive affect at the end of the intervention compared with time 1 measurement. Participants in this condition reported higher average levels of positive affect after each of the three writing sessions, compared with participants in the other two conditions, who tended to experienced decreases in positive affect after each writing. Possible implications for these differences are examined further in the discussion section.

Figure 1. Negative Affect Across Time By Condition

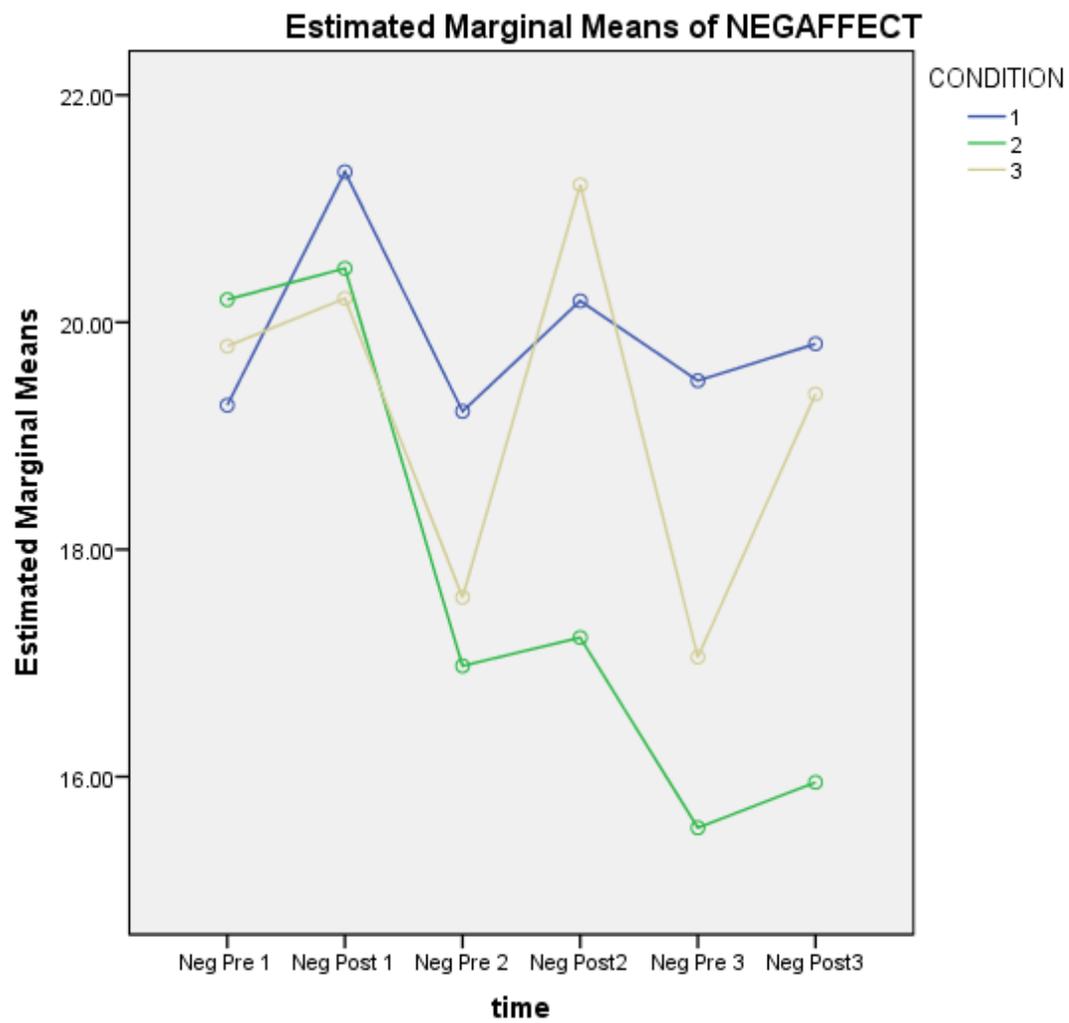
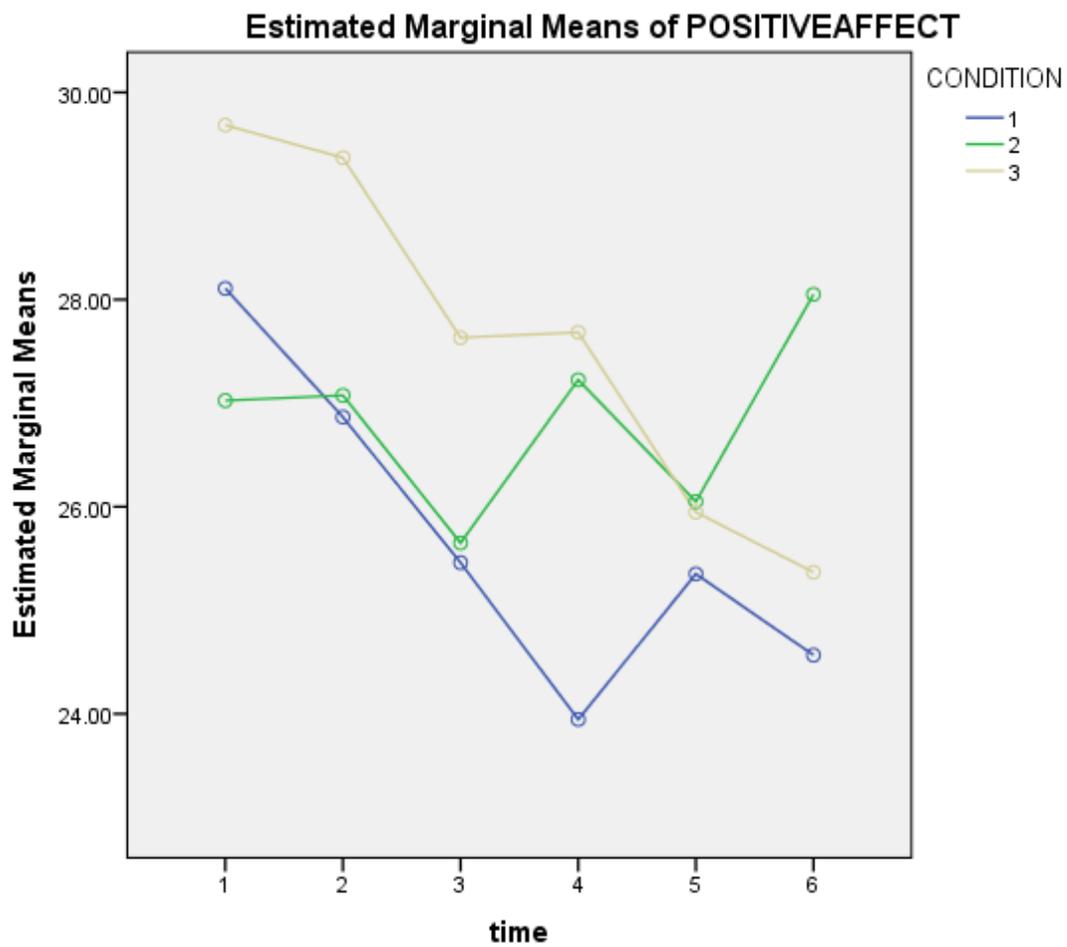


Figure 2. Positive Affect Across Time By Condition



## Discussion

This chapter will provide a summary and interpretation of the findings of the study, contextualizing it within the caregiver and expressive writing literatures. Limitations of the study, clinical implications, and future directions for research will be discussed. This study explored five main outcome variables as an investigation into variables that may have a significant impact on caregiver quality of life. For example, caregivers' depression, burden, and stress are particularly important to understand and mediate through psychological intervention. While more general outcome variables, life satisfaction and affect provide important information about the current experience of caregivers. Finally, meaning in life has proven to be an important psychological factor for caregivers (Folkman, 1997) and may be a mechanism through which change occurs.

### **Impact on Psychological Well-being**

This study aimed to explore whether writing about thoughts and feelings about being a caregiver, meaning about the caregiver experience, and time-management regarding caregiver responsibilities influenced changes in reported psychological well-being. All five outcome variables were assessed to draw conclusions about this effect.

### ***Main effects of expressive writing***

The primary set of hypotheses, that participants in the meaning-focused writing condition would report greater pre-post benefits in scores of depression, intrusiveness, caregiver strain, satisfaction with life, and search for meaning was not supported. The results of this study indicate no main effect for time for participants across writing conditions on the hypothesized outcome variables. A summary of findings for the main outcome variables is presented in Table 5. These results are in line with much the

previous research, which did not find consistent effects of expressive writing for all caregivers on immediate and follow-up measures of depression, anxiety, psychological well-being, post-traumatic symptoms, mood, and caregiver burden (Ashley, O'Connor, & Jones, 2011; Barton & Jackson, 2008; Mackenzie et al., 2007, 2008; Schwartz & Drotar, 2004). Attention in research is turning toward why expressive writing works for some participants and not for others. A discussion of characteristics of the sample that affected some outcomes in this study is presented later in this chapter. One possible reason for the lack of significant findings for treatments could be the level of distress reported by participants. The caregivers in this sample had extremely high baseline rates of clinical depression (68% with CES-D scores of 16 or higher). Although the percentage of clinically depressed caregivers in the present study was higher than in most other studies, this sample characteristic is in line with previous research as caregivers typically report higher levels of depression than non-caregiver counterparts (Aschbacher et al., 2008; Bandeira et al., 2007; Dura, Stukenberg, & Kiecolt-Glaser, 1991; Haley et al., 1995; Shaw et al., 1999). Persons providing care to a loved one have also been found to experience significantly higher levels of stress (Vitaliano et al., 1991), lower well-being (Rose-Rego, Strauss, & Smyth, 1998), and more feelings of burden (Dunkin & Anderson-Hanley, 1998) when compared with non-caregiver populations. High levels of depression, intrusion, and negative affect in the current sample may have limited this study in terms of detecting significant differences on these variables due to the intervention. Caregivers who have experienced the chronic stress of this role for years may need more intensive and targeted intervention to make a difference on variables that tend to remain stable in brief interventions or that may be difficult to change, such as

depression and strain.

Table 6. *Summary of significant and non-significant findings for main outcome variables*

<b>Outcome Variables</b>	Main Effect for Time	Main Effect for Condition	Interaction b/t Time and Condition	Meaning as Mediator
Depression	No	No	Yes	Yes*
Caregiver Strain	No	No	No	Yes**
Intrusiveness	No	No	No	No
Life Satisfaction	No	No	No	No
Meaning (Violation of Beliefs and Goals)	Yes (Goals)	No	No	No
Meaning (Search for and Presence of)	No	Yes (Search)	No	Yes***
PANAS – PA	No	No	Yes	--
PANAS – NA	No	No	No	--

Yes=significant findings; No=non-significant findings; Significance based on  $p \leq .05$

\*Change in presence of meaning predicted change in depression scores, controlling for treatment vs. control condition.

\*\*Change in search for meaning predicted time 2 caregiver strain, controlling for time 1 strain and treatment condition.

\*\*\*Change in search for meaning also significantly predicted time 2 presence of meaning, controlling for time 2 presence of meaning and treatment condition.

Though no pre-post intervention differences were found for the five hypothesized outcome variables, further analysis indicated a significant main effect for time across conditions on the Worldview Violation Scale, where there was a significant increase in violation of goals. Previous research has shown an increase in cognitive outcomes such as rumination and negative affect for highly stressed populations such as caregivers (Mackenzie et al., 2008). This effect (although not significant for PANAS scores) was present in this study despite an effort to focus expressive writing on prompts that were

generally positive. One possible explanation for this increase in violation of goals is participants' awareness of the impact caregiving has on their lives, such as lost hours in the personal and professional domain (Sherwood et al., 2008). Participants may not have engaged in-depth with their thoughts and feelings about caregiving prior to the intervention, and writing about their role as a caregiver may have made them more aware of what they sacrifice to help another, such as time with other loved ones, professional pursuits, and leisure time. Another possible explanation for this result is that follow-up measures were captured at a single point in time and may have been influenced by participants' momentary experience in addition to their participation in the intervention.

Finally, the considerable variability on outcome measures across this sample of caregivers as evidenced by the range of scores and high standard deviations warranted thought about the characteristics of this sample. There were many caregivers who reported levels of distress related to depression, strain, intrusiveness, violation of beliefs and goals, and negative affect that were much higher than normative samples. This very distressed group of caregivers may have had levels of chronic stress that were not sensitive to a brief intervention. A cluster analysis was performed to gain insight in this area, which will be discussed following discussion of the remaining hypotheses and research questions.

### ***Discovery of Meaning as a Mediator***

In addition to hypothesizing changes in outcome variables based on treatment condition, we examined a possible mechanism that explains the relationship between expressive writing intervention and outcomes. We initially hypothesized that search for meaning would mediate the link between expressive writing and changes in depression

scores. While that prediction was not supported, we further hypothesized that discovery of meaning would mediate the relationship between expressive writing and changes in depression scores. This hypothesis was based on the theoretical notion that change would come if participants were able not only to search for meaning through their writing, but to experience changes in the sense that they had meaning in their lives (Park, 2010).

Analyses testing that notion supported a full mediation model, in which participants' change in presence of meaning mediated the relationship between expressive writing and change in depression scores. This supports the theoretical notion espoused by Park (2010), that the product of the search for meaning (operationalized in this study as presence of meaning) is a critical factor in coping with stressful events. While participants in the meaning-focused condition reported lower levels of search for meaning from baseline to follow-up, it was changes in the presence of meaning, instead of the search for it that explained outcomes. This contributes to the literature, because results show that a direct manipulation of meaning-focused writing compared with traditional writing and control writing found that the discovery of meaning mediates change in expressive writing, but that directly asking participants to discover new meaning about their experiences does not significantly differ from their ability to find meaning without direct instruction. . While previous studies have suggested that meaning is a positive force underlying expressive writing (e.g., Boals, 2012; Park, 2010), we did not find other studies that examined the theoretical components of meaning making (e.g., search for meaning and presence of meaning) as mediators. Previous research that did not manipulate meaning-making in contrasting writing prompts, but instead operationalized meaning through judges' ratings, found that participants who found an event highly

distressing experienced decreases in intrusiveness after writing because of making meaning (Boals, 2012). This has implications within and beyond expressive writing. Those who engage in the expressive writing interventions may be better served by a search for meaning that yields a result or end to the search. Some participants may find an end to that search through three writing sessions while others will have just begun to search or engage in rumination rather than finding meaning. The benefits to the process of making meaning can be found in the completion of the process, for example for a caregiver who comes to feel that the many hours spent bathing and feeding a parent has given him or her a new understanding of unconditional love (Park et al, 2008; Park, 2010). Clinicians may consider this to be similar to the way we encourage clients to find answers or make some meaning of questions that have plagued them for months or years instead of ruminating about possibilities. Future implementations of and research about expressive writing should consider both components of Park and Folkman's (1997) meaning-making model (searching for meaning and made or discovered meaning) to further understand the way in which expressive writing can support the adaptive possibilities of meaning-making.

### **Additional Analyses**

This study found few significant findings for hypothesized outcomes and research questions, yet the distressed characteristics of the sample and the high variability of scores warranted an investigation into how these factors might be related to outcomes. A cluster analysis and further examination of changes in positive and negative affect over time provided more context for understanding the correlates of outcomes for this sample.

### ***Cluster Analysis***

Cluster analysis was selected as a way to learn more about participant differences that could be associated with outcomes. Three clusters emerged, associating participant scores on depression, strain, intrusiveness, satisfaction with life, violation of goals, violation of beliefs, positive affect, and negative affect with varying levels of overall distress: high, medium, and low. These clusters provide perspective about this study's sample and the characteristics that may be associated with outcomes. Results of the analysis indicated a discernable pattern of distress among clusters, where negative constructs grouped together to represent overall levels of distress. Cluster analyses show that participants high on one distress variable tended to report high levels of distress on other variables. Because this study used self-report measures, this could signify a negative response bias, or could reflect chronic and generalized distress due to the psychologically taxing nature of caregiving. While clusters 1 and 2 described caregivers with lower levels of distress, cluster 3 represented a group of caregivers who can be described as chronically distressed.

From a clinical standpoint, caregivers in cluster 3 represented those with higher levels of distress (and high levels when compared to normative samples) on variables that are historically related to poor outcomes. Additionally, this level of distress may be difficult to change through brief intervention. The results of this cluster analysis indicate the need to further consider the appropriateness of brief intervention for highly distressed individuals or to consider different interventions. Results also further underscore the need to identify individual characteristics that can facilitate change. In the case of this study, lower levels of distress across multiple variables may signify participants who are more likely to have the ability to derive benefit from intervention.

### *Changes in Depression*

Investigation into the hypothesis that expressive writing would have an effect on depression scores did not yield significant results. This result warranted a further investigation into individuals who did report decreases in depression scores in this sample. Previous research has considered change from levels of clinical depression to below-clinical cutoff to be meaningful. Thirteen participants (13.5%) reported depression scores consistent with clinical depression before the intervention but reported post-intervention depression scores that were considered low risk. This indicates that the intervention may have provided some relief from psychological distress for a group of participants. Forty-eight percent of participants who began and finished the intervention with levels of clinical depression reported neither a meaningful increase nor decrease in depression symptoms. Participants who began the intervention with sub-clinical levels of depression reported a non-significant mean increase in depression symptoms from pre to post intervention, which although insignificant, may be a result of an increase in conscious focus on the impact caregiving has had in their lives. Though there are few studies that corroborate the commonality of these negative effects, expressive writing may not always provide immediate benefits to all participants.

Additional analyses were conducted to understand possible characteristics of the group that may have benefitted most from the intervention in terms of depression. Though not significant, analyses revealed that persons caring for a spouse reported small increases in depression from baseline to follow-up, while those caring for another loved one reported small decreases levels of depression pre-to-post intervention. Although conclusions cannot be drawn from these analyses, future research with larger sample

might look more closely at these types of caregivers. For example, caregivers looking after loved ones with severe cognitive/neurological impairments such as Alzheimer's, Parkinson's, and dementia have shown worse outcomes than persons caring for a loved one with other conditions (e.g., Ory et al, 1999). Analysis of this moderator also revealed differences, though non-significant, in baseline to follow-up levels of depression, where those caring for someone with a cognitive condition had increased levels of depression from baseline to follow-up, and those caring for someone with a non-cognitive condition had lower levels of depression from baseline to follow-up. Moderated regression analysis to further test this difference, with condition of care recipient included as a predictor of follow-up levels of depression indicated a significant trend ( $\beta=-.30, p=.057$ ). This trend may prove statistically significant with a larger sample.

### *Changes in Affect*

This study also explored whether participants reported changes in positive and negative affect during their writing experiences. Findings indicated high overall levels of negative affect and higher than positive affect, with negative affect increasing slightly after each writing session. This is consistent with previous expressive writing studies, which often show increases in negative affect after disclosure of thoughts and feelings (e.g., Francis & Pennebaker, 1992; Gillis et al., 2006; Greenberg et al., 1996). A previous expressive writing study with caregivers of children and adolescents with chronic illness found that participants who wrote about their stressful experiences had more negative affect and less positive affect immediately after writing than those who wrote in a control condition (Schwartz & Drotar, 2004). Negative affect also increased over time, though not significantly, more for participants in the traditional and time-management conditions

than for participants in the meaning-focused condition. This may be because the meaning-focused condition was more consistent with positive writing prompts. However, in-depth investigations into the qualities of expressive writing essays has revealed that asking participants to write positively does not always produce positive writing. Research with a chronic pain population has suggested that positive prompts produced more negative tone than positive tone in writing similar to studies that did not use positive prompts when considering the sample as a whole. However, Ziemer et al. found that higher levels of positive affect prior to beginning expressive writing and maintaining higher levels of positive affect was related to more positive outcomes, as this was associated with higher levels of resilience and improved outcomes over time (Ziemer, Fuhrmann, & Hoffman, *under review*). In contrast, the reverse was found for those expressing higher levels of negative affect and tone of writing.

Participants in the current study across writing conditions did not differ significantly on levels of positive affect. However, results did reveal a significant interaction between time and condition, indicating that participants in the meaning-focused condition experienced an increase in positive affect while those in the traditional condition experienced decreased positive affect and those in the time management condition reported about the same levels of positive affect. Other positive writing studies (e.g., Burton & King, 2004) have also found a greater changes in positive affect than in negative affect as a result of the writing intervention. In line with Folkman's proposition (1997), positive emotions may provide an adaptive function for caregivers as a respite from everyday stress. The distressed sample of participants in this study may also have influenced these results. Participants who were already experiencing high levels of

distress may have been more easily distressed by writing about their situation compared with those who had lower levels of depression, strain, intrusiveness, and worldview violation. In addition, the traditional expressive writing paradigm asked participants to write about a traumatic event but that event may not have been occurring in real time as was the experience of caregiving for this sample.

### **Limitations**

This study has several limitations. First, the sample used in this study poses several challenges. While participants were recruited for six months through dozens of online forums and in-person support groups across the country, the number of participants who enrolled in and completed the study make statistical analyses underpowered. A priori power analysis indicated that about 150 participants would be needed to detect between-group differences of a medium effect with three experimental conditions. Given the 65 million caregivers in the U.S., recruitment of just over 100 participants seems low. One explanation for this is that caregivers have a limited time to attend to their own needs. This might include selecting to participate in a study that targets these needs.

Recruitment of participants created some additional challenges. Because participants were recruited largely from websites, listservs, and online forums, it was not possible to calculate the response rate. Potential participants may have clicked on the study but not completed the baseline measures. It is not possible to determine the reason that participants chose not to follow through on completing baseline measures, though the researcher did streamline the process from baseline measure to randomization to condition about halfway through data collection so that participants had to wait less time

to begin the intervention. Some people may have clicked on the study just to view it rather than as potential participants. Recruitment from online outlets creates sampling bias just as does recruitment from one or two medical/treatment sites. Online organizations were selected for participant outreach since they have the potential to reach a wider array of participants, however, this method may have also reached only those who seek help or resources over the internet. To address this limitation, participants were recruited from in-person support groups in Maryland, Virginia, and Washington, D.C. Participants who were interested in and enrolled in the study may have been a subset not representative of all informal caregivers, as they may have been more comfortable with online technology and were certainly those with access to online resources. It should be noted, however, that the intervention reached persons up to 79 years of age, indicating that online interventions such as this are not always restrictive to technological generations. Finally, knowledge of and participation in the study required that people think of themselves as caregivers. Of the millions of caregivers in the U.S. it is unknown how many of these individuals would label themselves a caregiver and identify with in-person or online support groups for support in this role. This subjective distinction may have skewed the sample toward those who are consciously identified as caregivers. To combat this, we also attempted to recruit from illness-related websites that did not specifically target caregivers. Often, persons with an ill loved one seek information online about the illness rather than specifically about providing care. This may have mitigated the mandate that participants identify as caregivers. Finally, the researcher is still collecting data to add to the sample of this study. More data will increase the range of represented caregivers and increase statistical power for analyses.

A different limitation involves the implementation of the intervention.

Participants were able to write in the comfort of their own environment rather than in a laboratory environment. Therefore, we were unable to ensure extraneous variables and determine adherence to treatment. As an example of this, one participant emailed the primary researcher to describe how her husband had “an episode” during the writing and it had to be completed in two parts. This seemed to be a rare occurrence, however, as most participants seemed able to comply with our directions that they write in a quiet, comfortable, private setting. Time stamps were gathered as data describing when participants entered and exited the writing website and were reviewed as a rough estimate of the amount of time spent writing. The findings indicate that most participants complied with the writing time. Participants were also emailed on the specific days that they were expected to complete the writing to ensure that the writing sessions occurred approximately a week apart.

The use of self-report measures are a limitation of this study as the accuracy of the data collected is a measure of participants’ assessment of their own psychological health. Self-reports are typically only modestly related to real-world behaviors (Pennebaker, 2004) and can make it difficult to assess unconscious processes such as were of interest in this study (e.g., meaning-making) (Park, 2010). Additionally, self-report measures can be influenced by participant mood, and participants may have over- or-underestimated their levels of distress and well-being.

Another limitation of this study is the selection of outcome variables. Variables such as depression, caregiver strain, satisfaction with life, and meaning in life may not be malleable in a time-limited study with a highly-distressed sample. Researchers did not

expect the level of distress present in this sample of caregivers. The implications of this limitation are discussed further in the next chapter.

### **Future Research**

First, the effect of positive and negative affect in this study shows a need to further explore the impact of mood on intervention outcomes and to develop interventions that target affect as a source of change. While it is not possible to distinguish whether high levels of negative affect result from high levels of distress or if the reverse is true in this study, future research that targets caregiver affect can contribute further understanding in this area as it is known that negative affect contributes to a myriad of poorer outcomes. Many expressive writing studies have shown changes in affect as an immediate result of the intervention although most have found drops in positive affect and increases of negative affect during the course of the intervention. Because negative affect is associated in psychological literature with many negative psychological and health outcomes, future interventions may target affect, which could then have an impact on more robust outcomes over time, such as strain and depression.

Family caregivers may provide emotional, physical, and financial support to a loved one for a short time or for many years. The caregivers who shared their stories and experiences for this study were typically among those experiencing the chronic stress of caregiving for a decade or more. Over half of participants had been or expected to be a caregiver for more than 10 years. It may be that shorter-term caregivers do not identify themselves as caregivers, yet when they begin this process, they often do not know where it will lead. Future research should consider early intervention for family caregivers, who may be able to frame a long-term caregiving experience as meaningful before

encountering an aimless search for meaning about years of dedicated work. Interventions should also be sensitive to the relation of caregiver to care recipient, as this study suggested spousal caregivers are less likely to experience the positive effect of a brief intervention. This may be due to an increased sense of violation of beliefs and goals, tied to a kind of loss in the quality of relationship that once fulfilled these thoughts and feelings. Alternatively, it may be important that spousal caregivers, unlike other caregivers who augment the care of those living in assisting living facilities, are typically living with the care recipient.

Future studies using the expressive writing paradigm could benefit from a larger sample of caregivers, including those who may not explicitly identify themselves as caregivers. This may also provide benefit in reaching a sample of caregivers with a representative array of psychological distress, since more identity with the caregiver role may indicate a stronger sense of having left other parts of identity behind. Increased caregiver identity may also be indicative of participants who have a limited amount of time to complete psychological interventions of any kind. This may have been a reason for participant decisions to not begin the study or to drop-out during the course of the intervention.

Future studies should continue to consider mediator and moderator variables that contribute to equivocal outcomes across expressive writing literature. As discussed, affect appears to be an important moderating factor related to outcomes. In line with the theoretical underpinnings of expressive writing, studies of the paradigm should continue, as this study did, to look at types of coping, such as emotion approach coping (e.g., meaning-making), that may operate as mediators to explain outcomes.

In this study, the three writing conditions were assessed to be effective to the extent that they had a positive effect on depression, caregiver strain, intrusiveness, satisfaction with life, and meaning in life. However, there were few differences on these measures between writing conditions. The researcher is aware that there are many expressive writing studies that find no significant effects and are not published. Still, individual differences in outcomes point to the importance of further investigation about the aspects of the writing that may have produced these changes. While researchers have analyzed the linguistic content of participants' writings to identify factors associated with benefit (e.g., Pennebaker & Graybeal, 2001; Mackenzie et al., 2008), the Linguistic Inquiry Word Count (LIWC; Pennebaker & Francis, 1999) used to do so often falls short of capturing dynamic factors that could account for beneficial outcomes. Researchers of the current study plan to use qualitative methods, such as consensual qualitative research (Hill, Thompson, & Williams, 1997) to analyze the content of the writing samples. This method can provide this and other studies with a deeper understanding of how participants used the writing intervention. Additionally, it can provide valuable information about the specific experiences of caregivers, such as helpful resources and barriers to well-being. Qualitative analyses may also be able to capture what self-report measures about making-meaning could not. The qualitative data from this study is the first available about how participants write directly about making meaning of their experiences.

Finally, it would be beneficial to determine not only what aspects of the writing increase well-being and decrease distress, but also which participants were able to experience more of an increase in these areas than others. This study saw a trend toward

greater benefits for non-spousal caregivers and caregivers for a person with a condition other than Alzheimer's, Parkinson's, and dementia, all of which are associated with cognitive decline. However, other personal characteristics and outside factors may be important determinants of who benefits more from expressive writing. For instance, it is unknown why certain participants in this study reported an increase in presence of meaning, regardless of writing condition, than others. Future research should attempt to clarify the characteristics of individuals who benefit the most from expressive writing. Specifically, there may be more advantages to employing expressive writing with caregivers who are not in the midst of emotional turmoil, such as those who are no longer in an active caregiving role as a loved one transitions to a care facility. The lead researcher was contacted many times by individuals who wished to participate in the study but who were no longer active in a caregiving role. Expressive writing has been found to be most effective after trauma (Pennebaker & Chung, 2007). Still, researchers and clinicians should balance the evidence about effectiveness and the need to help those currently struggling with stressful experiences.

### **Clinical Implications**

Results from this study indicate that the participants were experiencing levels of depression at or above that of typical caregiver populations. The study showed that the intervention helped to reduce the experience of depression for a subset of participants, indicating that this intervention may be beneficial for other caregivers. Further, participants were able to engage in thinking about the meaning serving as a caregiver has in their life, with some participants finding greater presence of meaning as a result of this search. While they may or may not have expressed so in their writing, about a dozen

participants emailed the primary researcher reporting that they felt positively about and benefitted from the intervention. Another posted on a caregiver site about her appreciation for being able to participate and that someone was studying the caregiver experience. The researcher received only positive correspondence from participants who appreciated their experience in the study. Psychologists should consider the value of this type of intervention, which many caregivers find appealing both logistically and economically.

The results of this study indicate that these writing interventions may particularly benefit certain types of caregivers, such as those caring for a parent, sibling, child, or other loved one. These caregivers may have moderate levels of distress related to their caregiving and may be able to benefit from a brief intervention. For caregivers who have higher levels of depression and strain, more active interventions that provide them with psychological resources they lack (e.g., social support; psychotherapy) may prove more effective. For example, informal caregivers with whom the primary researcher interacted tended to express a lack of understanding from others such as family and friends. Connecting with others and decreasing social isolation may provide something that a one-way writing exercise cannot. Another possible extension of the expressive writing paradigm has root in this sentiment. Further research about the expressive writing paradigm could involve writing to a practitioner such as a psychologist. It is possible that feeling attended to be the recipient of the writings could provide additional benefit to disclosure of thoughts and feelings in writing. There was no evidence from participants' self reports that they felt negatively about the intervention. While results of analyses indicated that some caregivers were helped as evidenced by reduced levels of distress and

some were not, it seemed that the participants felt grateful that someone cared about their experience. Expressive writing may not be the most effective intervention for caregivers who have limited time and psychological resources to devote to intervention. Still, attention to their experience seems to produce a positive response. For instance, participants were recruited through online communities of caregivers. These online groups may provide the kind of accessible, cost-effective intervention that addresses the psychosocial needs of caregivers. Caregivers may also benefit from more programs that address their psychological needs at locations where they travel in service to their care recipient (e.g., hospitals, clinics). No matter the intervention, it seems that fostering positive affect and reducing negative affect is a critical component to improving the well-being of caregivers.

### **Conclusion**

This study contributes to both the caregiving and expressive writing literatures. Regarding caregivers, this study shows that a brief intervention can have a beneficial effect on psychological outcomes for a subset of caregivers. It further highlights the differences between caregiver experiences and encourages further investigation about these differences through research and consideration of unique experiences of different caregiver situations. Overall, participants in all three writing conditions reported a mix of mostly non-significant effects related to the specific interventions. Despite non-significant differences between conditions, 13.5% of participants experienced meaningful decreases in clinical depression. Upon further investigation, it became apparent that there are individual differences that may account for intervention outcomes.

Importantly, this study provides some evidence that some of the positive effects of expressive writing can be explained by the discovery of, but not simply the search for, meaning. This valuable evidence provides grounds for further investigation and corroboration. Research should continue to explore the qualities of expressive writing that enhance participants' abilities to discover meaning.

## Appendix A

Informed Consent**What it Means to Care**

<b>Purpose of the Study</b>	<p><i>This research is being conducted by Amy Fuhrmann, M.S., a doctoral student under the supervision by Mary Ann Hoffman, Ph.D. in the Department of Counseling, Higher Education, and Special Education at the University of Maryland, College Park. We are inviting you to participate in this research project because you are at least 18 years of age, you are providing care, without pay, to a loved one, and you are providing this care for a minimum of 3 hours per day. The purpose of this research project is to explore the effects of writing about your experiences as caregiver.</i></p>
<b>Procedures</b>	<p><i>This is an online study that involves writing about your experiences as a caregiver for 15 minutes, three times over the course of several weeks. If you are eligible to participate, you will complete a baseline survey about your emotional health and well-being, which should take between 15 and 25 minutes. You will then be randomized to either one of three writing conditions. The writing conditions in this study are writing about your thoughts and emotions about being a caregiver, writing about what it means to be a caregiver, and writing about how you manage your time. Random assignment to one of these three conditions is like flipping a coin. You will then complete three separate writing sessions for your assigned writing condition. . You will also be asked to complete a short survey directly before and after writing. You will complete these writing sessions (15-25 minutes each) for a total of 3 times. Three weeks after the final writing session, you will again fill out a survey about your emotional health and well-being. In total, this study is anticipated to require about 2 hours of your time.</i></p> <p><i>The surveys included in this study are listed below with example items:</i></p> <ul style="list-style-type: none"> <li>- Stress     <i>“I tried not to think about it.”</i></li> <li>- Depression     <i>“I felt that everything I did was an effort.”</i></li> <li>- Satisfaction with life     <i>“If I could live my life over, I would change almost nothing.”</i></li> <li>- Caregiver strain     <i>“It is a financial strain.”</i></li> <li>- Meaning in life     <i>“I am searching for meaning in my life.”</i></li> <li>- Worldview violation</li> </ul>

	<p>“How much does this stressful experience violate your sense of being in control of your life?”</p>
<b>Potential Risks and Discomforts</b>	<p><i>There may be some risks from participating in this research study. You may have both positive and negative feelings about your experiences as a caregiver, and writing about negative feelings may induce feelings of discomfort or sadness. There will be no one monitoring your writing on a regular basis and there will be no one giving you feedback on your writing. If for any reason you feel you need to contact the researchers, you can do so at <a href="mailto:fuhrmann@umd.edu">fuhrmann@umd.edu</a>. You will also be provided with a resource to locate a psychologist in your area.</i></p>
<b>Potential Benefits</b>	<p><i>There are no direct benefits to participation. We hope that, in the future, other people might benefit from this study through improved understanding of what can be helpful for caregivers.</i></p>
<b>Confidentiality</b>	<p><i>The research team will minimize any potential loss of confidentiality by storing data in a locked office and password protected computer. Moreover, your identifying information will not be linked to your survey or written responses. Only members of the research team will have access to your responses. There is also the risk of inadvertent disclosure if you do not complete the intervention in a private location and someone sees your responses. If we write a report or article about this research project, your identity will be protected to the maximum extent possible. Your information may be shared with representatives of the University of Maryland, College Park or governmental authorities if you or someone else is in danger or if we are required to do so by law.</i></p>
<b>Medical Treatment</b>	<p><i>The University of Maryland does not provide any medical, hospitalization or other insurance for participants in this research study, nor will the University of Maryland provide any medical treatment or compensation for any injury sustained as a result of participation in this research study, except as required by law.</i></p>
<b>Right to Withdraw and Questions</b>	<p><i>Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time.</i></p> <p><i>If you decide to stop taking part in the study, if you have questions, concerns, or complaints, please contact the primary investigator, Amy Fuhrmann, at 2147H, Biology-Psychology Building, University of Maryland, College Park, MD 20742, <a href="mailto:fuhrmann@umd.edu">fuhrmann@umd.edu</a></i></p>
<b>Participant Rights</b>	<p><i>If you have questions about your rights as a research participant or wish to report a research-related injury, please contact:</i></p>

	<p style="text-align: center;"><b>University of Maryland College Park Institutional Review Board Office 1204 Marie Mount College Park, Maryland, 20742 E-mail: <a href="mailto:irb@umd.edu">irb@umd.edu</a> Telephone: 301-405-0678</b></p> <p><i>This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.</i></p>
<b>Statement of Consent</b>	<p><i>By clicking on the “next” button, this indicates that you are at least 18 years of age; you are able to read and write in English; you are providing care for at least 3 hours per day to a person with a disease; you have read this consent form or have had it read to you; your questions have been answered to your satisfaction and you voluntarily agree to participate in this research study. Remember that you may choose to stop participating at any time. You may print a copy of this consent form.</i></p> <p><i>If you agree to participate, please click “next”.</i></p>

## Appendix B

Eligibility Criteria

Thank you for your interest in this study. Before you proceed, please answer the following questions to determine if you are eligible to participate.

Eligibility Criteria (\*=does not meet eligibility)

1. Are you at least 18 years of age? Yes \_\_\_ No\* \_\_\_
2. Are you able to read and write in English? Yes \_\_\_ No\* \_\_\_
3. Do you currently provide unpaid care for someone with a disease? Yes \_\_\_ No\* \_\_\_
4. Do you provide this unpaid care for at least three hours per day on average?  
Yes \_\_\_ No \* \_\_\_
5. Do you currently reside with the care recipient? Yes \_\_\_ No\* \_\_\_
6. Is the care recipient currently in hospice or palliative care? Yes\* \_\_\_ No \_\_\_

If participants are ineligible

Thank you for your interest in this study. In order to participate in this study, it is important to meet specific inclusion criteria. Due to these conditions, we regret to inform you that we cannot take you as a participant at this time.

## Appendix C

Demographics

1. What is your age?
2. With what gender do you identify? \_\_\_M \_\_\_F \_\_\_other
3. Country of residence:
4. State of residence (if applicable):
5. What is your relationship status:
  - \_\_\_ Married
  - \_\_\_ In a long term relationship
  - \_\_\_ Divorced
  - \_\_\_ Widowed
  - \_\_\_ Single
6. With which ethnic background(s) do you identify most strongly? (Mark all that apply)
  - \_\_\_ African-American
  - \_\_\_ Asian-American/Pacific Islander
  - \_\_\_ Indian
  - \_\_\_ Latin American
  - \_\_\_ Middle Eastern
  - \_\_\_ Native American/Native Alaskan
  - \_\_\_ European American
  - \_\_\_ Other (please specify): \_\_\_\_\_
7. What is your highest level of education completed?
  - \_\_\_ Grade school/Junior High
  - \_\_\_ High School
  - \_\_\_ Some College
  - \_\_\_ Associate's Degree
  - \_\_\_ Bachelor's Degree
  - \_\_\_ Graduate Degree
8. What is your employment status? (check **all** that apply)
  - \_\_\_ Not employed (unrelated to caregiving)
  - \_\_\_ Full-time employee or student
  - \_\_\_ Part-time employee or student
  - \_\_\_ No longer employed
  - \_\_\_ Working at home
  - \_\_\_ Working outside of the home

- On paid family leave  
 On unpaid family leave
9. What is your annual household income (before taxes?)
- Under \$20,000  
 Between \$20,001 and \$40,000  
 Between \$40,001 and \$60,000  
 Between \$60,001 and \$100,000  
 Above \$100,000
10. For how many people do you provide unpaid care (for disease such a cancer)? \_\_\_\_\_
11. What is your relationship to the person for whom you care?
- Spouse  
 Partner  
 Parent  
 Child  
 Sibling  
 Other Relative  
 Other (please specify): \_\_\_\_\_
12. What type of disease is the person for whom you care diagnosed?  
 \_\_\_\_\_
13. Please list other health problems of the person for whom you care (e.g., diabetes). \_\_\_\_\_
14. Have you been diagnosed with any mental illness (e.g., depression, anxiety)?
- Yes (please specify)  
 No
15. Number of hours spent per day caring for care recipient: \_\_\_\_\_
16. For how long have you been providing care for this person from the start of your caregiving experience through today? \_\_\_\_\_
17. Expected total duration of caregiving experience:
- less than 6 months  
 6 months – 1 year  
 1 year – 2 years  
 2 years – 5 years  
 5 years – 10 years  
 10 – 15 years  
 more than 15 years

## Appendix D

## The Center for Epidemiological Studies - Depression Scales (CES-D)

Please indicate how often you have felt this way during the past week by using the following numbers:

- 0 = rarely or none of the time (less than one day)
- 1 = some of the time (1-2 days)
- 2 = occasionally or a moderate amount (3-4 days)
- 3 = most or all of the time (5-7 days)

1. I was bothered by things that usually don't bother me.
2. I did not feel like eating; my appetite was poor.
3. I felt that I could not shake off the blues even with help from my friends.
4. I felt that I was just as good as other people.
5. I had trouble keeping my mind on what I was doing.
6. I felt depressed.
7. I felt that everything I did was an effort.
8. I felt hopeful about the future.
9. I thought my life had been a failure.
10. I felt fearful.
11. My sleep was restless.
12. I was happy.
13. I talked less than usual.
14. I felt lonely.
15. People were unfriendly.
16. I enjoyed life.
17. I had crying spells.
18. I felt sad.
19. I felt that people disliked me.
20. I could not get "going."

**SCORING:** The scoring of positive items is reversed. Possible range of scores is zero to 60, with the higher scores indicating the presence of more symptomatology.

## Appendix E

## The Impact of Event Scale - Revised

**INSTRUCTIONS:** Below is a list of difficulties people sometimes have after experiences with pain. Please read each item, and then indicate how distressing each difficulty has been for you **DURING THE PAST SEVEN DAYS** with respect to physical pain. How much were you distressed or bothered by these difficulties?

0 = Not at all; 1 = A little bit; 2 = Moderately; 3 = Quite a bit; 4 = Extremely.

1. Any reminder brought back feelings about the pain.
2. I had trouble staying asleep because of the pain.
3. Other things kept making me think about the pain.
4. I felt irritable and angry because of the pain.
5. I avoided letting myself get upset when I thought about the pain or was reminded of the pain.
6. I thought about the pain when I didn't mean to.
7. I felt as if the pain hadn't happened or wasn't real.
8. I stayed away from reminders of the pain.
9. Pictures about the pain popped into my mind.
10. I was jumpy and easily startled because of the pain.
11. I tried not to think about the pain.
12. I was aware that I still had a lot of feelings about the pain, but I didn't deal with them.
13. My feelings about the pain were kind of numb.
14. I found myself acting or feeling like I was back at the time when the pain started.
15. I had trouble falling asleep because of the pain.
16. I had waves of strong feelings about the pain.
17. I tried to remove the pain from my memory.
18. I had trouble concentrating because of the pain.
19. Reminders of the pain caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.
20. I had dreams about the pain.
21. I felt watchful and on-guard because of the pain.
22. I tried not to talk about the pain.

**Scoring:**

Avoidance Subscale = mean of items 5, 7, 8, 11, 12, 13, 17, 22

Intrusion Subscale = mean of items 1, 2, 3, 6, 9, 14, 16, 20

Hyperarousal Subscale = mean of items 4, 10, 15, 18, 19, 21

## Appendix F

## Satisfaction with Life Scale

*Directions:* Below are five statements that you may agree or disagree with. Using the 1 - 7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding.

- 7 - Strongly agree
- 6 - Agree
- 5 - Slightly agree
- 4 - Neither agree nor disagree
- 3 - Slightly disagree
- 2 - Disagree
- 1 - Strongly disagree

\_\_\_\_\_ In most ways my life is close to my ideal.

\_\_\_\_\_ The conditions of my life are excellent.

\_\_\_\_\_ I am satisfied with my life.

\_\_\_\_\_ So far I have gotten the important things I want in life.

\_\_\_\_\_ If I could live my life over, I would change almost nothing.

- 31 - 35 Extremely satisfied
- 26 - 30 Satisfied
- 21 - 25 Slightly satisfied
- 20 Neutral
- 15 - 19 Slightly dissatisfied
- 10 - 14 Dissatisfied
- 5 - 9 Extremely dissatisfied

## Appendix G

***The Caregiver Strain Index:*** I am going to read a list of things that other people have found to be difficult. Would you tell me if any of these apply to you? (Give examples)

	<b>Yes=1</b>	<b>No=0</b>
Sleep is disturbed (e.g., because _____ is in and out of bed or wanders around at night)		
It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help)		
It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)		
It is confining (e.g., helping restricts free time or cannot go visiting)		
There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy)		
There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)		
There have been other demands on my time (e.g., from other family members)		
There have been emotional adjustments (e.g., because of severe arguments)		
Some behavior is upsetting (e.g., because of incontinence; _____ has trouble remembering things; or _____ accuses people of taking things)		
It is upsetting to find _____ has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be )		
There have been work adjustments (e.g., because of having to take time off)		
It is a financial strain		
Feeling completely overwhelmed (e.g., because of worry about _____; concerns about how you will manage)		
<b>TOTAL SCORE</b> (Count yes responses. Any positive answer may indicate a need for intervention in that area. A score of 7 or higher indicates a high level of stress.)		

## Appendix H

Worldview Violations Scale

<b>When you think about how you felt before and after your most stressful experience:</b>	<b>Not at all</b>				<b>Very much</b>
How much does the occurrence of this stressful experience violate your sense of the world being fair or just?	1	2	3	4	5
How much does this stressful experience violate your sense that other forces have control in the world?	1	2	3	4	5
How much does this stressful experience violate your sense that God is in control?	1	2	3	4	5
How much does this stressful experience violate your sense of being in control of your life?	1	2	3	4	5
How much does this stressful experience violate your sense that the world is a good and safe place?	1	2	3	4	5

<b>How much does your stressful experience interfere with your ability to accomplish each of these?</b>	<b>Not at all</b>				<b>Very much</b>
Companionship (being with others)	1	2	3	4	5
Social support and community	1	2	3	4	5
Spirituality	1	2	3	4	5
Self-acceptance	1	2	3	4	5
Physical health	1	2	3	4	5
Inner Peace	1	2	3	4	5
Financial security	1	2	3	4	5
Educational Achievement	1	2	3	4	5
Achievement in my career	1	2	3	4	5
Creative or artistic accomplishment	1	2	3	4	5
Athletic accomplishment	1	2	3	4	5
Intimacy (Emotional closeness)	1	2	3	4	5

## Appendix I

## MEANING IN LIFE QUESTIONNAIRE (MLQ)

Please take a moment to think about what makes your life and existence feel important and significant to you. Please respond to the following statements as truthfully and accurately as you can, and also please remember that these are very subjective questions and that there are no right or wrong answers. Please answer according to the scale below:

<b>Absolutely Untrue</b>	<b>Mostly Untrue</b>	<b>Somewhat Untrue</b>	<b>Can't Say True or False</b>	<b>Somewhat True</b>	<b>Mostly True</b>	<b>Absolute True</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>

- \_\_\_\_ 1. I understand my life's meaning.
- \_\_\_\_ 2. I am looking for something that makes my life feel meaningful.
- \_\_\_\_ 3. I am always looking to find my life's purpose.
- \_\_\_\_ 4. My life has a clear sense of purpose.
- \_\_\_\_ 5. I have a good sense of what makes my life meaningful.
- \_\_\_\_ 6. I have discovered a satisfying life purpose.
- \_\_\_\_ 7. I am always searching for something that makes my life feel significant.
- \_\_\_\_ 8. I am seeking a purpose or mission for my life.
- \_\_\_\_ 9. My life has no clear purpose.
- \_\_\_\_ 10. I am searching for meaning in my life.

**Scoring:**

Item 9 is reverse scored.

Items 1, 4, 5, 6, & 9 make up the Presence of Meaning subscale

Items 2, 3, 7, 8, & 10 make up the Search for Meaning subscale

**Reference:**

Steger, M. F., Frazier, P., Oishi, S., & Kaler, M. (2006). The Meaning in Life Questionnaire: Assessing the presence of and search for meaning in life. *Journal of Counseling Psychology*, 53, 80-93.

## Appendix J

### Positive and Negative Affect Schedule (PANAS)

*Directions:* This scale consists of a number of words that describe different feelings and emotions. Read each item and then circle the appropriate answer next to that word.

Indicate to what extent you feel this way right now.

Use the following scale to record your answers.

- (1) = Very slightly or not at all      (2) = A little      (3) = Moderately      (4) = Quite a bit      (5) = Extremely

	Very slightly or not at all	A little	Moderately	Quite a bit	Extremely
1. Interested	1	2	3	4	5
2. Distressed	1	2	3	4	5
3. Excited	1	2	3	4	5
4. Upset	1	2	3	4	5
5. Strong	1	2	3	4	5
6. Guilty	1	2	3	4	5
7. Scared	1	2	3	4	5
8. Hostile	1	2	3	4	5
9. Enthusiastic	1	2	3	4	5
10. Proud	1	2	3	4	5
11. Irritable	1	2	3	4	5
12. Alert	1	2	3	4	5
13. Ashamed	1	2	3	4	5
14. Inspired	1	2	3	4	5
15. Nervous	1	2	3	4	5
16. Determined	1	2	3	4	5
17. Attentive	1	2	3	4	5
18. Jittery	1	2	3	4	5
19. Active	1	2	3	4	5
20. Afraid	1	2	3	4	5

## Appendix K

**Recruitment Notice**

## Online Study for Caregivers

Are you an unpaid caregiver for a loved one? Are you at least 18 years of age? If you answered “yes” to all of these questions, you may be eligible to participate in a study conducted by researchers at the University of Maryland.

The study explores participants’ caregiving experiences through 2 surveys and 3 writing exercises. Some people find writing as a way to record what happens to them or as a way to talk about difficult experiences. There has been great interest in recent years with writing to understand important experiences in your life.

Often times care for a patient takes precedence, and the wellbeing of the caregiver is largely ignored. This is your chance to help other caregivers and help researchers to develop ways to improve the lives of caregivers.

The 2 surveys and 3 writing exercises will be spaced out so that you complete one per week for five weeks. It will take approximately 15-25 minutes of your time each week. You can complete the entire study online. This research is being conducted by Amy Fuhrmann, M.S. and Mary Ann Hoffman, Ph.D., professor and co-director of the counseling psychology program at the University of Maryland, College Park. If you would like to participate in this research, please contact Amy Furhmann at [fuhrmann@umd.edu](mailto:fuhrmann@umd.edu) or follow the link below. To participate, you must meet the eligibility requirements of the screening questionnaire.

[https://umdsurvey.umd.edu/SE/?SID=SV\\_cx9yds8u0Vs3vtH](https://umdsurvey.umd.edu/SE/?SID=SV_cx9yds8u0Vs3vtH)

Thank you!

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## Appendix L

## Reminder Email To Participants

Hello,

You recently received an email to complete part \_\_\_\_ of the study. It is important that you complete this part of the study as soon as possible so that the study remains consistent. I appreciate your participation in my study!

Best,

Amy Fuhrmann, M.S. and Mary Ann Hoffman, Ph.D.

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