THE EFFECT OF A POETRY WRITING INTERVENTION ON SELF-TRANSCENDENCE, RESILIENCE, DEPRESSIVE SYMPTOMS, AND SUBJECTIVE BURDEN IN FAMILY CAREGIVERS OF OLDER ADULTS WITH DEMENTIA

By

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*We also certify that written approval has been obtained for any proprietary material contained therein.
DEDICATION

For Mom, the most wonderful and important caregiver in my life

Neither words nor poems can express the debt I owe you and the love I have for you
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The Effect of a Poetry Writing Intervention on Self-transcendence, Resilience, Depressive Symptoms, and Subjective Burden in Family Caregivers of Older Adults with Dementia

Abstract

By

LORI IRENE KIDD

The purpose of this pilot study was to test the effectiveness of a poetry writing intervention on outcome variables self-transcendence, resilience, depressive symptoms, and subjective burden in family caregivers of older adults with dementia. The theoretical framework synthesized theories of Adler, Frankl, and Reed’s Theory of Self-Transcendence. Research questions were: 1) Are there differences on self-transcendence, resilience, depressive symptoms, and caregiver burden between family caregivers of older adults with dementia who write poetry (Group A) and family caregivers not writing poetry (Group B) from Time 1 to Time 2; 2) Are higher positive psychological resources (self-transcendence and resilience) associated with lower negative psychological outcomes (depressive symptoms and caregiver burden) over time with continued poetry writing?; 3) Will there be improvements on psychological resources and negative outcomes in both groups from before writing poetry to after writing poetry?; 4) What common themes emerge from the poetry written by family caregivers? 5) Will caregivers (Group A) who participate in poetry writing continue to write or verbalize intent to write poetry after they are no longer required to do so?; 6) What is the feasibility of conducting a larger clinical trial?
Methodology was a mixed methods, longitudinal, crossover design. Participants (n=20) were drawn from a convenience sample of dementia caregivers in the Midwest. Instruments were administered to all participants at baseline (Time 1). Participants were then randomized to one of two intervention groups. Group A was first asked to write and share with the PI at least three poems written over a four week period. Instruments were administered again to all subjects (Time 2). Next, participants in Group B were asked to write poetry for four weeks. Then, all subjects were asked to complete study instruments (Time 3). Participants in Group A were asked whether they continued to write poetry after the 4-week writing time was over. Participants were interviewed about their poetry writing experiences. Data analysis involved examination of descriptive statistics and thematic analysis of poem content. Feasibility of a larger clinical trial was assessed. Implications were that poetry writing can be a valuable nursing intervention to support dementia family caregivers.
CHAPTER ONE

Background and Significance

The population of persons aged 65 and older is expected to double between 2000 and 2030, with those older than 85 growing at the fastest rate (Federal Interagency Forum on Aging-Related Statistics, 2000). A population-based survey (n=1,247) conducted by the National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP) revealed that approximately 21% or 4.4 million persons aged 18 and older reported themselves as caregivers (2004). Care duration was reported as averaging 4.3 years (NAC/AARP, 2004). It is reasonable to conclude that many more 65-year-old seniors will care for parents aged 90 or older (Talley & Crews, 2007). As advanced age increases risk for dementing illnesses such as Alzheimer’s Disease (National Institutes of Health, 2007), another consequence is that more older adults with dementia will require care from family members.

Approximately 4.5 million people were diagnosed with Alzheimer’s disease according to the 2000 U.S. Census (Hebert, Scherr, & Bienias, 2003). Cost estimates range from over $18,000 for mild Alzheimer’s to over $36,000 for more severe Alzheimer’s disease. U.S. businesses suffer over $61 billion annually in losses, including lost productivity and absenteeism (Nichols et al., 2008). The financial costs of informal dementia caregiving are very high (Nichols).

The tangible economic costs of caregiving pale compared to physical and psychological costs imposed on caregivers. The authors of the NAC/AARP study (2004) concluded that caregiving produced more emotional than physical strain. One third of caregivers (35%) rated their stress level as 4 of 5 on a five point scale. Those
experiencing the greatest emotional stress were: female (40% vs. 26% male respondents); white or Hispanic (36% vs. 30% African American and 23% Asian American); and in fair or poor health (35% of Level 5 caregivers). Almost 3 in 10 (29%) caregivers also reported a need for more help or information in managing emotional and physical stress. In addition, those caring for someone with dementia reported higher stress levels than other types of caregivers (42% vs. 32%). It is crucial at a societal level to build an arsenal of interventions to help protect and defend dementia caregivers from negative emotional consequences of caregiving.

Although heaviness of caregiving burden and intensity of care is most predictive of physical and emotional health-related problems (Talley & Crews, 2007), caregiving at any level or degree can produce negative psychological consequences for the caregiver. Caring for a person with dementia has been associated with decreased psychological and physical well-being of the caregiver (Bell, Araki, & Neumann, 2001; George & Gwyther, 1986; Zarit, Reever, & Bach-Peterson, 1980). Self-report measures have consistently shown increased depression and anxiety in dementia caregivers as opposed to age and gender based norms (Schulz, 2000).

Caregivers are at greater risk for depressive symptoms whether residing with or separately from the demented care recipient (Gibson, Butkus, Jenkins, Mathur, & Liu, 1997); when care recipients have lower Mini Mental Status Exam scores (Shua-Haim, Haim, Shi, Kuo, & Smith, 2001); and when caregivers more negatively appraise caregiving tasks and the meaning attached to the tasks (Yates, Tennstedt, & Chang, 1999). These negative appraisals, or subjective burden (Maurin & Boyd, 1990), render the caregiver vulnerable to psychological consequences such as depression, anxiety, worry,
and guilt (Bell, et al., 2001; Nijboer, Triemstra, Tempelaar, Sanderman, & Van den Bos, 1998). In a meta-analysis, Schulz, Vistainer, & Williamson (1990) found that caregivers were more likely to experience psychiatric and physical morbidity than the general population. Subjective burden and generalized perceived stress can predict depression in caregivers (Etters, Goodall, & Harrison, 2008; Gallagher-Thompson & Powers, 1997).

Depressive symptoms may result in major depression. Major depressive disorder is one of the top ten causes of disability worldwide (Murray & Lopez, 1996). Individuals disabled by depression may be unable to function or perform adequately in occupational, social, or family roles. Therefore, one depressed person will affect others in widening circles of influence, affecting families, friends, and workplaces. Even without the diagnosis of major depression, symptoms such as loss of interest and pleasure, and lack of energy and motivation enhance the tendency of depressed persons to withdraw from their environment and from others and into themselves. Living with chronic depressive symptoms may be a reality for some caregivers. A goal for the nursing profession, therefore, is to help prevent or minimize the negative consequences of depressive symptoms in caregivers before it leads to further psychiatric disability.

Some studies have documented positive effects of caregiving to family members with dementia, including gratification, feeling uplifted, and gaining satisfaction and mastery of challenges (Kinney & Stephens, 1989; Lawton et al., 1989; Motenko, 1989). In their study of formal and informal family caregivers of those with mild dementia, Andren & Elmstahl (2005) found co-existence of moderate burden and great satisfaction. They concluded that caregivers can experience satisfaction irrespective of their subjective perception of burden or their health. Lawton et al. (1989) did not find a strong
relationship between burden and caregiver satisfaction. When the caregiving experience results in positive emotions, these should be reinforced to strengthen the caregiver themselves and the caregiving bond. It is also incumbent upon nurses to promote wellness in their clients and family members.

Nursing is concerned with caring for individuals, families, and communities. Thus, it is critically important to develop nursing interventions to help offset depression and other subjective burden felt by family caregivers and to strengthen resources already present. One intuitive way to help caregivers is to promote positive psychological resources, which act as internal buffers for life stressors. Psychological resources have been defined as internal mechanisms or personality characteristics that help individuals prevail against environmental threats (Pearlin & Schooler, 1978). Self-transcendence and resilience may be viewed as positive psychological resources, although some authors would argue that resilience is a process and a behavior, not an internal personality trait (Harris, 2008). Nevertheless, self-transcendence and resilience are intrapersonal resources that can be strengthened to assist caregivers.

More recently, researchers have investigated the biopsychosocial efficacy of expressive writing as an intervention in various populations. College students who wrote expressive letters reported longer sleep duration and fewer days of activity curtailment due to illness (Mosher & Danoff-Burg, 2006). Expressive writing of a month’s duration helped to lower systolic and diastolic blood pressure in young to middle aged adults (McGuire, Beckwith, Greenberg, & Gevirtz, 2005). Expressive writing has been used as a psychosocial intervention to promote resilience in older adults and caregivers (Caldwell, 2005); to help elders cope with loss in later life (Caplan, Haslett, & Burleson, 2005).
2005); and to reduce stress or improve health in family caregivers (Mackenzie, Wiprzycka, Hasher, & Goldstein, 2007). Expressive writing research has taken the form of letters or specific or nonspecific journaling.

Empirical evidence about expressive writing has noted that positive health benefits may be related to forced reflection—writing requires the writer to pause to think about themselves and their lives (Connolly Baker & Mazza, 2004). Expressive writing uses words to help make situations and feelings “more manageable”; the writer feels in control and may gain greater “self-understanding, clarification, resolution and closure” (Connolly Baker & Mazza, 2004, pp. 144-145). Pennebaker (1989) proposed that emotional expression, verbal or written, required confronting stressful thoughts and feelings, then restructuring thoughts about them. Using the expressive medium of poetry, participants in this study had the opportunity to reflect on and even restructure thoughts and feelings in their poems.

Poetry writing is a form of expressive writing that has seldom been explored aside from a psychotherapeutic context. Poetry has been used as a method of healing therapy for many years. Poetry is “an expressive therapy not limited by space, time, organization, rhyme, form, placement on paper, or even word structure” (Springer, 2006, p. 69). The symbols and images of poetry reflect the thoughts, moods, and beliefs of the writer.

In those suffering from trauma, the value of poetry lies in its ability to unite the emotional, sensory right brain unable to assimilate overwhelmingly painful experiences with the verbal, cognitive left brain (Springer). The language of poems can alter brain wave patterns and provide a “bridge” between the halves of the brain (Springer, 2006, p. 71). Poetry writing has most often been used to encourage catharsis and healing in those
being treated for diagnosed psychiatric problems, experiencing mental disabilities, or recovering from abusive situations (McGarry & Prince, 1998; Papadopoulous, Wright & Harding, 1999; Tilly & Caye, 2004).

Previous research has also focused on poetry writing as a nursing education strategy (Holmes & Gregory, 1998; Olson, 2001; Kidd & Tusaie, 2004). There have been no studies of poetry writing in family caregivers or in family caregivers of older adults with dementia.

This study is significant because of its potential contributions to nursing theory, practice, and research. Theory generation may result from the unique application of artistic expression and measurement of positive psychological resources in the study. The intervention to be pilot tested is an innovative strategy that could generate more nursing research into methods for decreasing negative caregiving consequences and increasing positive caregiving consequences. Nursing practice can be enhanced by reaching beyond traditional interventions for caregiver stress to creative interventions to promote emotional wellness in family caregivers.

Problem

In this study, caregiving will be defined as unpaid care that is provided to any relative to help them care for themselves. This includes personal care, as well as household, financial care, transportation, or making arrangements for regular visitation and services for appointments. The caregiver does not have to live with the care recipient (NAC/AARP, 1997). Caregiver characteristics will be measured by demographic questions in an initial questionnaire (Appendix A). Studies of dementia caregiver interventions have demonstrated that interventions have achieved clinical significance in
terms of improving depressive symptoms and reducing feelings of caregiver burden (Shulz et al., 2002).

Although Shulz et al. (2002) noted a need for increased methodological rigor and study participants who more clearly represented variables of interest, they applauded the effectiveness of psychosocial interventions for caregivers. They also noted that there was no single method that was effective, but that diversity of methods existed. Nursing interventions to promote positive psychological resources such as resilience and self-transcendence in family caregivers of older adults with dementia are an important way of preventing negative outcomes such as severe caregiver burden and depressive symptoms. Nursing interventions also help to build strengths that moderate and buffer stressors contributing to burden and depression.

The theories of Frankl (1969), Adler (1956), and Reed (2003) provide a framework for identifying specific nursing interventions to promote transcending and creating meaning from experiences, consistency of thought, feeling, and goal-directed action, and attitudinal choices such as self-transcendence and resilience. Poetry writing can help family caregivers transcend stresses, affirm meaning, and achieve positive outcomes by encouraging caregiver expression of emotion (positive or negative), diverting attention from onerous caring tasks, or enhancing positive feelings about the care recipient. Poetry writing as a psychosocial intervention has not been studied in a population of family caregivers of demented adults.

Positive psychological resources such as self-transcendence and resilience should be promoted in family caregivers of demented elders. Self-transcendence is the human ability to rise above or go beyond oneself toward others in caring or toward the
advancement of social causes (Das, 1998). It also refers to the ability to expand self boundaries toward others, the environment, and toward integration of past and future (Reed, 1997). Self-transcendence provides a means to pull oneself out of everyday stressors to a more elevated plane of consciousness and unity (Frankl, 1969). Self-transcendence and resilience and their relationships to negative psychological outcomes have not been previously measured in a sample of family caregivers of demented elders.

Caregiver burden in this study will refer to subjective burden, or the caregiver’s personal appraisal of stress, anxiety, or other negative feelings related to the caregiving situation (Faison, Faria, & Frank, 1999; Hunt, 2003). Greater subjective burden is predictive of depression in caregivers (Hunt, 2003). Study participants may experience some depressive symptoms, but do not have to meet full criteria for major depressive disorder. Subjective caregiver burden and depressive symptoms have not been previously studied in this population in juxtaposition to positive psychological variables that include self-transcendence and resilience.

It is important to determine the existence of negative psychological outcomes (subjective burden, depressive symptoms) and positive psychological resources (self-transcendence and resilience) across time in family caregivers as well as the influence of the intervention on these variables. For this reason, a longitudinal design was used in this descriptive study with three time points of data collection. This specific design using the study variables has not been implemented within a nursing or health-related field study.

Expressive writing has been studied in many healthy and ill populations, including studies demonstrating effects on immune function (Christensen et al., 1996; Pennebaker, Kiecol-Glaser, & Glaser, 1988); rheumatoid arthritis (Smyth, Stone,
Hurewitz & Kaell, 1999); and recovery from traumatic events (Pennebaker & Sussman, 1988).

Poetry writing has been employed with older adults to promote successful aging through creativity (Flood, 2005); and as group therapy for older adults (Papadopoulos, Wright, & Harding, 1999). In a recent study similar to the proposed study, Mackenzie, Wiprzycka, Hasher, & Goldstein (2007) explored whether expressive writing reduced stress and improved health for family caregivers of older adults. The study did not specifically assess family caregivers of those with dementia. The independent variable was expressive writing. The independent variable in the proposed study was poetry writing. Dependent variables also differed from Mackenzie et al.’s (2007) dependent study variables of stress and improved health. Poetry writing has not been investigated in a population of family caregivers for demented elders.

Purpose

The purpose of this intervention trial was twofold: 1) to examine the effectiveness of a poetry writing intervention in increasing positive psychological resources (self-transcendence and resilience) and decreasing negative psychological outcomes (depressive symptoms and subjective caregiver burden) in family caregivers of older adults with dementia, and 2) to examine the feasibility of conducting a larger clinical trial. To achieve the first aim, this longitudinal study compared caregivers who wrote poetry to those who do not write poetry on the four study outcomes. Analysis was conducted to determine whether changes occurred on the four study variables in those caregivers who wrote poetry during the 4-week intervention phase, and whether changes were sustained over time. Data triangulation was accomplished through analysis of poem
content to determine shared themes. Poem themes reflecting the study variables would support and validate quantitative data. The second aim was achieved by asking all participants questions about acceptability of aspects of the study (amount of time required to participate in study, number of poems, difficulty of writing poems and completing instruments, and compensation received) as well as through interview responses and comments about participation gathered from participants.

*Theoretical Framework*

The guiding framework for this research study was derived from Frankl’s existential psychology theory (1969), Adler’s theory of Individual Psychology (1937), and Reed’s mid range nursing Theory of Self-transcendence (1993). From Frankl’s existential theory, constructs selected were finding life meanings (at level of experiential and ultimate) and self-transcendence (Das, 1998); from Adler’s Individual Psychology, constructs of lifestyle and goal-directed movement (Ansbacher & Ansbacher, 1979) provide direction for study concepts; and from Reed’s nursing Theory of Self-transcendence, constructs drawn included expansion of self (self-transcendence) and vulnerability (Coward, 2006). Frankl and Reed’s theories also share the major construct of self-transcendence.

*Frankl’s Existential Theory*

Frankl emphasized the social role of man and the importance of a phenomenological understanding of the individual (Kelman, 1962). According to Cloninger (2004), Frankl’s development of logotherapy had a core construct of Will to Meaning. When mature, Will to Meaning led to self-transcendence, an elevated plane of intellect which included “self-directedness, cooperativeness, persistence, patience, and
faith” (Cloninger, 2004, p. 106). Frankl described self-transcendence as “the essence of existence” (1969, p. 50). He believed this self-transcendent quality could only be captured when persons were focused on someone or something outside themselves (Frankl, 1969). Caregivers are an excellent example of persons possessing an external focus.

Another key construct, part of Frankl’s First Triad (Frankl, 1969) was Meaning of Life. Meaning of Life, discovered rather than invented, was found in the outside world, not inside the self. If fulfilled, meaning would indirectly lead to happiness. This construct considered the impact of contextual and environmental influences upon outcomes. Reed (2003) also described contextual variables such as age and gender as mediating one’s level of vulnerability and subsequently, self-transcendence. However, in his discussion of self-transcendence in a concentration camp, Frankl (1969) noted man’s capacity for self-transcendence regardless of environmental context. His theory suggested that environment may moderate or influence outcomes more than mediate them. Meaning of Life will not be included as a theoretical construct in the proposed study, due to its similarity to Will to Meaning and lack of clarity about its role in the development of study outcomes.

Freedom of Will meant that each individual was alone responsible for finding the potential meaning in his or her own life. Although very subjective, some meanings were universal. Life had meaning under any circumstance. Frankl noted that pain and suffering, while not required to make meaning, could engender meaning for a person (Frankl, 1969). Human beings have a motivating drive toward making sense and coherence from life events. Meaning helps to define sense of self; lack of meaning can
lead to ambiguity and fragmentation, as in personality disorders (Baumeister, 1991). Excess meaning given to the self can lead to escapism, as found in thrill-seeking and other self-destructive behaviors (Baumeister, 1991). Frankl concluded that will to meaning can help someone survive suffering; more importantly, it can help maintain mental health (Das, 1998).

Meaning existed at three levels—common, everyday meanings, meaning of the moment, and ultimate meanings (Das, 1998). Ultimate meanings indicated awareness of patterns of the universe and each person’s participation in the universe. Sources where universal meaning could be found included “religion, philosophy, science, and art” (Das, 1998, p. 205). Man found meaning through creative values (giving to the world through creation), experiential values (taking from the world via encounters), and attitudinal values (taking a stand when circumstances could not be changed). Attitudinal values reflected one’s facing the unavoidable when confronted with the “tragic triad” of inescapable pain, guilt, and death (Frankl, 1969, p. 73). Nurse theorist Travelbee (1971) also noted that “human beings are motivated by a search for meaning in all life experiences and meaning can be found in the experience of illness, suffering, and pain” (p. V).

Through logotherapy, clients were taught that any tragic event could be transformed into a positive accomplishment by the nature of one’s response (Frankl, 1969). This ascription of meaning could be achieved through diversion of attention from an immediate problem, helping clients reframe or view their problems from different angles, instilling an openness to new meanings, or by helping clients set and pursue new goals (Das, 1998). Frankl (2000) also noted that man possessed “creative values,”
Frankl’s philosophy corresponds well to Adler’s concept of life movement.

**Adler’s Individual Psychology**

The theoretical definition of Lifestyle is each person’s “own creation, the product of his creative power” (Adler, 1979, p. 6). All psychological processes—including cognition, apperception, world view and opinion of one’s self in the world—are directly influenced by one’s lifestyle. The definition also includes consistency of thought, emotion and behavior of the self (Sweeney, 1998). Adler wrote that lifestyle included three themes of work, friendship, and love, and alluded to themes of self and spirituality (Sweeney, 1998). He posited that man was “fundamentally concerned with the meaning of his existence and with plans and projects to solve his existential problems” (Adler, 1979, p. 8). He ascribed qualities of altruism, cooperation, creativity, and uniqueness to man, writing that man had dignity and could be master of his fate as opposed to a victim of circumstance (Adler, 1979).

According to Adler (1979), human beings were always engaged in goal-directed movement. This movement had a unity of pattern and utilized creative power to overcome obstacles. Adler (1979) believed individuals could only be understood by understanding their subjective viewpoint. He also emphasized the role of cooperation and socialization in one’s life, believing that interpersonal as well as intrapersonal experience was formative. Adler’s key concept of social interest acknowledged man’s creative self in interaction with others; human beings were “firmly embedded in society” (1979, p. 8).

**Reed’s Theory of Self-transcendence**
Reed (2003) also viewed self-transcendence as key to human existence, initially as a developmental aspect of older age, but increasingly, as applicable to persons of all ages. In the nursing Theory of Self-transcendence, Reed (2003) noted that increased vulnerability, which included awareness of personal mortality, and other life crises (disability, chronic illness, parenting) often led to increased self-transcendence. Reed defined self-transcendence as a construct incorporating multidimensional personal boundary expansion. This expansion occurred “outward (toward others and the environment), inward (toward greater awareness of one’s own beliefs, values, and dreams), and temporal (toward integration of past and future in a way that enhances the relative present)” (Reed, 1997, p. 192). Reed (2003) further expanded her theory to include a transpersonal component, which included dimensions not typically discernible in the world.

In her research, Reed (2006) noted positive relationships between increased self-transcendence and increased well-being. She posited that nurses could intervene to increase self-transcendence directly, through attention to personal resources, or indirectly, by altering contextual factors affecting one’s vulnerability; either point of intervention resulted in increased well-being. In this study, self-transcendence was defined theoretically as “the ability to rise above or go beyond oneself in a caring relationship or toward the advancement of social causes” (Das, 1998, p. 7) and as the expansion of self boundaries inward, outward, temporally, or transpersonally (Coward, 2006).

In this study, poetry writing was viewed as a creative process that reflects the writer’s lifestyle. As art, it can provide a way of helping caregivers find ultimate meaning and experiential meaning in everyday events. Creation through poetry writing is
viewed as a powerful process, as well as one that assists the writer and others in gaining understanding of subjective experiences. The caregiver of the older adult with dementia is vulnerable and at increased risk for perceived burden and depressive symptoms. This vulnerability allows a simultaneous opportunity for the caregiver to gain increased self-transcendence and well-being. Those choosing to continue to write poetry after completion of the intervention phase of the study will implement freedom of will by taking responsibility for finding meaning through a creative effort. Searching for meaning through poetry writing is one way in which caregivers may direct movement towards goals. These goals could include engagement in tasks of friendship, love, self, or spirituality or expansion of boundaries inward or outward (when shared with others or when recorded as a testimony to the care recipient). An indirect consequence of finding meaning may include positive psychological resources (i.e. self-transcendence and resilience).

In conclusion, in this study, poetry writing was examined as a nursing intervention for family dementia caregivers. It was proposed that poetry writing would enhance positive psychological resources (self-transcendence and resilience) while decreasing negative psychological outcomes (caregiver burden and depressive symptoms). Selected theoretical constructs of Frankl, Adler, and Reed (Figure 1) form the framework for this study. Separately, each theory contains pieces valuable to guide examination of relationships between the nursing intervention poetry writing and positive psychological resources and negative psychological outcomes; in their synthesis, a theoretical framework emerges that is flexible enough to capture a wide spectrum of possible outcomes.
The construct, Will to Meaning, was defined as finding life meanings through self-reflection, subjective interpretation and valuing of life experiences (Das, 1998) and vulnerability to life events.

**Will to Meaning**

Will to Meaning is the central concept of the theoretical framework. Meanings influence one’s lifestyle, goal selection, and goal directed movement. One is free to choose meaning, and has responsibility for choices based on those meanings. Self-
transcendence is a choice one can make in response to vulnerability. The theoretical level of the study substruction is portrayed in Figure 2 below.

**Figure 2. Theoretical Framework**

![Diagram of Theoretical Framework](image)

*Self-transcendence*

Will to Meaning allows human beings to find meaning in any situation, no matter how stressful or painful. Indeed, one can even transcend circumstances to find meaning. Man has the capacity for self-transcendence (Frankl, 1969). The concept self-transcendence was defined theoretically as “the ability to rise above or go beyond oneself toward others in a caring relationship or toward the advancement of social causes” (Das, 1998, p. 7) and the expansion of self boundaries inward, outward, temporally, or transpersonally (Coward, 2006). The concept was measured operationally by The Self-transcendence Scale (Reed, 1986). As caregivers are focused on caregiving relationships and have an external focus, they are capable of self transcendence. It was expected that
poetry writing would contribute to increased self-transcendence in family caregivers. Self-transcendence was also expected to be inversely related to burden and depressive symptoms.

*Life Style*

According to Adler, the construct life style was an expression of individual consistency of thought, emotion, and behavior (Sweeney, 1998). Each life style had its own creative power, a power directed at resolving problems concrete and existential. Human beings were deeply interested in the meaning of their existence. To find meanings and resolution of problems, individuals used goal-directed movement (Ansbacher & Ansbacher, 1979). At the conceptual level, resilience was defined as a complex interaction between personality characteristics of an individual and his or her larger environment influencing the individual’s recovery from a traumatic or stressful event (McCubbin & McCubbin, 1996). Resilient persons use their personal characteristics and the environments they function in to make meaning from their experiences and to move toward recovery in a goal-directed manner. At the operational level, resilience was measured by the Resilience Scale (RS) (Wagnild & Young, 1993). It was expected that poetry writing would enhance resilience in family caregivers in this study, and that increased resilience would have a negative relationship with burden and depressive symptoms.

*Attitudinal Values/Vulnerability*

The final construct at the theoretical level, attitudinal values is defined theoretically as meaningful attitudes toward “pain, guilt, and death” (Frankl, 1969, p. 73). In the face of extreme suffering or grief, Frankl (1969) noted that optimistic persons
could take dire or tragic circumstances and transform them into “positive accomplishments” (p. 73). Accepting an unchangeable fate was one means of creating meaning and ascribing value in life (Frankl, 1969). Guilt may especially motivate one to make more responsible choices. Vulnerability is also part of the theoretical definition and refers to personal awareness of fragility and potential for harm in crisis situations such as disease, childbirth, parenting, or disability (Reed, 2003). Reed noted that increased vulnerability provided a context for maturation and development across the life span, and that someone who was more vulnerable also had a potential for greater self-transcendence (Coward, 2006). Reed (2003) and Frankl (1969) agreed that negative life events could provide fertile ground for personal and spiritual growth.

In contrast, however, failure to transform circumstances for the better would lead to negative outcomes. Among those negative outcomes for caregivers are increased depressive symptoms and subjective burden. Research has established a link between larger perceived burden and depression in caregivers (Hunt, 2003). The theoretical definition of depressive symptoms is defined according to American Psychiatric Association DSM-IV-TR (2000) criteria and include: persistently sad or irritable mood; pronounced changes in sleep, appetite, or energy; difficulty thinking, concentrating, and remembering; physical slowing or agitation; lack of interest or pleasure in activities that were once enjoyed; feelings of guilt, worthlessness, hopelessness, and emptiness; recurrent thoughts of death or suicide; or persistent physical symptoms that do not respond to treatment, such as headaches, digestive disorders, and chronic pain. In this study, depressive symptoms were measured by the Center for Epidemiologic Studies-Depression Scale (CES-D) (Radloff, 1977).
Subjective caregiver burden was theoretically defined as the caregiver’s personal appraisal of stress, anxiety, or other negative feelings related to the caregiving situation (Faison, Faria, & Frank, 1999; Hunt, 2003), and was operationally measured by the Zarit Burden Interview-Short Form (Bedard et al., 2001). It was anticipated that a poetry writing intervention would decrease levels of perceived burden and depressive symptoms in family caregivers. The researcher also proposed an inverse relationship between positive psychological resource variables (self-transcendence and resilience) and depressive symptoms and burden.

The concept, poetry writing, was theoretically defined as using written or spoken language in an imaginative, rhythmic and personal way in an attempt to describe the world (poetry.magic.co.uk/whatispoetry.html, 2006). Poetry writing was the intervention in this study. The operational definition of poetry writing was the writing of three poems over a 4-week period by family caregivers. It was expected that individual interpretation of experiential and ultimate meanings of caregiving in this study would be reflected in poetry writing, which would in turn be related to enhancement of positive psychosocial resources (self-transcendence and resilience) and inhibition of negative psychological outcomes (subjective burden and depressive symptoms).

Assumptions

Several assumptions undergirded the organizing theoretical framework for this research study. These assumptions included:

1. Human beings possess creative power, which includes the ability to translate positive or negative life experiences into transformative events.
2. Human beings are capable of self-unity of thought, emotion, and behavior; thus, life meaning can be organized through personal experiences.

3. Human beings may be able to express thoughts and feelings more coherently and meaningfully in a nontraditional, creative format than by standard traditional means.

4. Poetry writing is conceptualized as a mode of aesthetic expression through which individuals can transcend life experiences, expand self-boundaries, and create personal meaning.

5. Man is free to make choices about his thoughts, attitudes, and perceptions, and is responsible and accountable for those choices.

6. Movement that is goal-directed can occur through every life development phase, and maximizes the potential for self-transcendence.

7. Attitudinal values about pain, suffering, and death can predispose persons toward increased vulnerability, including outcomes of increased depressive symptoms and caregiver burden or outcomes of improved psychological resources (self-transcendence and resilience).

8. Self-transcendence and resilience are positive psychological resources that inhibit development of depressive symptoms and subjective burden.

Research Questions

Research questions addressed by the study included:

1. Are there differences on self-transcendence, resilience, depressive symptoms, and caregiver burden between family caregivers of older adults with dementia who write poetry (Group A) and family caregivers not
writing poetry (Group B) from before poetry writing (Time 1) to after four weeks of writing poems (Time 2)?

2. Are higher positive psychological resources (self-transcendence and resilience) associated with lower negative psychological outcomes (depressive symptoms and caregiver burden) over time with continued poetry writing?

3. Will there be improvements on psychological resources (self-transcendence and resilience) and on negative outcomes (depressive symptoms and caregiver burden) from before poetry writing (Group A, Time 1 and Group B, Time 2) to after 4-weeks of poetry writing (Group A, Time 2 and Group B, Time 3)?

4. What common themes emerge from poetry written by family caregivers of older adults with dementia?

5. Will family caregivers in Group A who participate in poetry writing first continue to write poetry or verbalize intent to write poetry after they are no longer required to do so?

6. What is the feasibility of conducting a larger clinical trial?
The following outcomes are proposed in this study:

1. There will be differences from pre-test to post-test in the two intervention groups on mean scores of outcome variables at Time 2.
   a. Group A will have higher mean scores on self-transcendence and resilience instruments than Group B at Time 2
   b. Group A will have lower mean scores on depressive symptoms and subjective caregiver burden than Group B at Time 2

2. In Group A, there will be higher mean scores on instruments measuring positive psychological outcomes at Time 2 and Time 3 as compared with Time 1 (the effect of the intervention will be sustained over time)
   a. Higher self-transcendence and resilience scores will correspond to lower depressive symptoms scores and lower subjective burden scores at Time 2
   b. Higher self-transcendence and resilience scores will correspond to lower depressive symptoms scores and lower subjective burden scores at Time 3
3. Those from Group A who have written poetry at Time 2, as well as those in Group B who have written poetry at Time 3 will have higher self-transcendence and resilience scores and lower depressive symptoms and lower subjective burden scores than baseline (see Figure 3 Research Model). In addition, subjective comments gathered in open ended interviews will reveal participant perception of benefit from the intervention.

4. A majority of participants in intervention Group A will continue to write poetry at Time 3 or will verbalize the intent to continue poetry writing in the future.

5. Poem content and theme analysis will reflect study variables of self-transcendence, resilience, depressive symptoms and/or burden in family caregivers.

6. Descriptive statistics will reveal that the intervention is feasible for a larger clinical trial.
CHAPTER TWO

Introduction

Included in this chapter is a review of theoretical and evidence-based literature describing concepts of interest and their interrelationships. This study examines multiple variables associated with Frankl’s existential (1969) and Adler’s (1979) individual psychology theories, and Reed’s midrange nursing Theory of Self-transcendence (2003). Theoretical constructs of will to meaning, lifestyle, freedom of will, and attitudinal values and their relationships to constructs self-transcendence, resilience, burden, and depressive symptoms will be expounded upon.

Poetry writing, the intervention that was examined in the study, is viewed as a tool to help create meaning in the lives of family caregivers. The larger body of literature documenting studies conducted using expressive writing as a therapeutic intervention will be reviewed, followed by the body of literature discussing poetry writing as a therapeutic intervention. Poetry writing was expected to be directly related to such positive psychological resource outcomes as self-transcendence and resilience and inversely related to negative psychological outcomes subjective caregiver burden and depressive symptoms. Empirical literature elucidating these positive relationships will be discussed, as will empirical literature documenting interrelationships between negative outcome variables i.e. burden and depressive symptoms, and relationships between depressive symptoms and the positive psychological resource variables of the study. To conclude, independent and dependent variables for the study will be identified and anticipated outcomes restated prior to discussion of methods.
Theoretical Foundations

This study is rooted in existential principles. Existential philosophies propose a departure from strict empirical methods of viewing the world. As opposed to using natural laws to interpret facts and draw conclusions, existential method “focuses on the individual and the way he personally encounters the world” (Gould & Truitt, 1973, p. 3). Existential philosophy calls into question values and validity of scientific procedures, suggesting that reduction of philosophy to scientific method abandons human reason (Gould, 1973). Existentialists theorize that reason transcends scientific knowledge; technical information alone does not deserve the label of knowledge (Gould & Truitt).

Heidegger (1973) viewed poetry as a very powerful means of speech and language, through which being was established. He argued that the arts such as poetry help to express understandable truths, and the use of language itself helps safeguard human beings against the dehumanization of technology (Biley & Galvin, 2007). Conducting a phenomenological study is a possible future avenue for research. In this study, although psychological concepts were measured with quantitative instruments, poetry theme analysis went beyond reductionism in that subjective experiences were used for data triangulation.

Will to Meaning connotes the fact that man strives to find purpose or meaning in his life. Frankl (2000) viewed Will to Meaning as a reliable indicator of mental health. The more a person focuses outside of himself the more likely he is to transcend his circumstances and find the true meaning for which he searches. The goal of Frankl’s psychoanalytic process, logotherapy, was to help the person find meaning. Meanings are unique to each person’s experiences, although ultimate meanings and values may have
universal themes. Frankl (2000) also noted that individuals have wisdom and knowledge buried in their unconscious that merely needs to be released and brought to their awareness. Poetry is a unique vehicle for accomplishing this task. Poetry may help “magnify the meanings of everyday experiences that may otherwise go unnoticed” (Kookén, Haase, & Russell, 2007, pp. 904-5). Poems help express individual meanings that increase self-awareness, but can also portray more universal meanings that are known to others. Poetry writing could help family caregivers of dementia patients become aware of meanings in their lives related to caregiving. It can help them express their unique meanings or shared meanings that hold ultimate values for others.

Self-transcendence

Self-transcendence is simultaneously a primary theoretical construct, research concept, and operational variable in this study. Self-transcendence was previously defined as “the ability to rise above or go beyond oneself toward others in a caring relationship or toward the advancement of social causes” (Das, 1998, p. 7) and the expansion of self boundaries inward, outward, temporally, or transpersonally (Reed, 2003). In the context of caregiving, self-transcendence means the ability to find meaning through or outside of stressful caring activities, whether the meaning be found through the care recipient, others in a social network, or a spiritual connection. Frankl (1969) viewed self-transcendence as the human capacity to grow, integrate experiences, and achieve greater personal fulfillment and meaning. He noted that self-transcendence necessarily was directed towards someone or something external to the self (Frankl, 2000). Self-transcendence can become a more permanent part of one’s personality or occur specific to a situation.
Nursing Theories Containing the Concept of Self-transcendence.

There are a number of nursing theorists whose work has incorporated the concept of self-transcendence. Nurse theorist Joyce Travelbee (1971) incorporated self-transcendence into her paradigm when defining human being. She viewed self-transcendence as efforts taken by a human being “to rise above the limitations of his human condition, or instead of transcending, to escape…” (Travelbee, 1971, p. 27). Thus, she viewed self-transcendence as an outcome of active effort. Although not explicit, Travelbee’s conceptualization seems to be similar to that of developmental lifespan theorists (i.e. Maslow), who acknowledge that—even if self-transcendence is viewed as a normal developmental process—not everyone achieves it.

Rogers’ Science of Unitary Human Beings. Unitary man means wholeness, and Rogers viewed nursing as the only discipline that studied man in his entirety or wholeness. Her theory melded physics, biology, and social sciences in a unique way. She theorized human beings as energy fields continuously interacting with their environments in increasingly complex, orderly, yet heterogeneous patterns that resulted in mutual change in person and environment (Fitzpatrick & Whall, 1983). Rogers conceptualized health and illness as manifestations of person-environment interaction, a process that was constantly unfolding (Rogers, 1970). She also proposed a four dimensional universe with infinitely expanding boundaries. Although she didn’t specifically use the term self-transcendence in her theory, Rogers theorized that the goal of nursing was to redirect human interaction with energy fields (environments) in a way that would maximize health and human potential (Fitzpatrick & Whall, 1983). Rogers’
theory provided a base for development of both Parse’s grand theory and Reed’s middle range nursing theory.

**Parse’s Theory of Human Becoming.** Parse (1981) believed that human beings were co-participants in their health, interacting with the environment to create and become more open and free to choose and grow. As the person lives his values, he makes choices that help him create meaning in the world, transcending self and expanding boundaries beyond present circumstances (Fitzpatrick & Whall, 1983). Similar to Rogers, she described a mutual process of person-environment interaction, in which rhythmic interactions propelled both towards greater complexity and an emergent process of co-transcendence. This evolutionary exchange of energy both enabled and limited the person continuously moving towards becoming (Fitzpatrick & Whall, 1983).

**Paterson and Zderad’s Theory of Humanistic Nursing.** Paterson and Zderad (1976) proposed that nurses view their practice with an existential lens, positing that nursing science would be best built by phenomenological description. They wrote that man struggled to become, to confirm existence, and to understanding life’s meaning. The authors cited the work of existential theorists including Frankl, Buber, and Kierkegaard in their text (Paterson & Zderad). Nurses assisted man through authenticity, choice based upon human knowledge, and genuine presence (Paterson & Zderad). Nurses helped man to develop well-being and more-being. Nurses sharing themselves enabled others to become more.

Paterson and Zderad (1976) described the importance of words. Words helped man give meaning to his lived experiences, limited though they might be. Words were “a mode for self-explosion, expression, and self-understanding…they hold much
purpose...necessitates one selecting words that depict one’s perspective, his unique human angular view; or depict for another, this particular man as he perceives and responds to his unique experience” (Paterson & Zderad, 1976, p. 67). Humanistic nursing was conceptualized as a genuine art form, and art and nursing were related. For example, poetry was an art form that could help patients become aware of and express feelings via the use of powerful words. Human potential was developed through relationships with others, and self-awareness helped increase well-being and more-being.

Reed’s Theory of Self-Transcendence. Reed drew from developmental lifespan theorists and Rogers’ nursing theory in development of her own middle range theory (Coward, 2006). According to Reed (2003), vulnerability, such as arises during aging or personal crisis precipitated by health or life events, provided a context for realization of self-transcendence. A major proposition of the theory stated that persons in vulnerable situations, such as end-of-life, aging, and other situations increasing awareness of their own personal mortality, would achieve greater self-transcendence. Caregiving is an example of a situation enhancing vulnerability.

A second proposition of Reed’s theory is that self-concept boundaries are directly linked to well-being; thus, positive or negative boundary fluctuations have a positive or negative influence on well-being. Expansion of boundaries to include greater intrapersonal and interpersonal connections would positively influence well-being. This aspect of Reed’s theory is clearly influenced by both Rogers and Parse’s discussion of energy fields and boundaries. An example of a negative influence that could impact well-being and mental health would be the inability to reach out (expand boundaries) to others following a loss or illness. The inability to expand boundaries could result in
negative outcomes, such as depression or caregiver burden, as in this study. A third proposition is that personal and environmental variables such as age, gender, cognitive ability, life experiences, spiritual perspectives, social environment, and historical events may moderate or mediate “relationships between vulnerability, self-transcendence and well-being” (Coward, 2006, p. 649). Positive relationships were conceptualized between increased vulnerability and increased self-transcendence, and self-transcendence and well-being, with personal and contextual factors noted above having a direct influence on these relationships.

Reed (1991) further developed her theory to include four patterns of self-transcendence: generativity or involvement with others; introjectivity or degree of personal reflection and life learning; temporal integration or viewing the past with acceptance and the future with hope; and body transcendence or the ability to go beyond preoccupation with bodily illnesses and deficits.

Based on her theory, Reed (1993) proposed two points of intervention. Nurses could focus their efforts on enhancing a person’s inner resources for self-transcendence directly (as in a poetry writing intervention) or build upon personal and contextual resources affecting their vulnerability and well-being, and impact self-transcendence indirectly. In a critique of Reed’s theory, Coward (2006) noted that the theory is simple enough to be understood, generalizable to many situations involving health and healing, empirically precise, and has led to the development of new, testable nursing knowledge. Reed’s Theory of Self-transcendence was selected as a theoretical foundation for this intervention study instead of other nursing theories because of its simplicity and testability.
Lifestyle. Lifestyle is a consistent unity—of thinking, feeling, acting, and personal expression—of the self (Adler, 1956). Each person moves toward a goal in a continuous way; creativity helps him do that. Creative power helps one to direct drive, select a meaningful goal, and remove obstacles (Adler, 1956). Adler (1956) stated that an individual could be viewed as “the artist of his own personality” (p. 177); at the same time, he was the picture in constant process of being created.

Creativity is essential to resilience. Creative acts go beyond logic, being rooted in emotions and intellect sometimes beyond consciousness (Flach, 1988). Creativity aids resilience in that it assists with problem-solving through an arsenal of tools such as redefining the problem, acquiring information, accessing the unconscious, playing, and using humor (Flach, 1988). Language also helps an individual be creative by restructuring or reframing the words used to think about something or someone (Flach, 1988). Poetry writing is a creative act using language. Through this creative act, caregivers can express their unique lifestyles and continue to identify and move toward meaningful goals. Poetry writing should reflect or increase resilience in caregivers.

Attitudinal Values/Vulnerability

Attitudinal values allow individuals to find meaning even in the face of tragedy. Pain, guilt, or death can be transformed into unconditionally meaningful experiences via creativity and positive attitude (Frankl, 2000). On one end of a spectrum, the circumstance that leaves one vulnerable can be transcended and turned into a triumph (Reed, 2003). On the other end of the spectrum, however, negative attitudes will promote negative psychological outcomes such as increased depressive symptoms and increased subjective burden.
Thus, situational crises or chronic stressors approached by persons possessing resilience can provide fertile opportunities for self-transcendence to flourish. In summary, the theoretical foundations for this study incorporate existential psychology theories and nursing theories. Together, the constructs form a framework for testing an innovative intervention that closely corresponds to philosophical principles of the theory, as well as a framework for testing relationships between variables.

This study of family caregivers proposed that an increase in one of the positive psychological resources will trigger simultaneous increases in the others; for example, growth in resilience will be accompanied by growth in self-transcendence. Likewise, negative attitudes will be reflected by fewer depressive symptoms and lower subjective burden. It was also anticipated that increases in positive psychological resources would be associated with decreases in depressive symptoms and burden. In the next sections, theoretical and empirical literature supporting the variables examined in the study will be expounded upon.

Expressive Writing

Theorized explanations for physical and psychological health benefits conferred by expressive writing include catharsis, increased insight, and active inhibition (King, 2002; Pennebaker, 1989). Pennebaker (1989) proposed that emotional expression, verbal or written, required confronting stressful thoughts and feelings, then restructuring thoughts about them. In this way, instead of actively inhibiting, persons can safely release held-in emotions that are weakening their immune system and literally making them sick. In his studies, experimental participants were asked to focus on and write about traumatic events and were compared to control groups not writing or writing about
unrelated topics. One criticism is that many of Pennebaker’s anecdotal studies used healthy college students as subjects (King, 2002). Pennebaker (2002) noted that empirical studies have suggested that expressive writing decreases “common illness visits to physicians…reduced use of pain medication, and long-term changes in immune function” (p. 287).

Studies have demonstrated the effects of expressive writing on biological markers, including immune function (Knapp, et al., 1992; Lutgendorf, Antoni, Kumar, & Schneiderman, 1994; Pennebaker, 1993), improvements in disease activity among rheumatoid arthritis patient (Smyth, Stone, Hurewitz, & Kaell, 1999), and increased risk for health problems among those unable to express feelings about traumas such as sexual abuse and rape (Golding, Stein, Burman, & Sorenson, 1988). Glaser et al. (1993) found poor immunologic function after stress in professional caregivers (medical students) with limited ability to express themselves to others.

In their review of expressive writing and health outcomes, Lepore and Smyth (2002) cited studies of expressive writing and blood pressure, working memory, and cognitive and physiological regulatory processes. Only preliminary pilot data is available to demonstrate the effect of expressive writing on blood pressure; however, preliminary findings found a significant decrease in diastolic blood pressure (p<.05), with only a borderline (p<.07) effect on systolic blood pressure in 26 participants (Lepore & Smyth, 2002).

Researchers have also demonstrated that participants can garner health benefits even when writing about others’ traumas a single time (Greenberg, Wortman, & Stone, 1996). In another study, persons who added a happy ending to a traumatic life event
demonstrated health benefits (lower illness visits) identical to those who wrote about the traumatic event only, and demonstrated more positive emotion words in their writing (King & Miner, 2000). In other words, it may not be necessary to discharge negative emotions only, but reframing and focusing on positive emotion in writing may also have significant health benefits.

Although some researchers have reported more robust findings for physical outcomes than psychological outcomes (Pennebaker, 1989; Smyth, 1988), a large and growing body of literature has investigated the positive effect of expressive writing on psychological outcomes in various populations (Butcher, 2004; Lepore, 1997; Mosher & Danoff-Burg, 2006; Smyth, 1998). A meta-analysis of 13 studies of written emotional expression documented improvements in psychological well-being that included changes in positive and negative affect, happiness, less intrusive thoughts, and better adjustment to college or high school (Smyth, 1998). In nine studies assessing psychological well-being, a mean effect size of .66 (p<.001) with a 31% improvement of the experimental group over the control group was found (Smyth). This effect size was higher than studies’ effects sizes for reported health or general functioning. All outcomes were measured at least one month after writing; however, there was a positive relationship between amount of time over which the writing intervention was applied and overall effect size. This result suggests that increasing the length of the writing task would increase its effect. In this study, duration of writing task will range from 4- to 8-weeks.

Finally, Mackenzie, Wiprzycka, Hasher, & Goldstein (2007) investigated whether written emotional disclosure mitigated stress and improved health outcomes in family caregivers of physically frail and cognitively impaired adults. Forty primary caregivers
were divided into three treatment groups—expressive writing (about the most stressful and difficult aspect of caregiving); history writing (about any significant world event not affecting the participant personally); or time management (writing about how time is spent as a caregiver). Participants wrote on four occasions over a 2-week period. Measures included Caregiver Burden (Bedard et al., 2001), Impact of Events Scale (Horowitz, Wilner, & Alvarez, 1979), and General Health Questionnaire (Goldberg & Williams, 1988). At one month’s time, the written emotional disclosure group failed to show significant improvement in perceived burden scores (less improvement than either of the other two groups), reduction in intrusive thinking and avoidance, or improvement in mental and physical health. Contrary to hypothesized findings, the only group demonstrating significant benefit in physical and mental health was the time management group (p<.001) (Mackenzie et al., 2007).

The authors offered several possibilities for disconfirmation of their hypotheses about the benefits of expressive writing, including: age of caregivers (developmentally, older adults regulate emotion by selective attention to positive information); insufficient time (physiologic effects of writing may not emerge until several months afterward); and time management more effective because it was a problem-focused as opposed to an emotion-focused coping method (Mackenzie et al., 2007). There are a number of design similarities between the Mackenzie, et al. study and the study described here. The population was similar, and perceived burden was measured in the same way. However, important differences include the duration of study (longitudinal design of this study targeted other positive effects of the intervention), possible age differences in the sample, and a different intervention (i.e. poetry writing as compared with expressive writing). In
the current study, poetry writing was not intended as an effort for caregivers to express as many negative emotions as possible; rather, it involved open-ended expression in the form of poetry, which allowed the caregivers to attend to positive information in their poems as desired.

*Poetry Writing*

Poetry writing has been used in psychotherapy for many years (Leedy, 1969; Lerner, 1978). Among its uses have been helping patients explore and express feelings and become more spontaneous and creative (Leedy, 1969). In groups, poetry recitation can help individuals “increase ego strength, decreases the duration and intensity of anxieties, and decreases…tendencies toward introversion and paralyzing inhibitions” (Leedy, 1969, p. 71). Hitchings (1969) and Stainbrook (1978) noted that poetry reflects inner turmoil, bringing those conflicts to outer consciousness and awareness where they can be worked on. In this way, persons may help develop increased insight.

Heninger (1978) added that poetry “makes arrangement out of derangement, harmony out of disharmony, and order out of chaos” (p. 56). Poetry may be used to emote during times of crisis or catastrophe when ordinary language isn’t sufficient and may “spring from us naturally in times of need” (Carroll, 2005, p. 161). Giving verbal and poetic form to experiences and feelings can assist the therapist in providing an external focus for therapy (Schloss & Grundy, 1978). According to Parker (1969), poetry’s therapeutic uses include creation, insight and empathy, and expression and catharsis.

Bolton (1999) agrees that catharsis is a significant initial benefit of poetry writing, but points out that “reworking” of poems will encourage “insight and consolidation” as
authors attempt to truly capture an experience (p. 120). This poem review process may even help the author assert a degree of control (Bolton). Gaining a sense of control would be very valuable to dementia family caregivers, who often function in very out of control situations with significant others. Other benefits of poetry include creation of a concrete product; poets may feel pride and increased self-confidence as a result of their creations. They may also find the process of writing fun and satisfying (Bolton). In summary, some of the possible therapeutic benefits of poetry writing include catharsis, increased self-awareness and insight, increased self-confidence, self-respect, pleasure and enjoyment. Other positive outcomes may also arise from participating in poetry writing.

Kobak (1969) used poetry therapy with four socially and emotionally maladjusted male students enrolled in a specialized educational facility in New York City. She found that poetry helped the boys re-create themselves and stated that “creativity is a natural companion to the therapeutic process, which builds step by step, until mental health wholeness is attained” (Kobak, 1969, p. 187). Kramer (1969) posited that especially emotionally vulnerable persons were more apt to “record their emotional upheavals and imaginative wanderings” (p. 210) through poetry than another artistic venue. Poetry may even help the writer problem-solve, as giving form to thought takes effort and may be considered “a growth-producing experience” (Robinson & Mowbray, 1969, p. 192). Lerner (1991) stated that poetry use in therapy situations may allow the individual to gain increased “understanding of feelings and lifestyle” (p. 213). He added that persons responded uniquely to situations based on their experience, values, and culture (Lerner, 1991). This interpretation of poetry therapy is consistent with Adler’s (1979) discussion of lifestyle.
A number of empirical studies using poetry writing have been conducted outside of the nursing field. An interdisciplinary professional journal entitled *Journal of Poetry Therapy* has published case studies, practice reports, and research conducted in the area of poetry therapy. Also included is bibliotherapy, or other forms of literature used to aid healing and personal growth (Reiter, 1997). Although approximately 200 articles between 1987 and 2007 in the Journal of Poetry Therapy dealt with poetry and poetry writing, no studies involving caregivers were published.

In a study of over 150 school age children and teachers participating in 11 different workshops, Lorenz (1998) analyzed 330 poetry products within a structured creative poetry therapy model. All “products” (or segments of written poetry) were similar in terms of expressed psychological needs for love and belonging. Participants also noted enjoyment in the workshops, “enhancing self-confidence (98%); catharsis (73%), learning (60%), and enhancing social confidence (52%)” (Lorenz, 1998, p. 82).

Papadopoulous, Wright, & Harding’s (1999) study of a poetry group for five older adults with functional mental health problems documented that members perceived therapeutic and respite benefits of the group. In their study, poetry was read to participants, followed by discussion. Quantitative measures used were Beck’s Hopelessness Scale (Beck & Steer, 1988) and the Self-Efficacy Scale (Sherer & Maddux, 1982). The instruments demonstrated a decrease in hopelessness for only one participant, while three had increased hopelessness; self-efficacy gains were demonstrated in 4 of 5 participants (Papadopoulous, 1999). The authors reported a general correlation between therapeutic gains and decreases in hopelessness and increases in self-efficacy, and a general correlation between respite gains and increases in hopelessness and decreases in
self-efficacy. A limitation of their study was its sample size. In addition, participants did not write their own poetry or produce their own “product.” In the study reported here, instruments providing quantitative measurement of positive and negative psychological outcomes were administered. In addition, study participants will produce poetry as a “product.”

Collaborative writing in a poetry therapy group was assessed in thirty-three graduate students (Golden, 2000). Outcomes were measured by the Group Environment Scale (Moos & Hanson, 1974), an instrument addressing levels of commitment, involvement in a group, and concern and friendship shown to other group members. In the experimental group, participants collaborating on the writing of poetry scored significantly higher on a measure of cohesion (p>.032). A strength of that study was the use of a control group; however, the population and variables of interest are substantially different from the study described here.

In a study of a small group (6-10) of women who were parenting sexually abused children (Tilly & Caye, 2004), the researchers originally planned to engage participants in therapeutic writing only, but added poetry as it was so well received. Both poetry and writing were ranked by the women as being more helpful in assisting them to resolve their emotional issues than oral presentations of their stories.

Howard (1997) found that on-task behavior was equally improved whether women and adolescents with chemical addictions participated in poetry or music therapy activities. A study of song writing (a form of poetic expression) versus recreational music on PTSD symptoms in abused children (Coulter, 2000) revealed no significant change in overall scores due to either treatment condition. The author noted that the
general direction of their findings indicated perception of PTSD symptoms worsened during recreational music and improved during song writing and that a larger sample might show a true difference in treatment effects (Coulter). Participants in the study described here were family caregivers who were not known to have been diagnosed with a mental disorder, and the intervention that was examined was not designated as a form of therapy; however, it was anticipated that many of the helpful benefits cited above would be experienced by the family caregivers after writing poetry.

The use of poetry in nursing has been primarily anecdotal and narrative in nature. Although advocates view poetry as a unique way of knowing (Hunter, 2002), nurse researchers have not explored this use. Nurse poets have emphasized the art of nursing (Bice-Stephens, 1992; Bryner, 1996; Holmes & Gregory, 1998); nurses have also used poetry to help explicate nursing theorists such as Parse (Cody, 1994; Hodnick, Horner, & Simmons, 1993). Poetry has also been used in nursing education to help teach students concepts, increase empathy, or help guide them in critical thinking skills (Anthony, 1998; Olson, 2001; Peck, 1993; Raingruber, 2004; Smith, 1996).

Psych-mental health nurses McGarry and Prince (1998) reported on creative expression groups initiated on a psychiatric inpatient unit. Their mediums included individual and group poetry, music, storytelling, and individual drawing and painting. Pre- and post-measures included changes in selection of colors used to represent feelings, modification of a smiley face scale to select facial affect, and questions about feeling safe and accepted in the group. Group poetry in acrostic form was more effective than individual poetry writing. Overall benefits for patients included expression of negative and positive feelings, and feeling accepted by a group and by self (McGarry & Prince,
Other nurses have found poetry groups to be of benefit to clients with mental illness (Carty, 1988; Chouvardas, 1996; Felver, 1982; Madden, 1990; McArdle & Byrt, 2001).

Empirical evidence for the benefits of poetry writing in nursing is very limited. Only two studies have attempted to quantify the impact of poetry in older adult populations. McKoy (1984) assessed well-being in an elderly population before and after being taught to read and write poetry. Increased social interest was a significant finding (p<.05) for the poetry group compared to the control group. Flood and Scharer (2006) used Roy’s Adaptation Model as a theoretical framework to examine relationships between creativity, performance, and successful aging. In their pre-post-test experimental design, participants were randomly assigned to either a control group or an 8-week treatment group receiving various creative interventions (including poetry group writing). Outcome measures included successful aging (Life Satisfaction Index A, Purpose in Life Test) and functional performance (Arthritis Impact Management Scale Short Form) and a mediating variable, creativity (Similes Preferences Inventory). Hypotheses predicting improvements in functional performance and successful aging and mediation by creative processes were not supported in their study. Relationships tested were not significant. A finding of interest, however, was that of a racial component: Black participants scored higher than White participants on measures of creativity, purpose in life, and life satisfaction, both at pretest and post-test.

Other studies have been qualitative in nature, using hermeneutic analysis to describe the lived experience of homelessness in women with children (Barleben, 1993), the basic experience of being human (Cody, 1994), and the lived experience of nursing
students in a psych-mental health nursing course (Kidd & Tusaie, 2004). A strength of the study reported here was its mixed design, in which both quantitative and qualitative measures were used. In addition, the majority of poetry writing studies have been group ventures. Previous research has noted that individual interventions may be more effective in reducing depression and improving well-being among caregivers (Sorenson, Pinquart, Hidal, & Duberstein, 2002). In this study, individuals will write poetry.

Self-transcendence

The concept of self-transcendence has been defined theoretically in a previous section. Literature review indicates that self-transcendence has been empirically tested in populations of older and oldest old adults (Reed, 1986, 1989, 1991; Young & Reed, 1995) and among adults facing end-of-life or life threatening illnesses (Coward, 1990; Pelusi, 1997). The Theory of Self-Transcendence has also been applied to populations of middle-aged adults facing serious illness. Significant correlations were found between emotional well-being and self-transcendence in women with breast cancer and in women with AIDS (Coward, 1990, 1995). Men with prostate cancer demonstrated high self-transcendence scores (Chin A Loy & Fernsler, 1998), as did adults who had experienced significant life trauma (Mishara, 1995, as cited in Ellermann & Reed, 2001) or had psychiatric illnesses (Cloninger, Svrakic, & Svrakic, 1997). Depression in middle-aged adults was inversely correlated to self-transcendence scores ($r = -.51$ to $r = -.68$), as were the tested concepts acceptance and spirituality (Ellermann & Reed, 2001).

Many studies assessing self-transcendence have been descriptive, such as Acton’s (2002) qualitative study of caregivers of adults with dementia. She found a dearth of self-transcendence in her participants, noting personal boundaries restricted by social
isolation, ambivalence about caregiving and feeling overburdened by care, and negative attitudes about their own aging. Her findings demonstrated that self-transcendence is not an automatic response to a life trauma or stressful situation, but may require active assistance and intervention by caregivers (Acton, 2002).

Indeed, studies applying self-transcendence theory to clinical interventions are prevalent. Stinson & Kirk’s (2006) study tested structured reminiscence as a way to promote self-transcendence and decrease depression in older women. While they found anecdotal evidence of a decrease in depression and increase in self-transcendence in the reminiscence group over a 6-week period, results were not significant. A more significant inverse correlation ($r = -.55$) was found between low death wish and high self-transcendence scores (Buchanan, Farran, & Clark, 1995), as well as between lack of death wish and higher self-transcendence scores. Coward (1996) demonstrated strong correlations between self-esteem, hope, and emotional well-being in well elderly. In another study, group psychotherapy for older adults was demonstrated as an effective way to increase self-transcendence (Young & Reed, 1995).

Self-transcendence has not been examined in a population of family caregivers or in chronic illness. Dementia is a chronic illness that may require ongoing care for a long period of time, thus requiring caregivers to find methods of coping and managing stress. This study examined self-transcendence in a sample of family caregivers of dementia patients and applied an intervention to help actively promote that self-transcendence.

Self-transcendence also has not been examined in persons younger than middle age. Although Reed (2003) theorized that self-transcendence could be achieved in persons before middle age when vulnerability is present, her body of research has not
provided evidence for this proposition. Caregiving demands in the life of an adolescent could enhance vulnerability and perhaps precipitate crisis. New quantitative measures may be required for a younger population, but present instruments available have not been tested. It is incumbent upon researchers to do so. Also, studies using qualitative methods of inquiry would be a first step in building evidence that self-transcendence exists in younger persons. It was possible that participants in this mixed design study would be younger than middle aged.

Longitudinal studies measuring self-transcendence have not been conducted. Previous studies have been cross-sectional in design. Data collected before, during, and after the occurrence of life-threatening, life-altering, or traumatic events could help to predict who and how one may become self-transcendent. Although this study is of only 8 weeks duration, it will help document the change in self-transcendence of participants vulnerable to the ongoing, potentially life-altering stresses of caregiving and health challenges of loved ones.

Resilience

Resilience is a complex concept, one that may be comprised of a number of ideas such as creativity, hardiness, and open-mindedness (Flach, 1988). In this study, resilience was defined as a complex interaction between personality characteristics of an individual and his or her larger environment influencing that individual’s recovery from a traumatic or stressful event (McCubbin & McCubbin, 1996). Flach (1988) identified the following components of resilience: strong self-esteem; independence of thought and action but ability to rely on others when needed; give and take in interactions and a well-established personal social network; well-developed personal discipline and
responsibility; ability to recognize and develop personal talents; open-minded reception of new ideas; willing to dream; diverse interests; sharp sense of humor; insight into the feelings of self and others, as well as the ability to communicate these insights; significant tolerance of discomfort or distress; focus; commitment; and a philosophy of life that enables interpretation of life experiences as hopeful and meaningful.

Polk (1997) posited that resilience was “an ability to transform disaster into a growth experience and move forward” (p. 1) and proposed a four-dimensional construct based on Newman’s simultaneity paradigm: 1) Dispositional pattern—physical (health, intelligence) and psychosocial characteristics (mastery, self-confidence, self-reliance and autonomy); 2) Relational pattern—resilient persons are committed to personal intimacy and are skilled in relating to positive role models and confiding in others. They also have multiple social activities, diverse interests, and engagement in work and education; 3) Situational pattern—Typical approaches to resolution of stressors, such as problem-solving, cognitive appraisal, flexibility, perseverance, and resourcefulness; and 4) Philosophical pattern—personal beliefs that motivate, such as the belief that positive meanings can be found in life experiences (Polk, 1997). Hoge, Austin, & Pollack (2007) pointed out that resilience can be viewed as intrinsic to a person, yet capable of being modified.

Much of the early research on resilience focused on children and adolescents. In longitudinal analyses, researchers found that temperament or disposition of the child, family ties, and support systems besides family contributed to later resilience in children of mentally ill parents (Garmezy, 1993; Garmezy, Masten, & Tellagen, 1984). The protective nature of family or surrogate family relationships was confirmed by other
researchers (Bifulco, Brown, & Harris, 1987; Werner, 1989). Other factors such as sociability or ability to be verbally fluent when communicating offered protection in adolescents (Luthar, 1991).

In adults, resilience has been assessed in those with medical problems or those experiencing major life stresses (Kobasa, 1979). Similar to children and adolescents, the perception of social and family support promotes resilience in adults (King, King, Fairbank, Keane, & Adams, 1998; Perry, Difede, Musngi, Frances, & Jacobsberg, 1992). Concepts such as hardiness were investigated in populations of patients with HIV-AIDS; hardiness was associated with higher quality of life and lower psychological distress (Farber, Schwartz, Schaper, Moonen, & McDaniel, 2000); and with less time lost to injury in athletes (Ford, Ecklund, & Gordon, 2000). Internal locus of control has also been positively associated with resilience in some studies (Bolstad & Zinbarg, 1997; Soet, Brack, & Dilorio, 2003).

Resilience has rarely been assessed in older adults. In their study of oldest old adults, Nygren et al. (2005) discussed how resilience may be conceptualized as a trait and/or a process. Their research findings included higher resilience in older adults than those found in younger age groups. Current research focuses on strategies to maximize resilience in diverse populations. In this study, resilience was promoted through a poetry writing intervention.

*Relationships between positive psychological resources variables (self-transcendence and resilience)*

The literature search for this section was restricted to the previous five years using interaction terms to examine relationships between variables self-transcendence and
resilience, as well as relationships between the positive psychological resource variables and negative psychological outcome variables depressive symptoms and caregiver burden. Peer reviewed English articles in databases MEDLINE, CINAHL, Sociological Index, PubMed, PsychoInfo, and Psychological and Behavioral Sciences Collection were accessed.

Resilience and self-transcendence were significantly correlated (r=.49, p<.001) in a study of perceived physical and mental health among the oldest old (Nygren et. al, 2005). Other scales measuring sense of coherence and purpose in life were also significantly correlated. While the authors’ model accounted for 30% of the variance in mental health for women in the study, it only accounted for 6% of the variance for men and was not statistically significant. Correlations were not found between the scales and physical health for either women or men. Physical and mental health measures are not included in this study; however, psychological resource variables are anticipated to decrease negative psychological outcomes of depressive symptoms and caregiver burden.

**Depressive symptoms**

As a major cause of global disability (Murray & Lopez, 1996), depression is of concern to nurses. Depressive symptoms have been previously defined in this study as outlined by the American Psychological Association, DSM-IV-TR (2000). Depressive symptoms mean that persons may experience some or most of these symptoms, but do not have to meet full criteria for major depressive disorder.

Individuals disabled by depression may be unable to function or perform adequately in occupational, social, or family roles. For the individual, depressive illness may directly result in pain, suffering, and diminished quality of life (Finkelstein, Berndt,
& Greenberg, 1996). Losses can be occupational, financial, or interpersonal. Each untreated major depressive episode lasts approximately nine months and over 80% of those untreated will relapse within two years (Kapur & Mann, 1992). Each additional episode of depression worsens the prognosis. After three or more episodes, the risk of relapse within three years is more than 70 percent.

On a broader societal scale, each depressive episode thus increases the risks of chronicity, suicide (a major cause of death in the U.S.), and disability (Thase & Sullivan, 1995). Those who are depressed may not seek treatment for a mental disorder, but frequent their physicians’ offices for a host of other physical complaints requiring diagnostic procedures and substantial expense (Greenberg, Stiglin, Finkelstein, & Berndt, 1993). Thus, depression also burdens scarce health care resources. Mood disorders, including major depression, cause impairment in mental and/or physical health in 7% of Americans in a given year (Surgeon General’s Report, 1999). Mood disorders are of concern to nursing, as they prevent individuals from achieving optimal (or even adequate) health and wellness. Recovery from depressive symptoms or depression is critical.

Depressive symptoms and higher rates of depression in family caregivers of dementia patients has been well documented in the literature (Baumgarten et al., 1992; Gallagher-Thompson & Powers, 1997; Max, Weber, & Fox, 1995; McConaghy & Caltabiano, 2005; Morano, 2003; Rosenthal, Sulman, & Marshall, 1993; Takahashi, Tanaka, & Miyaoka, 2005). The demands of caregiving that contribute to depressive symptomatology include perceived stress associated with care tasks and behavioral problems in the relative being cared for (McConaghy & Caltabiano, 2005).
In several studies of spousal caregivers for dementia patients, higher mean scores on the CES-D Scale were found in women than men (Carretero, Garces, Rodenas, & Sanjose, 2009; Lutzsky & Knight, 1994; Pruchno & Resch, 1989; Rose-Rego, Strauss, & Smyth, 1998; Yee & Schulz, 2000). Although not always reaching the cutoff for high risk of clinical depression, mean score differences between women and men were significant (Schulz & Williamson, 1991; Williamson & Schulz, 1990).

While noting an increased incidence of depression in caregivers experiencing financial strain and poorer health, Yoon (2003) also found an indirect effect of cognitive impairment on depression. This was because caregivers of those with cognitive impairment usually had provided care for a longer period of time, which indirectly affected finances and caregiver health through lack of emotional support. Takahashi et al. (2005) found rates of clinical depression approaching 31% in their sample of informal caregivers. Caregivers caring for relatives with greater cognitive impairment (Mini Mental Status Exam scores of ≤ 20) were also more likely to experience depression than those caring for family with normal cognition (Shua-Haim et al, 2001).

**Relationships between depressive symptoms and self-transcendence and resilience**

A link between self-transcendence and depression was noted in a study of Japanese students (Matsudaira & Kitamura, 2006). Using the Temperament and Character Inventory (Cloninger, Svrakic, & Przybeck, 1993) to measure self-transcendence and the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) to measure depression, self-transcendence conceptualized as a personality trait correlated significantly (p<.05) with depression (Matsudaira & Kitamura, 2006). A negative correlation was found between depression and self-transcendence in a study of adults
aged 18 to 94 (Trouillet & Gana, 2008). The researchers noted that self-transcendence increased with age, and was highest in the oldest age groups. In their study, self-transcendence was key to predicting depression (Trouillet & Gana, 2008).

Previously cited, Stinson and Kirk (2006) provided anecdotal evidence of the effectiveness of an intervention (structured reminiscence) in decreasing depression and increasing self-transcendence in older women. No quantitative studies have assessed self-transcendence in family caregivers of dementia patients. Only one qualitative study (Acton, 2002) was conducted in the nursing field.

A study of resilience in sheltered battered women revealed a significant inverse correlation between resilience scores and depressive symptoms (r=-.49) (Humphreys, 2003). The researcher also noted that her subjects reported higher levels of resilience as measured by the Resilience Scale (Wagnild & Young, 1993) than Alzheimer’s caregivers (Humphreys, 2003). In a longitudinal study of dementia caregivers, low baseline resilience (defined as low burden) was associated with lower rates of institutionalization (Gaugler, Kane, & Newcomer, 2007). Depression was not measured in the study.

Evidence that supports a negative association between depressive symptoms in caregivers and making meaning from experiences also exists (Noonan & Tennstedt, 1997). In the sense that one component of resilience is interpreting life experiences as meaningful, poetry writing may promote resilience and creation of meaning from caregiving experiences. No previous studies have measured the association of depressive symptoms with self-transcendence and resilience.
**Caregiver burden**

Caregiver burden is “the extent to which caregivers perceive their emotional or physical health, social life, and financial status as suffering as a result of caring for their relative” (Zarit, Todd, & Zarit, 1986, p. 261). While objective burden refers to disruptions of life or household, subjective burden was defined in this study as the caregiver’s personal appraisal of stress, anxiety, or other negative feelings related to the caregiving situation (Faison, Faria, & Frank, 1999; Hunt, 2003). Frequently, researchers chose The Zarit Burden Interview (Zarit, Reever, & Bach-Peterson, 1980) or the Burden Interview (Zarit, Todd, & Zarit, 1986) as the instrument to assess caregiver burden (Gallagher-Thompson & Powers, 1997; Hooley, Butler, & Howlett, 2005; Kim et. al, 2006; Tremont, Davis, & Bishop, 2006; Yoon, 2003).

Burden may begin early in the caregiving relationship. In a study of caregiver burden and psychiatric morbidity (depression and anxiety) in spouses of persons with mild cognitive impairment, researchers found a significant correlation (p<.05) between greater responsibility for nursing tasks and greater caregiver burden (Garand, Dew, Eazor, DeKosky, & Reynolds, 2005). Burden may also be related to gender. Although some research findings have been inconsistent in regards to whether women or men experience greater caregiving burden, a narrative analysis of 30 empirical studies published from 1985-1998 revealed that women are at greater risk for psychiatric symptoms such as depression, anxiety, and lower life satisfaction, as well as other adverse outcomes such as less time for social life and less sleep (Yee & Schulz, 2000). Ten of the 30 studies involved caregivers for family members with Alzheimer’s or a related dementia (Yee). Male caregivers were more likely to seek outside help, give up
their caregiving role, or engage in proactive, preventive health behaviors such as rest or exercise (Yee). Campbell et al. (2008) also found increased role strain and burden among females caring for demented elders.

Relationship between caregiver burden and depressive symptoms

Research has documented a positive relationship between caregiver burden and depressive symptoms. In his study of appraisal and coping in 204 Hispanic and non-Hispanic Alzheimer’s caregivers, Morano (2003) found that caregivers who formed a more positive appraisal of burden significantly mediated stressful behavior in care recipients and caregiver psychological outcomes of somatic complaints and depression. In other words, if caregivers were able to reframe and emotionally adapt their situation, they experienced lower levels of depression and increased life satisfaction. Morano’s (2003) study used the CES-Depression Scale to measure depression; however, he used a different instrument from the one used in the study reported here to measure burden appraisal. Although his sample was large, it was a convenience sample, limiting ability to generalize findings.

In a study of caregivers for congestive heart failure patients, greater burden correlated with more severe depressive symptoms (Beck Depression Inventory-II) (Hooley, Butler, & Howlett, 2005). Similarly, caregiver burden was significantly related to depressed mood in a study of head and neck cancer patient caregivers (Dwyer, Wisawatapnimit, & Murphy, 2006). The Zarit Burden Interview (ZBI) and the Geriatric Depression Scale were used in a study of family functioning contribution to caregiving of patients with mild to moderate dementia (Tremont, Davis, & Bishop, 2006). The researchers found a moderate but significant correlation between perceived burden and
depression ($r=.40, p<.001$). In their study, variables such as time patient had been diagnosed, duration of caregiving, or extent of caregiver knowledge about dementia were unrelated to adverse psychological measures in the caregiver (Tremont).

In confirmation of Yee and Schulz’ meta-analysis (2000), Gallachio, Siddiqi, Langenberg, & Baumgarten (2005) found that informal female caregivers were 2.6 times more likely to experience burden than males. However, their logistic regression showed a non significant odds ratio of depression in female caregivers (1.3) as opposed to male caregivers. Strengths of that study included its large sample size ($n=327$); however, limitations were that it was a secondary analysis of a data set, and some participants may have provided only a limited amount of care to relatives, thus minimizing depression and burden, and the design was cross-sectional. In the study described here, although sample size was small because of its pilot nature, data were collected at three times during the course of the study.

In a Japanese study of depression in informal vs. formal caregivers of dementia patients, 30.4% of informal caregivers scored >17 on the BDI, indicative of high risk for clinical depression (Takahashi, M., Tanaka, K., & Miyaoka, H., 2005). The authors also found correspondingly high ZBI (Zarit Burden Interview) and BDI (Beck Depression Inventory) scores in informal caregivers. Burden was a significant precursor to depressive symptomatology in a longitudinal (5 year) study of informal dementia caregivers living with care recipients when controlling for baseline depression, patient illness, and demographic variables (O’Rourke & Tuokko, 2004). Although fewer depressive symptoms, less anxiety, and less burden were noted at earlier stages of cognitive
impairment than in typical community samples of dementia caregivers, where greater burden existed, greater depression and anxiety followed (Garand et al., 2005).

Although a number of empirical studies have demonstrated a relationship between caregiver burden and depressive symptoms, the majority of the studies have been descriptive and cross-sectional in design, while the proposed study was longitudinal and examined an intervention, with the hypothesis that the intervention would decrease caregiver burden and depressive symptoms over the course of the study (Time 1 to Time 3). Another unique aspect of the study described here was that it examined changes in positive psychological outcomes (self-transcendence, resilience) as well as negative psychological outcomes (depressive symptoms, caregiver burden).

Rel**relationships between positive psychological resources (self-transcendence, resilience) and negative psychological outcomes (depressive symptoms, caregiver burden)**

The relationships between the four variables listed above have not been examined together in previous research. While correlations between depressive symptoms and caregiver burden have been made in a number of studies, as well as associations between resilience, and self-transcendence, caregiver burden has not been studied in relation to any of the positive psychological resource variables. Moreover, changes in all variables’ relationships over time and in response to an intervention have not been previously studied. This study helped to fill the gap in knowledge about how positive psychological resources are related to negative psychological outcomes, as well as what impact a poetry writing intervention has upon all the study outcomes. Future application of this new knowledge should include further testing of poetry writing interventions as well as development of new nursing interventions to enhance positive psychological resources.
**Significance for nursing practice**

Promoting mental health in family caregivers of dementia patients is an important focus for nursing practice. As the population ages and increased numbers of individuals are diagnosed with dementing illnesses, nurses will provide more direct and indirect support, supervision, and assistance with care. Maintenance of psychological health in caregivers protects them from devastating consequences of depression such as increased morbidity and mortality (Baumgarten et al., 1992; Schulz, O’Brien, Bookwala, & Fleissner, 1995). Lessening burden may also be protective of the care recipient, as increased caregiver burden is also associated with an increase in psychiatric and behavioral symptoms in those with dementia (Michon, Weber, Rudhard-Thomazic, & Giannakopoulos, 2005). Therefore, lessening of burden and depression affects more than the caregiver, but also the families and communities for whom nurses care.

Nurses are engaged in the process of maximizing well-being in clients in any circumstance, but also maximizing human potential in each life (Paterson & Zderad, 1976). When there are positive aspects of caregiving acknowledged by the carer, it behooves the nurse to identify and reinforce these positive aspects. This will help nurses to understand when and where to intervene effectively in the often long, drawn out process of caregiving (Andren & Emstahl, 2005).

Caregivers who score high on measures of self-transcendence and resilience at baseline may be helped to maintain or gain strength in these variables through the act of reflecting on their experiences or creating additional meaning in poetry. Caregivers scoring low on measures of self-transcendence and resilience at baseline may find that the act of creation and expression inherent in poetry writing will help them gain strength.
in these intrapersonal characteristics. In addition, negative psychological outcomes of depressive symptoms and burden may be decreased.

Summary

Poetry writing is an innovative intervention designed to assist family caregivers of dementia patients to express feelings (positive and negative) and create meaning from their life experiences. It was proposed that the intervention, poetry writing, would be associated with changes in outcome or dependent variables (increased scores for positive psychological variables self-transcendence and resilience, and decreased scores for negative psychological outcomes depressive symptoms and caregiver burden). If changes in scores were not present, it was expected that participants would find poetry writing to be of personal benefit in improving positive psychological resources or decreasing negative outcomes. Although a number of studies have examined relationships between some of the study outcomes, no previous research has examined relationships between the two positive outcome variables and two negative outcome variables in this population. No nursing research or evidence based data in any other discipline has examined poetry writing as an intervention for family caregivers.

A second expected outcome of the study was that caregivers would find poetry writing of sufficient value to continue writing poems even when not specifically required to do so by the researcher. Poem content was analyzed for themes to validate, refute, or supplement data not captured by quantitative instruments. This qualitative method was helpful in establishing knowledge through an inductive process. Finally, information about the experiences of poetry writing was gathered from participants. This data was helpful in establishing parameters about the poetry writing intervention, as well as
feasibility of this pilot study. It was proposed that data obtained from this study would add to nursing knowledge about an intervention that promotes mental health and maximizes well-being and human potential through positive psychological resources in family caregivers.
CHAPTER THREE

Introduction

This chapter will detail methodological considerations of the study. First, the research design will be elucidated, followed by a discussion of sampling issues, including selection, inclusion and exclusion criteria, and sample size determination by power analysis for future clinical intervention trials. Next, instruments used in the study will be reviewed, including item description, scoring, interpretation, and psychometric testing. Explanation of procedures for instrument administration will be given, and discussion of protection of human subjects will be provided. Further procedures used in the study will be discussed, including how the intervention was administered to participants and how repeated measures were taken. In conclusion, quantitative and qualitative methods that were used to analyze research data will be summarized.

Design

This pilot study of a poetry writing intervention for family caregivers of older adults with dementia was conducted as an quasiexperimental or comparative, longitudinal, cross-over and mixed methods design. Repeated measures were used to collect data at three specified time intervals over an 8-week period. Participants were randomly assigned to Group A or B. Following baseline pre-testing (Time 1), Group A receive the poetry writing intervention for 4 weeks. Then, data were collected for both groups (Time 2). Next, Group B received the intervention. This 4-week period may be considered an untreated “washout” period for Group A (Hulley et al., 2001) or Group A members may have decided to continue the intervention on their own, as no specific instructions to stop or continue were provided by the researcher. Data were collected
again on both groups (Time 3). Finally, at least one-half of the total sample in each group (n=10) were asked to participate in randomly selected semi-structured interviews (Appendix H) at the conclusion of Time 3 data collection. The research design is illustrated below in Figure 4 (points of data collection designated as T1, T2, and T3; X=intervention, R=randomization; O=measure outcomes; Ø=no intervention; TC=Telephone Call):

Figure 4. Research Design

<table>
<thead>
<tr>
<th>T1</th>
<th>T2</th>
<th>T3</th>
<th>Interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>R(A)</td>
<td>O</td>
<td>(TC)</td>
<td>O</td>
</tr>
<tr>
<td>R(B)</td>
<td>O</td>
<td>(TC)</td>
<td>O</td>
</tr>
</tbody>
</table>

In general, a pilot study is conducted to determine feasibility for a larger study and to establish sufficient scientific evidence for more extensive research. Preliminary data are collected and analyzed in preparation for a larger clinical trial (Jaireth, Hogerney, & Parsons, 2000). In this study, pilot testing was necessary to demonstrate the clinical efficacy of a new application of an intervention previously untested in the study population.

Longitudinal designs are a good choice for studies when number of participants is limited. Pre-tests and post-tests used as repeated measures thus add power (Shadish, Cook, & Campbell, 2002). Another advantage of the longitudinal design is that it allows the researcher to note how and if effects change over time, as well as a better ability to track individual responses to treatment (Shadish et al., 2002). One disadvantage is higher risk for attrition; however, in this study, the entire trial period was just eight weeks.
A crossover design is a type of repeated measures design that randomly assigns participants to receive either Treatment A (poetry writing) or Treatment B (no poetry writing); in other words, one group receives active treatment while the other serves as control (Hulley et al., 2001; Shadish, Cook, & Campbell, 2002), then the order reverses. Again, statistical power of the trial is increased when each participant serves as his own control. Other advantages of a cross-over design include the ability to analyze between-group and within-group differences; furthermore, more causal information may be gained when the study continues after first post-tests are administered (Shadish et al., 2002). Disadvantages are increasing study duration and increasing the potential for “carryover effects” or the “residual influence of the intervention on the outcome during the period after it has been stopped” (Hulley et al., 2001, p. 169). Repeated measures designs were used frequently in caregiver evidence-based intervention studies in the 1990’s (Schulz, 2000). In a crossover design similar to the study reported here, caregivers and care recipients were randomized into treatment-first and treatment-delayed groups, with measurements at baseline, 16, and 32 weeks (Hinchliffe, Hyman, Blizard, & Livingston, 1995). Both groups received all treatments, with control provided by delay of intervention for Group B. Findings were that the treatment-first group (A) experienced improvement on health measures, while the treatment-delayed group (B) did not (Hinchliffe et al.). This study also illustrates a possible carryover effect.

In the design for this study, carryover effects are minimized because the interval between Time 2 and Time 3 measurement can be considered a “washout” period for Group A. Alternatively, Group A participants may continue to use the poetry-writing intervention independent of researcher directives to continue or to stop. Group A thus
becomes the group of greatest interest in the study; specifically, one study research question asked whether a majority of Group A participants would continue the intervention (poetry writing) on their own during the 4-week “washout” period. Carryover effects are often problematic because they may interfere with responses to later treatments (Burns & Grove, 2005); however there is no later treatment in the study. Carryover effects may even be considered a hoped for outcome; desirable as opposed to undesirable.

Rationale for the study duration was based on the literature review. Studies of expressive writing have demonstrated that a longer duration of the writing task was more effective in producing significance in experimental designs. In a meta-analysis of nine studies assessing psychological wellbeing (Smyth, 1998), a mean effect size of .66 (p<.001) was found, with a 31% improvement in the experimental group. The effect size was higher when outcomes weren’t measured until at least one month (4 weeks) of writing, with a larger effect size positively related to duration of writing task (Smyth, 1998). Although poetry writing has not been investigated, it was hypothesized that its effect and significance would be similar to expressive writing studies previously reported.

Mixed methods refer to methods triangulation, or incorporating more than one research method into a study (Speziale & Carpenter, 2003). This study used between-method triangulation at the design level, and within-method triangulation at the data collection level (Denzin, 1970). This means that quantitative and qualitative methods were integral to the study design, and were therefore implemented simultaneously during data collection. Although it is commonly difficult to implement quantitative and qualitative measures on the same sample, it is possible when the qualitative sample is a
subset of the larger sample (Speziale & Carpenter, 2003), as in the study reported here. The blending of quantitative and qualitative approaches in this study provided a more complete representation of the phenomenon under investigation. Obtaining a greater depth of information about the intervention was helpful as the intervention was being piloted in this study. Analytic interpretation can be merged into a more complete and cohesive portrait (Speziale & Carpenter, 2003).

Sample

Sample specification

Sampling theory emphasizes that study samples must be representative of the population of interest. They also should be acceptable in cost of time and money, and large enough to control random error and generalize findings to the larger population (Hulley et al., 2001). The study aim was to compare the effects of an intervention in a group of family caregivers that were randomized to receive the poetry-writing intervention between T1 and T2 or between T2 and T3.

The sample plan for the study was to recruit from two primary sources. The first source was Alzheimer’s Association support groups and clients coming into Alzheimer’s Association offices for information and assistance. The principal investigator (PI) contacted a gatekeeper through the Alzheimer’s Association who assisted her in compiling a pre-study profile of family caregivers at support groups (Appendix L) and in gaining access to support group leaders. The PI attended support group meetings and was introduced to explain the study to group members. In instances where personal contact was not possible, participants responded to recruitment flyers (Appendix I) and written information about the study provided by support group leaders. Attempts were
made to recruit all participants from the Alzheimer’s Association; however, the sample size of 20 could not be obtained from this source alone.

The second planned recruitment source was private practice physicians’ offices in the northeast Ohio area. Due to the difficulty of obtaining consents to recruit from this source, an adjustment was made to the sampling plan and this recruitment venue was eliminated. Instead, additional recruitment venues of area churches, online on craigslist.com and Case Daily, and the Summit County Area Agency on Aging were used in this study. All additional venues were approved by the Institutional Review Board.

Convenience sampling was used in this study. In this type of nonprobability sample, available persons who meet criteria are entered into the study until designated sample size is reached (LoBiondo-Wood & Haber, 2002). Disadvantages of this sampling method included lack of representativeness or risk of bias, as participation was voluntary and participants were self-selected (LoBiondo-Wood). Major advantages included lower cost and ease of obtaining subjects (Hulley et al., 2001). Considering the study design, and inclusion and exclusion criteria designed to maximize sample homogeneity, convenience sampling was an appropriate choice for this pilot study.

**Inclusion and exclusion criteria**

Inclusion criteria for family caregivers of older adults with dementia included: 1) Adults (over age 18) of any racial or ethnic background; 2) able to read English at an 8th grade level; 3) able to write English at a sixth grade level; 4) sufficient cognitive ability to participate (as determined by Short Portable Mental Status Questionnaire; 5) reports performing direct or indirect caregiving activities and responsibilities for an older family member with dementia on a weekly basis; and 6) denies currently using poetry or any
other method of expressive writing (i.e. journaling) as a method of stress reduction or coping strategy related to caregiving activities. Exclusion criteria include: 1) Inability to read or write English; 2) Functional inability to write using pen or word processor/computer; 3) under age 18; 4) Insufficient cognitive ability; and 5) Persons currently writing poetry or using other expressive writing as a means of coping with caregiving demands or other stress reduction.

Cognitive ability was measured by the Short Portable Mental Status Questionnaire (SPMSQ) (Pfeiffer, 1975) (Appendix K) and was administered during the first meeting with the PI to screen participants. This screening instrument was appropriate for older adults in particular, as it was likely that the majority of study participants would be older adults. Other advantages of this instrument were that it adjusts for educational differences among respondents and it doesn’t require special psychomotor skills (i.e. the Mini Mental Status Exam requires respondents to fold a piece of paper into several sections). Scoring of the SPMSQ was as follows: 0-5 errors indicates normal cognition to mild cognitive impairment for those with grade school education or less; 0-3 errors indicates normal cognition to mild cognitive impairment for those with more than high school education. Any participant scoring above the error cutoff for mild cognitive impairment would have been excused from the study as inclusion of persons with greater cognitive impairment would be ill advised in this study. Thus, the scoring algorithm was: greater than 5 errors grade school education or less—excused; greater than 3 errors high school education or more—excused.

Literacy level for this study was set at 8th grade reading and was determined by the Flesch-Kincaid Grade Level readability score formula (Flesch, 1948; Kincaid,
Fishburne, Rogers, & Chissom, 1975). When designing consent forms and explanations about the intervention, the researcher conformed to this level of readability. Any participant who was unable to understand the consent forms or written information would not have been enrolled in the study. Writing skills should be at a 6th grade level. Writing component standards that should be articulated by Grade Level 6 (Arizona Department of Education, 2004) included: clear ideas; appropriate details; effective transitions; effective word choice and style; varied and natural vocabulary; appropriate voice; varied sentence lengths; appropriate punctuation, grammar, and spelling; and an ending or closure. It was difficult, however, to hold poetry to these same standards, as poetry often flies in the face of conventional spacing, punctuation, focus and transitions. Thus, for the purposes of this study, if a participant was able to read at the 8th grade level, it was assumed that they were capable of writing at a 6th grade level or composing poetry for the study.

*Determinaton of Sample Size/Power Analysis*

In a pilot study, procedures and methods similar to those that would be employed in a larger scale study are used, with goals to determine feasibility for a larger study and to provide adequate evidence to justify more in-depth research (LoBiondo & Wood, 2002). Pilot study samples are by definition small, although sample size less than 10 would likely yield unstable results (LoBiondo). Sample size for this pilot study was targeted at $n=20$, with 10 participants each in both intervention groups.

In the event that a full clinical trial were to follow the proposed pilot study, power analysis would be necessary to determine appropriate sample size. Power analysis estimates how large of a difference should be observed between groups. The smaller the
difference expected, the larger the sample size must be to demonstrate actual differences through statistical analysis (LoBiondo & Wood, 2002). Lipsey (1990) defined power as “the probability that statistical significance will be achieved given that there really is a treatment effect” (p. 20). Power analysis requires determination of the statistical test appropriate to test for significance, followed by entering of relevant parameters (alpha or desired significance level, effect size or the magnitude of effect the experiment is designed to detect, and desired level of statistical power or 1 minus beta) (Lipsey). Based on entering three parameters into the equation, the fourth can be readily determined.

In this study, hypotheses would be unidirectional or one-tailed. This means that alternative hypotheses (indicating that the intervention has an effect) would be in a specified direction (i.e. lower scores on depressive symptoms and caregiver burden, higher scores on self-transcendence and resilience). Hypothesis testing is based on review of the literature providing sufficient evidence base. It is important to minimize Type II error (β or beta) as this study involves a relatively unexplored area of research. This would mean that the study would be less likely to err in saying there was no difference resulting from the intervention when there was a difference.

The computer-based G-power program (Faul, Erdfelder, Lang, & Buchner, 2007) assists researchers in estimating power. Because hypotheses are directional, a one-tailed test would be used. In addition, a larger alpha of 0.1 would be set, as little harm was anticipated to participants in this exploratory study. Beta would be set at 0.20, because a Type II error is considered as serious as a Type I error in this study. Effect size is difficult to determine, but a moderate effect size of 0.6 was postulated. Effect size is
based on the meta-analysis of expressive writing studies conducted by Smyth (1998) and adjusted slightly downward from his effect size of .66 (due to differences in variables being measured). If independent samples t-test were used as statistical test for Research Questions 1 and 3, one-tailed, power set at .80, effect size of 0.6, and alpha of 0.25 (Bonferroni correction for multiple t-tests), the total sample size would equal 90, with 45 in each group. For Research Question 2 the statistical test to be used could be the dependent or paired t-test. With a one-tailed test, standard power set at 0.80, effect size 0.60, alpha 0.025 equals total sample size 24 (size of Group A only).

Because of the pilot nature of this study and its major aims to obtain preliminary information concerning the usefulness and feasibility of a poetry-writing intervention for family caregivers, sample size determination was not based on power analysis. In fact, the examination of the richness of the qualitative data was viewed as more critical for future intervention development than were the quantitative measures and their analysis. However, trends in the quantitative data on the positive psychological resources (self-transcendence and resilience) and negative outcomes (depressive symptoms and caregiver burden) were examined for changes in mean scores in the hypothesized direction on the measures of the four major study variables. More sophisticated statistical analyses, including the use of independent t-tests to examine between group differences on the four variables, dependent/paired t-tests to compare within-group changes on the four variables, and correlational analysis to examine associations among the four variables would require the acceptance of substantially large effect sizes of d=.97, d=.70, and r=.46, with an alpha of .10 and power of .80 (G*Power, 3.1).
**Instruments**

Six instruments were administered to the study participants. These instruments included: a demographic questionnaire, Self-transcendence Scale (Reed, 1986), The Resilience Scale (RS) (Wagnild & Young, 1990), Center for Epidemiologic Studies-Depression Scale (CES-D) (Radloff, 1977), Zarit Burden Interview (ZBI)—Short Form (Bedard et al., 2001), and a feasibility questionnaire. Characteristics of interest, including items, scoring, and psychometric properties of instruments will be described in this section. Attempts to minimize threats to internal and external validity will be described. Finally, the process that was used to administer the instruments in the study will be described.

**Demographic Characteristics**

An open-ended questionnaire (Appendix A) was provided to participants; it included subject identification number and date of data collection. Demographic variables included: age, gender, marital status, religion, educational level, employment status, and annual income. Also included were questions about caregiving characteristics—relationship of person cared for, type of care provided, amount or frequency of care provided, duration of caregiving, and amount of satisfaction received from caregiving experience on a 1 to 6 Likert scale item developed by the researcher (1=very satisfied; 2=moderately satisfied; 3=slightly satisfied; 4=slightly dissatisfied; 5=moderately dissatisfied; 6=very dissatisfied). Finally, abilities of care recipients to complete personal care activities was measured by well established instruments—the Katz Basic Activities of Daily Living (ADL) Scale (Katz, Ford, & Moskowitz, 1963) and

**Self-transcendence**

In nursing and other research, Reed’s Self-Transcendence Scale (1986) (Appendix B) has been most commonly used. The unidimensional Self-transcendence Scale (STS) was developed by Reed (1986). It was used to measure self-transcendence in this study. The Self-Transcendence Scale contains 15-items. The intent of the STS is to identify and measure intrapersonal, interpersonal, and temporal experiences of later life reflecting expanded self boundaries” (Reed, 1991). Although the STS is often administered during interview, it can also be completed by the participant in a written format. Instructions are that the person is to answer items while reflecting on the current state of his or her life. Items are scored on a 4-point scale ranging from 1 (not at all) to 4 (very much). There is one reverse scored item. Scores range from 15 to 60, with higher scores representing a higher overall level of self-transcendence. Items are designed to avoid bias toward physically healthier individuals, but rather to measure non physical domains such as creativity, introspection, and socialization (Reed, 1991). Examples of items include “Being involved with other people or my community when possible,” “helping others in some way,” “finding meaning in my past experiences,” and “dwelling on my past unmet dreams or goals”(Reed, 1989).

The Self-transcendence Scale was chosen over other available instruments as it is well established and has extensive psychometric data reported. The “self-transcendence” factor identified in the scale had good internal consistency and explained almost half of the variance in the instrument. In addition, good criterion validity was demonstrated
through research on depressive symptoms (Reed, 1986). Face validity was established by study participant agreement that items were relevant to their current lives (Reed, 1991). Construct validity was demonstrated by establishing correlations between STS scores and other psychosocial measures, such as the Purpose of Life Test (.78), as well as by support of hypothesized scores (Coward, 1990; Coward & Reed, 1996; Haase, Britt, Coward, Leidy, & Penn, 1992).

Reliability coefficients in earlier studies have ranged from .80 to .93 (Reed, 1989) and in later studies from .80 to .88 (Ellermann & Reed, 2001). Other researchers have also reported high reliability. For example, Buchanan, Farran, and Clark (1995) adapted two items from Reed’s Self-Transcendence Scale (STS) to test for a correlation between suicidal thought and self-transcendence in older adults, finding a Cronbach alpha of .83. Reliability and validity of the Self-transcendence Scale has been supported by a number of studies with reported ranges of Cronbach’s coefficient alpha from .80 to .93 in samples of older adults and 0.86 in HIV-positive adults (Mellors, Riley, & Erlen, 1997; Reed, 1989; Reed, 1991). All studies using older adult samples have reported a Cronbach’s alpha of at least .80, the minimum standard coefficient for established instruments (Nunnally, 1978). One disadvantage of Reed’s Self-transcendence Scale is that it has only rarely been used outside of an older adult population; however, good results have been obtained on these occasions (Ellermann & Reed, 2001; Kilpatrick, 2002).

**Resilience**

Resilience was previously defined as a complex interaction between personality characteristics of an individual and his or her larger environment influencing that individual’s recovery from a traumatic or stressful event (McCubbin & McCubbin,
1996). Resilience was measured by the Resilience Scale (Wagnild & Young, 1988). The Resilience Scale (RS, Appendix C) contains 25 items, with a 7-point response score, ranging from 1-7. Ratings are from 1, disagree, to 7, agree (Wagnild & Young, 1993). Participants are asked to state the degree to which they agree or disagree with the items, with total scores ranging from 25-175. Higher scores indicate greater resilience.

The Resilience Scale was originally developed using a sample of older women in a qualitative study (Wagnild & Young, 1990). Using the resilience literature and participant perspectives, the authors identified five components of resilience: equanimity (balance of life and experience); perseverance (continuing in the face of adversity or discouragement); self-reliance (belief in oneself and one’s abilities); meaningfulness (believing life has purpose and one is capable of contributing); and existential aloneness (the sense that life is unique and cannot be fully share with another person) (Wagnild & Young, 1993). The authors attest to the scale’s application to males and a broad age range, however (Wagnild & Young, 1993). The instrument has also been found to have more sound psychometric properties and better application to adolescents than other resilience instruments (Ahern, Kiehl, Sole, & Byers, 2006).

Psychometric testing of the RS by its nurse authors was conducted on a sample of 810 community-dwelling older adults. Mean age was 71.1 years (Wagnild & Young, 1993). Internal consistency reliability was demonstrated with a Cronbach’s alpha of .91 (p<.001), and the authors noted previous study internal consistency reliability correlations of between .76-.91 (Wagnild & Young, 1993), with item-to-total correlations from .37 to .75 (majority between .50 and .70). Test-retest reliability data in a study of pregnant and postpartum women over an 18-month period with four data collection
points (Killien & Jarrett, 1993) demonstrated correlations ranging from .67-.84 (p<.01). These acceptable findings indicate that resilience is stable over time (Wagnild & Young, 1993).

Concurrent validity was demonstrated by high correlations of the Resilience Scale with other valid measures linked with resilience and its outcomes (Wagnild & Young, 1993). As the authors notes, the specific construct measures were “depression (r=.37), life satisfaction (r=.30), morale (r=.28), and health (r=.26)” (Wagnild & Young, 1993, p. 174). All relationships were significant at p<.001. Construct validity was supported through significant, positive correlations with other well-established instruments of self-esteem and perceived stress. Factor analysis with item loadings revealed “two factors that reflected the theoretical definition of resilience: Personal Competence and Acceptance of Life and Self” (Wagnild & Young, 1993, p. 174). These two factors explained over 40% of the variance at factor loadings of .40 or higher (Wagnild & Young).

This instrument was chosen over others for several reasons. One reason is that its items are more specific to the probable population of the study, family caregivers who are older adults. Its theoretical components such as meaningfulness and existential aloneness also fit well with the existential framework of the study. It was developed by nurse authors using community-dwelling participants, the same target population as the proposed study. Its psychometric properties are sound. The Resilience Scale was developed through qualitative analysis, but uses quantitative measures. As Tusaie and Dyer (2004) noted “The clearest descriptions and measurements of resilience today consist of a quantitative scale correlated with outcome measures specific to the
population...qualitative piece to address the individualized dynamics of resilience.” (p. 6). The study being reported combined quantitative and qualitative measures in measuring outcomes.

*Depressive symptoms*

Depressive symptoms have been extensively defined elsewhere in this paper. Depressive symptoms were measured by the Center for Epidemiologic Studies-Depression Scale (CES-D) (Radloff, 1977). The CES-D (Appendix D) is one of the most widely used instruments to measure depressive symptoms in a general population. It contains twenty items rated on a 0-3 scale. The respondent is to rate their responses based on frequency of agreement during the past week with statements such as “I was bothered by things that don’t usually bother me.” 0 points is “rarely or none of the time” (less than 1 day) to 3 points “Most or all of the time” (5-7 days) (Radloff). Maximum score is 60 points; however, a score of 16 or above is typically set as a cutoff point for those considered at high risk for clinical depression (Yee & Schulz, 2000). Scores above 16 in this study were considered to reflect a risk for clinical depression and caregivers were assessed for current suicidal ideation. As needed, these participants were also given psychiatric referral information. Participants expressing current suicidal ideation with a plan and no assurance of personal safety would have been excluded from the study and assisted to contact emergency psychiatric services for follow-up. Other participants would remain in the study, but would be excluded if they became suicidal.

The CES-D Scale is easy to use and has sound psychometric properties. Internal consistency was validated by the author through administration of the CES-D to thousands of patients and persons in the general population. Four factors (depressed
affect, positive affect, somatic and retarded activity, and interpersonal) were identified by Radloff (1977) and confirmed by factor analyses by other researchers in older adult samples, military personnel samples, and low SES African-American samples (Boisvert, McCreary, Wright, & Asmundson, 2005; Hertzog, Van Alstine, Usala, Hultsch, & Dixon, 1990; and Nguyen, Kitner-Triolo, Evans, & Zonderman, 2004).

Cronbach’s reliability coefficient alpha statistics ranged from .84 to .90, with Spearman-Brown estimates of reliability ranging from .86 to .92 (Radloff, 1977). Family caregiver studies using this instrument have reported high Cronbach’s alpha coefficients of .86 (McConaghy & Caltabiano, 2005) and .87 (Garand et al., 2005). Cronbach’s alpha in other studies has remained consistently above .80, such as the .89 result reported by Ellermann and Reed (2001) in their study of healthy middle-aged adults. The CES-D generally has high stability and reliability across time, indicating its usefulness as an instrument when symptoms remain stable across time. Test-retest reliability correlations were high (.63-.75) in a study of high-risk pregnant women remaining on bedrest that was conducted over 4 weeks (Maloni, Park, Anthony, & Musil, 2005), although some researchers have reported lower test-retest correlations when longer intervals were considered (Ellermann & Reed, 2001; Radloff, 1977). The differences in test-retest correlations may be attributed to cyclic changes occurring in depressive symptoms and responses to life events (Radloff, 1977, cited in Boisvert et al., 2005).

One disadvantage of the CES-D is that it may be less sensitive in detecting depressive symptoms over longer intervals. However, as quantitative data collection in this study occurred over a relatively short period of time (12 weeks), choice of the CES-D for this study was appropriate. Content and concurrent validity have also been
established (Weissman, Sholomakas, Pottenger, Prusoff, & Locke, 1977), as has convergent validity with the MAACL-R, the POMS, and the Hamilton Rating Scale for Depression (Maloni et al., 2005; Devins & Orme, 1985).

Subjective caregiver burden

Subjective (or perceived) caregiver burden in the study was measured by the Zarit Burden Interview (Bedard et al., 2001). This measure (Attachment E) is a short version of the original 29-item Zarit Burden Interview (Zarit et al., 1980). This instrument is suitable because it can be used in longitudinal and intervention studies (Bedard et. al, 2001), similar to the study reported here. Increased ease of administration is one advantage of a shorter version.

Items are scored from 0 (never) to 4 (nearly always), with a range of 0-48. A higher score indicates a higher level of perceived burden. Sample items are: “Do you feel….that because of the time you spend with your relative that you don’t have enough time for yourself?” and “…that your health has suffered because of your involvement with your relative?” (Bedard et. al, 2001, p. 657).

When developing the instrument, the authors used a large sample (N=413) and built on previous revisions of the instrument done by other authors. Items were selected via combination of high factor loadings and high item-total correlations across situations of Times 1 and 2 for Alzheimer’s patients and others, and change in Alzheimer’s patients and others. Correlations for the short version for Alzheimer’s caregivers were .96 at baseline and .97 at the second visit (six months later). All correlations were significant at the p<.001 level (Bedard et. al, 2001). Overall Cronbach’s alpha at baseline was .88.
longer version of the instrument. There were no main effects of time (burden changes over time) or diagnosis (greater burden for Alzheimer’s versus other caregivers), and only a marginally significant interaction effect (p<.10) (Bedard et. al, 2001). The authors noted probable generalizability of their results to a variety of groups, but noted that their sample was primarily spouse caregivers. In addition, their interval was only six months, so it was not possible to determine the utility of the instrument over longer time spans. In this study, the time interval of measurement is two months, within an acceptable time frame for this instrument. In conclusion, the shortened version of the ZBI retains adequate validity and reliability for use in the study described here.

Feasibility

A 5-item questionnaire was designed by the principal investigator. Its primary purpose was to determine whether it would be feasible to conduct a larger clinical trial using the same research design and protocol. The PI assessed all participants perceptions of critical aspects of the protocol in the final interview following semi-structured interview about the experience of poetry writing (Appendix H). These were: the number of poems required during the 4-week intervention period; the amount of time spent both writing poems and meeting with the researcher; the amount of money (financial compensation) provided for participation; the number of questionnaires and the difficulty of completing the questionnaires. Responses that could be chosen included “About right,” “More would be OK”, or “Too many/much.”

Intervention

An intervention is “direct action and implementation of a plan” (Watson, 1979, p. 66). Nursing interventions, while implemented by nurses, can occur at any point of
illness or wellness and promote health in an individual (Watson). In addition, although selected actions or plans could possibly be initiated by professionals of another discipline, the knowledge, background, and humanistic interaction of the nurse with the client makes the intervention unique to the nurse. In the current study, nurses have discipline-specific perspectives about dementia clients and their family caregivers. In this study, then, poetry writing becomes a nursing intervention.

Poetry uses written or spoken language in a unique way. Although some prose is aesthetic, poetry has unique characteristics of rhythm, metaphor, and choice of words. It provides a sense of universality and catharsis to the reader and writer (Anderson, 1999). Fox (1997) noted essential elements of poetry as “simile, metaphor, image, line breaks, and word choice” (p. 59).

Simile helps the writer and reader to discover connections, such as “friendship is...like two little rivulets that flow side-by-side forever” (Fox, 1997, p. 61). Metaphors also help to associate more obscure connections between the specific and a broader reality—for instance, a poem about vegetable gardening could really be an explication of caregiving to a human being. Thus, metaphors can “offer great healing power” (Fox, 1997, p. 65). Images reflect direct sensory experiences and can impress themselves with rich complexity upon one’s mind (Fox). Line breaks form poem structure and organization, and may be of varying lengths. They may be whole or fragmented, compact or elongated, but they can communicate rhythm and flow of natural speech; thus conveying emotion and meaning (Fox). Word choices add aesthetic value to a poem, as they can surprise, energize, or add power to poetry. They can evoke sounds and images.
Among other things, word choices may be guided by desired repetition, relationship of word meanings, and freshness (Fox).

Participants were asked to write at least three poems during a four-week interval in the study. Poem topic and length were open-ended. An information sheet about what poetry (Appendix G) with examples was mailed to participants with informed consent documents prior to the first interview and actual enrollment.

Administration of Instruments

Instruments were administered to all participants by the researcher three times during the 8 week study period: Time 1—at initial enrollment and prior to application of the intervention; Time 2—at the midpoint of the study (4 weeks), after which one half of the participants have participated in the intervention; and Time 3—at the conclusion of the study (8 weeks), when all participants have completed a minimum of four weeks’ application of the intervention.

Procedure

Participants were enrolled on an individual basis as they volunteered for the study. Following scripted telephone contact with the researcher (Appendix M), or personal contact following a scripted presentation at a caregiver support group meeting (Appendix N), informed consent forms (Appendix F) and information and examples about poetry writing (Appendix G) were mailed to the potential participant with a cover letter (Appendix J). An initial meeting time was arranged within 2 weeks of the telephone contact. The location of the meeting was mutually determined, but the participant could choose to meet at their private home or at a public location such as a restaurant or library. The participant was encouraged to recommend what they designate
as a “safe place” to meet. Attempts were made to assist with respite care during interviews if participants could not leave their homes or their family member. For example, a research assistant would accompany the principal investigator to help provide companionship for the demented elder; however, no physical care would be provided.

At the initial meeting, the researcher reviewed and obtained signed informed consent from the participant. Participants were screened for ability to meet inclusion criteria (reading and writing English and sufficient cognitive ability as demonstrated by SPMSQ testing). If participants were unable to meet inclusion criteria, they were respectfully excused from the study (Appendix P) and referred for additional health care evaluation with a written copy of contact information (Appendix O) as appropriate. All four instruments were administered to the participants in an assigned order, which remained the same at all three data collection points. The researcher also reviewed and discussed characteristics of poetry and poetry writing examples with the participant. She asked for questions and assess understanding of informed consent. Finally, she informed the participant if he or she had been randomized to Group A or Group B.

Threats to Validity

Threats to internal validity include history, maturation, testing, instrumentation, mortality, and selection bias (LoBiondo-Wood & Haber, 2002). In this study, the greatest threat to internal validity was selection bias since participants volunteered for the study and were selected via convenience sampling. The cross-over design of the study will helped to control for selection bias. Although there is no designated experimental and control group, each participant served as his or her own control by experiencing the intervention as well as a time period without the intervention. Group A essentially
functions as an experimental group while Group B is a control group between Time 1 and Time 2. In addition, participants were randomized into poetry writing or non poetry writing groups at the beginning of the study. Although all participants (n=20) did complete a final interview about their experience of poetry writing, five participant interviews from each group (n=10) were initially and randomly selected for further qualitative analysis. If analysis of interview data and themes did not reach saturation at n=10, additional transcripts would be randomly chosen for analysis until saturation was reached. Poems were randomly selected for analysis; all poems from all participants were not analyzed in this study.

Another internal validity threat was maturation—the biological, psychological, or developmental growth processes occurring internal to a participant that are outside the realm of the study (LoBiondo-Wood & Haber, 2002). Randomization to groups helped to control for this issue; also, the 8 weeks duration of the study was fairly short, which helped to assure that less than substantial maturation changes would occur.

Testing effects may also be a factor threatening external validity—participants completed the same measures three times during the study period. The outcome could be higher scores related to participants’ sensitization to the instruments rather than the effect of the intervention (LoBiondo-Wood). The cross-over design helped to address this threat and reduce the possible error.

Other threats to internal validity included instrumentation and mortality. Instrumentation threats included changes in how the variables are measured or changes in observations of researchers (LoBiondo-Wood & Haber, 2002). In this study, the same instruments were administered without change in the same sequence three times. Any
research assistants administering instruments would have been pre-trained in a single session to assure consistency of method of administration.

Mortality means that participants withdraw from the study over its duration (LoBiondo-Wood). If analysis of group demographics prior to study revealed relative homogeneity of both groups, mortality was a less serious threat at the conclusion of the study. In addition, attempts to retain study participants were implemented. These measures included brief telephone contact with all participants at least once during each 4-week period during the study. During the telephone call, the researcher reminded participants of appointment dates and locations and encouraged participants’ continued implementation of the intervention. She also offered to address any concerns that may have arisen. Further, the researcher offered financial compensation and an incentive of $45-$60 to those completing the entire 8 weeks of the study. Finally, the PI was prepared to recruit an additional five participants (or extra 25% of original sample) if needed to allow for attrition and to ensure that both intervention groups maintained a minimum of 10 participants throughout the study.

Threats to external validity included selection, reactive, and measurement effects (LoBiondo-Wood & Haber, 2002). Selection effects incorporate the use of nonprobability sampling, which may affect ability to generalize to other groups (LoBiondo-Wood). Reactive effects, also known as the Hawthorne effect, mean that positive outcomes may result from participants’ awareness of being studied rather than the intervention itself (LoBiondo-Wood). Measurement effects refer to the impact repeated testing may have upon test results (LoBiondo-Wood). An attempt was made to ensure representativeness of the sample at the outset of the study; however, it was most
important to establish credibility of the study via assurance of internal validity. After internal validity is established as firmly as possible, study design helped address concerns about external validity. The small sample size in this pilot study will limit ability to generalize to outside populations; however, findings will be useful for future practice, research, and further clinical trials aimed to build data about the intervention.

Protection of Human Subjects

Ample measures were taken to provide protection of human subjects who participated in the study. First, participation was voluntary. No coercive maneuvers were instituted to leverage participation, and participants were allowed to withdraw at any time. Refusal to participate had no consequences in terms of care provided by a physician’s office or private non-profit organization such as the Alzheimer’s Association or a church. Written consent informing participants of the nature of the study and what was being requested of them was required in advance of enrollment. Prior to and after giving written consent, and at any point during the study, participants were encouraged to ask questions of the principal investigator and were assured that their questions would be answered as fully as possible.

Confidentiality of participant responses on questionnaires and study instruments was maintained throughout the study. Identification numbers were assigned to participants as a safeguard for anonymity. Only the identification number appears on poems, instruments, questionnaires, and other files pertinent to the participants. All data were kept in a locked cabinet in a private office and stored in security enabled and protected computer files. Data were only be available to the principal investigator and any research associates.
There were two possible violations of participant confidentiality, which included cases of danger to self or others. One exception would occur if a participant scored very high on the CES-D at the first interview (or any time during the study) and acknowledged suicidal depression with a plan and inability to assure personal safety. In this case, family members (if numbers were provided) or community crisis resources would have been notified as appropriate. In addition, if elder abuse (adults age 65 or older) is suspected (either the caregiver being abusive towards the care recipient, or the caregiver reporting being abused by another), it would have been reported to the appropriate county Adult Protective Services.

There were no anticipated negative physical, psychological, or social risks to participants; however, a plan was in place should distress or anxiety levels increase during interviews to the point of participant discomfort, the interview would have been terminated. Likewise, if participants reported significant distress during composition of poems, they would have been permitted to leave the study and referred for follow-up psychological assessment and counseling as needed. In addition, participants were informed that any indication of elder abuse or neglect suspected by the researcher would need to be reported.

Data Management and Preliminary Analysis

Data collection methods for this study consisted of completion of data collection forms, written scales/instruments, and semi structured interviews. These methods were selected over other methods because they provided the best fit and measurement of the research questions that guided the study. No studies have piloted this specific intervention, poetry writing, with this population, family caregivers of dementia patients.
Finally, positive psychological resources (self-transcendence, resilience) and negative psychological outcomes (depressive symptoms, subjective caregiver burden) have not been examined together with an intervention that may affect their relationships to each other. Data gathered from both quantitative and qualitative pieces of this mixed methods design may contribute to increased understanding and knowledge about this population. The qualitative data elicited from interviews and interpretation of poem theme content should also provide validation of the quantitative data in the study.

*Management and analysis of quantitative data*

Literature on expressive writing indicates that age may affect outcomes of the study variables (McKenzie et al., 2007); gender (female) may affect depressive symptoms (Lutzsky & Knight, 1994; Pruchno & Resch, 1989; Rose-Rego, Strauss, & Smyth, 1998) or subjective perception of caregiver burden (Yee & Schulz, 2000). As poetry is a related concept to expressive writing, a theory-based decision was made to examine and describe differences in results based on age and gender.

Research Questions 1-3 require analysis of changes in mean scores on the four major study variables, between and within groups. Question 1 proposed to answer “Are there differences on self-transcendence, resilience, depressive symptoms, and caregiver burden between family caregivers of older adults with dementia who write poetry (Group A) and family caregivers not writing poetry (Group B) from Time 1 (before poetry writing) to Time 2 (after four weeks of poetry writing)?” Research Question 2 asked “Are higher positive psychological resources (self-transcendence, resilience) associated with lower negative psychological outcomes (depressive symptoms, subjective caregiver burden) over time with continued poetry writing?” Research Question 3 asked “Will
there be improvements on psychological resources (self-transcendence and resilience) and on negative outcomes (depressive symptoms and caregiver burden) from before writing poetry to after four weeks of writing poetry (Group A Time 1 to Time 2 and Group B Time 2 to Time 3)?

Descriptive statistics (mean, median, standard deviation, skew, kurtosis, etc.) will first be reported on all study variables. Then, as sample size is too small for robust interpretation of t-tests of means, mean scores on the major study variables will be examined for changing trends between and within groups. Interview data about the experience of poetry writing will also be examined to answer Research Question 3. Common themes reported by participants will be examined in their context of caregiving along with individual demographic data. Research Question 4 will be analyzed through strictly qualitative methods, which will be discussed in the following section.

Research Question 5 “Will family caregivers (Group A) who participate in poetry writing continue to write poetry or verbalize intent to write poetry after they are no longer required to do so?” was answered through use of descriptive statistics. As only 10 participants in this pilot study had the opportunity to continue writing poetry after no longer being asked to do so (Group A), the percent of those who continue to write poems and the number and percent of those who verbalize an intent to write poems will be calculated. Specific demographic characteristics of those continuing to write poetry (i.e. age, gender, number of poems written during study period, etc.) will be reported as percentages and illustrated through histograms, tables and charts.

Research Question 6 “What is the feasibility of conducting a full clinical trial for the proposed study?” will also be answered through use of descriptive statistics. The five
questions in the interview guide that refer to practical protocol implementation measures (Attachment I) will be reported as overall percentages of participants selecting the designated responses.

**Management and analysis of qualitative data**

Qualitative data backs up quantitative data during design by assisting with concept development and instrumentation, during data collection by facilitating ease of the process, and during analysis by “validating, interpreting, clarifying, and illustrating quantitative findings, as well as through strengthening and revising theory” (Miles & Huberman, 1994, p. 41). Content and theme analysis was used to interpret qualitative data in this study (Research question 4). Content analysis may be viewed as a way of “dealing quantitatively with qualitative data” (Miles & Huberman, 1994, p. 49n). It is defined as “research techniques for making replicable and valid inferences from data to their context” (Krippendorff, 1980, p. 21). Existentialist Heidegger (1962) viewed hermeneutic interpretation as a unique way of recognizing meaning in all actions carried out on an everyday basis. This process is how people make sense out of their everyday world (Walters, 1995). This philosophy translates well to the inherent meaning embedded in caregiving activities. In this type of research, participants are asked to be involved in the interpretation phase, in order to allow emergence of new findings (Walters). In this study, participants were asked to give feedback on interpretation of their poems.

An inductive analytic process was used to analyze data collected from ten open ended in depth interviews with the family caregivers. Five interview participants were
randomly selected from each group. Qualitative data was used to demonstrate effectiveness of the protocol and the feasibility of a future expanded clinical trial.

A broad overview of qualitative analysis consists of three steps occurring concurrently with each other and with data collection. The three steps are data reduction, data display, and conclusion drawing or verification (Miles & Huberman, 1994). Data reduction is the process of “selecting, focusing, simplifying, abstracting, and transforming” data that appears (Miles & Huberman, 1994, p. 10). Early in the process, the researcher consciously or unconsciously selects a theoretical framework, research questions, and data collection approaches. Later, data reduction includes coding, identifying themes, clustering, and writing summaries). Data reduction is not strictly quantitative, but may include methods such as counting the number of times a word appears (as in content analysis of poems).

Data display presents an organized framework for making data readily accessible (i.e. matrices, charts, graphs, etc.). The researcher can then base his or her conclusions on visible display data and determine whether to move forward. Display design, such as deciding what rows and columns belong in a matrix, are important analytic tasks. Competent displays are systematic and iterative in nature (Miles & Huberman, 1994). The final step of the process, conclusion drawing or verification, begins during data collection, becoming increasingly grounded as the analysis process continues. Final conclusions may not be reached until the end of data collection; verification should be tested throughout by returning to notes, discussing data with colleagues or other readers, and finally, returning to participants for ultimate verification of findings (Miles &
Huberman, 1994). Testing findings with participants constitutes validity or “confirmability” of the study (Miles & Huberman, 1994, p. 11).

It is important when analyzing qualitative data to assure rigor. In a qualitative study, credibility, dependability, confirmability, and transferability should be assured by the researcher (Speziale & Carpenter, 2003). One means of ensuring credibility (analogous to validity in a quantitative study), or whether the research has credible findings, is to return to participants via telephone contact to confirm interpretation of data while analysis is ongoing (Jasper, 1994). Inter-rater reliability is another means of making sure interpretation is being consistently applied. Transferability (analogous to generalizability) of qualitative data in a phenomenological study differs from a quantitative study. Rather than using predictive theories, researchers view phenomenology as a way of generating theories that “provide descriptive data of a phenomenon which can be used to guide wider- and larger-scale studies from an informed starting point” (Jasper, 1994, p. 313).

In this study, creditability and confirmability of poem content analysis was assured by returning to select participants via telephone contact at the end of study. Miles and Huberman (1994) note that advantages of collecting feedback after final analysis include greater knowledge and awareness of lessons learned by the researcher, the ability to receive feedback at a “higher level of inference” (p. 242), and the ability to lay out findings in a more organized manner to the participants. Participants were asked to agree or disagree with study themes noted in their poem content by outside readers. The principal investigator and a second reader (a professional colleague of the primary investigator) assessed the content of poems and provided inter-rater reliability of
findings. Inter-rater reliability scores should correlate as .70 or higher (Krippendorf, 1980).

For the purposes of this pilot study, analysis of poem thematic content served as a triangulation process that was used to validate quantitative findings. For instance, collective poems written by caregivers may have demonstrated themes high in self-transcendence and resilience. This finding would then be compared to quantitative outcomes on relevant instruments. If scores on positive outcomes have increased or scores on negative outcomes decreased, this would be judged as additional evidence of the effectiveness of the intervention. A thematic analysis of interviews and poems was expected to provide a starting point from which to launch further studies about the utility of poetry writing as an intervention.

All data were coded to protect individual participant identity. A link to individually identifiable data or master list was provided for each participant. All data was password protected and were kept on discs (2 copies) and stored in locked file drawers in a private office. Codes were kept on a separate disc in a separate location away from other data. The codes disc were maintained only by the PI. Data and codes will be kept for a period of at least 10 years after research is completed. This time frame was noted in 31% of respondents in Thomas’s (1992) study of data storage amongst 153 researchers. The PI and other approved co-investigators only will have access to data and codes.
CHAPTER FOUR

Introduction

In this chapter, the study results will be presented. Findings will be discussed with a view to theoretical and practical applications. The chapter begins with a summary of demographic characteristics of study participants for both intervention groups. Following a more complete explication of demographics, results for each research question will be reported. This summary will include descriptive statistics for each question and variable, then the trends that were observed will be reported. The findings will also be discussed in relation to previous published research and theoretical models. Finally, relevance for nursing theory and practice will be discussed.

Results and Discussion

Demographic Characteristics of Participants

Twenty participants were interviewed and completed all study instruments and the poetry writing intervention. During the eight weeks of the study, there was no attrition; all participants who initially enrolled remained in the study for its duration. Of the total sample, 85% (n=17) were female, 15% (n=3) were male. Mean age was 60.2 years, with a range of 41-80 years of age. The majority (85%, n=17) were married. Highest level of education was high school for 40% of participants (n=8); however, 60% of the sample (n=12) had some college or a graduate degree. Race was predominantly Caucasian (95%), with only one participant being African American. The amount of time spent providing care each week ranged from 1 to 168 hours, with a mean of 88.9 hours and a standard deviation of 73 hours. The study sample matched several of the NAC/AARP
study (2004) demographics for highest caregiver emotional stress, in that the majority of participants were white females caring for dementia patients.

Four (20%) of participants were “very satisfied” with their caregiving role; two (10%) were “very dissatisfied”; two (10%) were “slightly dissatisfied”. The remainder of participants (n=12 or 60%) were “moderately satisfied” with their role as a caregiver. Additional demographic data analysis revealed that women caregivers scored more poorly than men caregivers on all study variables. As a group, they were lower in self-transcendence (49.7 compared to 53.4) and resilience (128 compared to 142.5), and higher in depressive symptoms (16.4 compared to 5.1) and burden (18.3 compared to 10.7). Older caregivers (over 60) scored higher than younger caregivers (under 60) on the study variables of self-transcendence with scores 52.8 compared to 48.5 and resilience with scores 136.1 compared to 126.3. Older caregivers also reported less depressive symptoms (10.3 compared to 17.8) and burden (14.4 compared to 18.9) than younger caregivers.

Analysis and Discussion of Scores on Instruments for Entire Sample (n=20)

A summary of the overall sample data has been provided in Table 1 below. Included is reporting of ranges, means, standard deviations, and skewness and kurtosis statistics for the four study outcomes at each data collection point (Times 1, 2, and 3). Cronbach’s alpha has also been reported for each scale used at each data collection point as an estimate of instrument reliability.
Table 1. Descriptive Statistics

<table>
<thead>
<tr>
<th>Descriptive Statistics N=20</th>
<th>Cronbach’s alpha</th>
<th>Range (minimum)</th>
<th>Range (maximum)</th>
<th>Mean (statistic)</th>
<th>Std. Dev.</th>
<th>Skewness</th>
<th>Kurtosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>STS 1</td>
<td>.80</td>
<td>42</td>
<td>59</td>
<td>51.6</td>
<td>4.717</td>
<td>-.597</td>
<td>-.096</td>
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<tr>
<td>STS 2</td>
<td>.86</td>
<td>39</td>
<td>59</td>
<td>50.1</td>
<td>5.776</td>
<td>-.529</td>
<td>-.125</td>
</tr>
<tr>
<td>STS 3</td>
<td>.86</td>
<td>38</td>
<td>57</td>
<td>50.4</td>
<td>5.335</td>
<td>-.867</td>
<td>.291</td>
</tr>
<tr>
<td>RS 1</td>
<td>.94</td>
<td>72</td>
<td>158</td>
<td>132.3</td>
<td>19.21</td>
<td>-1.978</td>
<td>4.881</td>
</tr>
<tr>
<td>RS 2</td>
<td>.95</td>
<td>67</td>
<td>155</td>
<td>128.8</td>
<td>20.13</td>
<td>-1.414</td>
<td>3.540</td>
</tr>
<tr>
<td>RS 3</td>
<td>.96</td>
<td>64</td>
<td>156</td>
<td>129.8</td>
<td>21.27</td>
<td>-1.619</td>
<td>3.756</td>
</tr>
<tr>
<td>CESD 2</td>
<td>.92</td>
<td>1</td>
<td>39</td>
<td>15.4</td>
<td>10.11</td>
<td>.630</td>
<td>.124</td>
</tr>
<tr>
<td>CESD 3</td>
<td>.90</td>
<td>1</td>
<td>40</td>
<td>13.95</td>
<td>9.338</td>
<td>1.256</td>
<td>2.288</td>
</tr>
<tr>
<td>ZBI 1</td>
<td>.85</td>
<td>5</td>
<td>32</td>
<td>16</td>
<td>8.54</td>
<td>.804</td>
<td>-.422</td>
</tr>
<tr>
<td>ZBI 2</td>
<td>.87</td>
<td>2</td>
<td>37</td>
<td>18.75</td>
<td>8.534</td>
<td>.015</td>
<td>.072</td>
</tr>
<tr>
<td>ZBI 3</td>
<td>.87</td>
<td>0</td>
<td>33</td>
<td>16.7</td>
<td>8.342</td>
<td>.076</td>
<td>-.393</td>
</tr>
</tbody>
</table>

In this small sample, scores were dispersed across a wide range for all instruments. Very low scores or very high scores had the potential to alter group results. As an example, scores on the Resilience Scale (possible 25-175) ranged from 67-158, while CES-D scores ranged from 1 to 40 (possible high score 60). Standard deviations were also large, indicating substantial dispersion of data.

The majority of scale scores demonstrated non-normal distributions. Self-transcendence and caregiver burden were the only study outcomes with normal distributions across all three data collection periods. Skewness statistics for self-transcendence, for example, indicated negative skew, indicating higher self-transcendence scores for the sample at each data collection point; however, skewness at Time 3 came close to exceeding parameters of -1 that would reflect a normal distribution. The mean on self-transcendence scores dropped from Time 1 to Time 3. Kurtosis, while
suggesting a normal distribution, went from positive in Times 1 and 2 to negative in Time 3, becoming more peaked with fewer outlier scores and a greater number of scores closer to the mean. Analysis of Resilience Scale and CES-D descriptive statistics showed non-normal distributions and large data dispersion, with the exception of CES-D Time 2 results, which suggested a more normal distribution (mean 15.4, standard deviation 10.117, skewness .630 and kurtosis .124).

The Cronbach’s alpha for all instruments used in this study were reliable. Reliability co-efficients ranged from .80 to .86 across three data collection points for the Self-transcendence Scale; .94 to .96 for the Resilience Scale; .90 to .92 for the CES-D; and .85 to .87 for the Zarit Burden Interview-Short Scale. All results exceeded the conventional minimum accepted level for Cronbach’s alpha of .70 and were at or above the desired level of .80 (Cronbach, 1951).

Research Question One Results

Research Question One asked whether there would be differences on self-transcendence, resilience, depressive symptoms, and caregiver burden between family caregivers of older adults with dementia who write poetry (Group A) and family caregivers not writing poetry (Group B) from Time 1 to Time 2? In other words, would those writing poetry for 4 weeks have higher or lower mean scores on instruments than waiting list controls at baseline? The expected result was that there would be differences between those who had written poetry for 4 weeks (Group A at Time 2) and those who had not written poetry (Group B at Time 2). Means of Group A at Time 2 were compared to means of Group B at Time 2 to answer this question. The graphs below
illustrate Group A and Group B mean scores on the four variables of the study (Figures 5-8).

Figure 5. Self-transcendence means

![Self-Transcendence graph]

Figure 6. Resilience means

![Resilience graph]
Figure 7. Depressive symptoms means

Figure 8. Caregiver burden means

Interpretation of Trends in Group Means

Group mean scores on the four variables from Groups A and B have been graphed above (Figures 5-8) so that differences at each data point (Times 1, 2, and 3) can more
readily be illustrated and interpreted. Baseline mean scores (Time 1) for Group A were lower than Group B for self-transcendence (51.2 compared to 52) and resilience (130.4 compared to 134.2), and lower for depressive symptoms (14.6 compared to 15.1) and caregiver burden (14.9 compared to 17.1). Self-transcendence means for Group A went down more than Group B at Time 2 (49.6 compared to 50.6). In a similar fashion, resilience mean scores for Group A started lower than Group B and remained lower at Time 2 (125 compared to 132.6). These results were the opposite of the anticipated outcome that the poetry writing group (A) would be higher in self-transcendence and resilience at Time 2 than Group B.

Comparison of depressive symptoms means revealed that Group A was less depressed at Time 1 than Group B (14.6 compared to 15.1), but scored higher on depressive symptoms at Time 2 (17.2 compared to 13.6). This finding was also the opposite of that expected (that poetry writing group at Time 2 would have lower depressive symptoms than non poetry writing group).

Finally, caregiver burden mean scores for Group A at Time 1 were lower than those of Group B (14.9 compared to 17.1). Both groups saw a rise in caregiver burden at Time 2, although Group A means were lower than Group B (17 compared to 20.5), in line with the desired outcome that the poetry writing group would have lower caregiver burden scores than the non poetry writing group at Time 2. Results from this variable alone of the four study variables showed improved mean scores for the poetry writing group. Possible explanations for these outcomes will be discussed after reviewing findings for Research Question Two.
Research Question Two Results

Research Question Two asked if higher positive psychological resources would be associated with lower negative psychological outcomes over time with continued poetry writing. The expected outcome was that self-transcendence and resilience scores would be higher at Time 2 and Time 3 in Group A, while depressive symptoms and burden scores would be lower. Analysis of trends from baseline to the end of the study was completed to address the question of whether change would be sustained over time with the poetry-writing intervention (from Time 1, baseline, to Time 3, end of study). Only data from Group A was analyzed to answer this question (Table 2).

Table 2. Group A Mean Scores

<table>
<thead>
<tr>
<th>Scale Mean Scores</th>
<th>Time 1</th>
<th>Time 2</th>
<th>Time 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-transcendence</td>
<td>51.2</td>
<td>49.6</td>
<td>48.9</td>
</tr>
<tr>
<td>Resilience</td>
<td>130.4</td>
<td>125</td>
<td>125.4</td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>14.6</td>
<td>17.2</td>
<td>15.2</td>
</tr>
<tr>
<td>Caregiver burden</td>
<td>14.9</td>
<td>15.1</td>
<td>15.5</td>
</tr>
</tbody>
</table>

One can see from the results that self-transcendence scores in Group A dropped across time (T1 to T3) from 51.2 to 48.9 instead of being higher as predicted. Similarly, resilience scores means dropped from 130.4 to 125.4. Depressive symptoms mean scores, expected to be lower, increased slightly from 14.6 to 15.2, although one may note that Time 2 scores were even higher (17.2) and dropped closer to baseline at Time 3.
Finally, burden scores, instead of being lower, increased as well (14.9 to 15.5). Therefore, actual results were diametrically opposed to anticipated results.

Discussion of Results Research Questions One and Two

Mean score results must be interpreted with caution, as sample size is small and mean differences are also small. It is interesting to note that any baseline differences that existed between Groups A and B remained at Time 3, the end of the study. For example, Group A started and finished lower on three of four study variables as opposed to Group B (depressive symptoms was an exception). While an immediate conclusion could be that the intervention had no effect on the study participants, this conclusion may be premature.

A possible explanation for the findings from Research Questions One and Two may be that the time of the intervention was too short to produce an effect. Although an effort was made to increase the length of the writing task over the majority of studies that have been done (4 weeks in the present study vs. 2 weeks for Mackenzie et al, 2007), four weeks may still not be a long enough duration. Research has demonstrated that the length of an intervention is important. In their metaanalysis of caregiver interventions, Sorenson, Pinquart, Habil, & Duberstein noted that duration was particularly important when attempting to address caregiver depression (2002). Also, measurement was conducted soon after conclusion of the writing task. For Group B participants, measurement of variables was conducted immediately after completion of poems; for Group A, the time elapsed was just 4 weeks. This may have been insufficient time for any effects of the poetry writing to emerge. Future longitudinal studies should incorporate a data collection plan with time points extending to 3 and 6 months.
It is instructive to note, however, that Group B participants, who had data collected immediately after writing poems (Time 3), had more improvement in group mean scores than Group A after writing poems (Time 2). In a sample of only 20, conclusions drawn require cautious interpretation since the changes observed may reflect baseline differences between the groups. An additional issue worth noting, however, was that Group A participants reported more depressive symptoms, greater burden, less resilience and lower self-transcendence at the end of the 8 weeks of the study compared to baseline. Although differences in scores were small, these changes could be of concern and may reflect an increased “awareness” of the caregiving situation—in short, reflecting more negative than positive changes. In the longer term, however, study participants might find poetry writing helpful in reducing burden and depressive symptoms as they continue to express emotions through this method. In fact, mean scores for depressive symptoms across both group dropped (14.85 to 13.95), so the intervention may have had some positive impact.

Another possible explanation for unexpected results could be that the intervention itself caused initial stress and anxiety before the study participants became familiar with poetry writing. However, this conclusion was not supported by interview data, as the study participants primarily spoke enthusiastically about the intervention and the positive “challenge” of writing the poems. However, more frequent monitoring and support during implementation of the intervention itself might be helpful as a solution; in addition, more frequent monitoring and provision of psychological support might need to be included in the study protocol to offset any negative effects. One Group A participant expressed suicidal thoughts and had a high CES-D score (39); however, she denied
suicidal ideation. Per study protocol, this participant was referred to community resources available for psychological support and counseling. As the study progressed, the participant verbalized improvement related to the poetry writing experience, although her CES-D score did not improve.

Another likely explanation is the presence of confounding variables such as changes in health status of care recipient or caregiver, or other personal stressors. Such extrinsic factors were assessed in interview by asking about other events taking place during the study that may have impacted caregivers’ feelings about self, caregiving, or loved one (Appendix H) and will be discussed elsewhere in this paper.

Scores of the study participants who wrote additional poems between Time 2 and Time 3 were also analyzed at Time 3. Six of 10 participants in Group A wrote one or more additional poems (n=7 poems) when not required to do so. Of those who wrote additional poems, three participants (50%) had higher or unchanged resilience compared to baseline; one (10%) had higher self-transcendence; four (66.6%) had lower depressive symptoms; and three (50%) had lower or unchanged burden. These findings are meaningful when compared to overall Group A Time 3 results. Interpreted in this way, 50% of those who wrote additional poems had higher resilience compared to 20% of those who did not write additional poems. While self-transcendence was generally lower (higher in only 16.6% of those who wrote additional poems compared to 30% of total Group A) and depressive symptoms scores were the same (50% for both groups), burden scores were lower in 50% of those who wrote additional poems as compared to only 30% of those in Group A who did not. Thus, one might conclude that writing additional poems was helpful in promoting positive psychological outcomes and decreasing
negative psychological outcomes in these participants. A larger effect of the intervention might be observed in future studies that use a larger sample and a protocol that requires writing additional poems.

Although Time 3 findings from Group B (control group) were of less interest than those from Group A, data trends were also examined to note whether variables scores on the study measures were in a positive direction or a negative direction. In Group B participants, there was a change in direction between Time 2 (waiting period) and Time 3 eleven of 40 times (27.5%). For example, two participants had lower resilience at Time 3 than Time 1 (baseline), but higher resilience than at Time 2. As Group B participants were not participating in the intervention until after Time 2, lower scores for positive psychological resource variables at Time 2 could be due to chance or other life events (i.e. worsening of mental or physical health of care recipient, personal health problems, etc.); higher scores may have occurred due to the Hawthorne effect or greater self-awareness through perusal of study measures. One participant became more self-aware of her level of depression after responding to the questionnaire Time 1, and informed the PI that she had taken action (i.e. counseling, self-care strategies) to cope with her depressive symptoms between Time 1 and Time 2 (Field notes, 5/09); consequently, her CES-D score Time 2 was substantially lower than Time 1 (11 compared to 35).

Of the Group B participants, 63.6% reported outcomes that moved in the direction expected (higher resilience and self-transcendence, lower depressive symptoms and caregiver burden) at Time 2 before beginning the poetry writing intervention. This effect appeared to be sustained at Time 3, as between 50 and 80% of scores reported by all of Group B participants were in the hypothesized direction. This effect could be interpreted
as being independent of poetry writing. In two instances, resilience and caregiver burden scores were higher and in two instances scores were lower between Times 2 and 3. However, in the case of self-transcendence, Time 2 scores were lower in two instances and went back up at Time 3; similarly, depressive symptom scores at Time 3 were twice higher than baseline, but lower than Time 2. Therefore, the poetry writing intervention for those who received it after Time 2 appeared to have had a neutral to positive effect on the study outcomes at Time 3.

Although examination of group means failed to note differences, individual scores of some participants showed significant change throughout the duration of the study. Participant #4, for example, showed significant movement in a positive direction on resilience (increase of 17 from 137 to 154), depressive symptoms (decrease of 8 from 9 to 1), and burden (decrease of 5 from 5 to 0). Her interview data also supported these changes, as she noted how much she liked and enjoyed writing poetry, how it gave her a sense of accomplishment and helped her think about and appreciate things around her. She also acknowledged feeling less burdened about her family member at Time 3. Other participants showed significant change as well. Participant #18 scored 35 on the CES-D Time 1, but merely 12 Time 3. This participant stated in interview that the instrument made her pay attention to her level of depression, and address it, which she did during the course of the study. Participant #20 scored 33 on the CES-D Time 2. After writing poetry, which she described in interview as being an excellent release for her emotions, her Time 3 CES-D score was 8.

Other researchers have obtained similar results when comparing group and individual means. In a study of dementia caregiver stress appraisals over 3 months,
group means were found to be stable over the time period. Change was noted at the intra-individual level, however, when some stress appraisals reflected significant intra-individual variability. One of the authors’ conclusions was that 3 months was too short a time period to delineate rate of change (Fauth, Zarit, Femia, Hofer, & Stephens, 2006). Likewise, in the present study, although causal inferences cannot be drawn for all these participants, aggregate scores may not adequately reflect the impact of the intervention upon individuals. For this reason, individual quantitative data will be displayed and qualitative data will be discussed more fully in another section of this paper.

Research Question Three Results

Research Question Three asked if there would be improvements on psychological resources (self-transcendence and resilience) and negative outcomes (depressive symptoms and caregiver burden) in Group A from Time 1 to Time 2 as compared to Group B from Time 2 to Time 3. Difference pre- and post-intervention could represent an effect of poetry writing on participant outcomes. The expected outcome was that Group A would have higher self-transcendence and resilience scores and lower depressive symptoms and burden scores at Time 2 than Time 1, while Group B would have higher self-transcendence and resilience scores and lower depressive symptoms and burden scores at Time 3 than Time 2 (pre- and post-intervention in both groups).

In line with the mixed methods design of the study, Research Question 3 was also evaluated through qualitative methods. Subjective perception of benefit of the intervention might be demonstrated but not fully captured by quantitative analysis. Thus, participant interview data about the experience of poetry writing was reviewed for themes; common themes were also tracked by individual participant within his or her
personal caregiving context (i.e. hours spend providing care, type of care provided, living
with care recipient or not, etc.).

*Interpretation and Comparison of Group Means*

In Table 3, visual inspection reveals that Group A mean scores did not move in the direction anticipated. Self-transcendence and resilience scores were lower at Time 2 (after poetry writing), while depressive symptoms and burden scores were higher at Time 2. This was the opposite result of that predicted.

<table>
<thead>
<tr>
<th>Table 3. Group A vs. Group B Mean Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>Mean Scores</td>
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<tr>
<td>----------------------------------------</td>
</tr>
<tr>
<td>Time 1</td>
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<td>Time 2</td>
</tr>
<tr>
<td>Time 2</td>
</tr>
<tr>
<td>Time 3</td>
</tr>
<tr>
<td>Self-transcendence</td>
</tr>
<tr>
<td>Resilience</td>
</tr>
<tr>
<td>Depressive symptoms</td>
</tr>
<tr>
<td>Caregiver burden</td>
</tr>
</tbody>
</table>

*Discussion of Research Question Three Results*

It is possible that Group A participants experienced a temporary decrease in scores due to increased “awareness” of the caregiving situation, or that changes in health status in themselves or in the family member they were caring for occurred between the first and second data collection point. One participant developed a significant personal health problem that she stated affected her mood and this appeared to make a notable difference in the scores on the study measures ratings at the Time 2 interview. As previously noted in discussion of Research Questions 1 and 2, more time may be needed
in order to observe a significant effect of the intervention. Perhaps the intervention effect would be more apparent if measured at 2, 3 or more months post-intervention. It would also be useful to ask participants if they were still writing poems as long as 6 months after the conclusion of the study.

In Group B, however, all mean scores on the study measures changed in the predicted direction. While the changes were small, self-transcendence and resilience mean scores were higher at Time 3 (after poetry writing) than Time 2, and depressive symptoms and burden scores were lower. While this may have represented some effect of the intervention on this group and may be considered support for its effectiveness, it is interesting to note that Group B self-transcendence score means were higher at Time 1 than Time 3, and burden scores were slightly lower at Time 1 than Time 3. An effect could not be detected since the post-intervention scores were less favorable than the baseline scores on the four study outcomes. In addition, the mean scores on all study variables except burden became worse at Time 2 in this group before improving at Time 3. As intervention did not occur before Time 2 in this waiting list group, worse mean scores could reflect no intervention or regression to the mean. However, scores at Time 3 did show improvement from Time 2 and may have reflected an effect of the intervention.

A plausible explanation for the differences between groups may be that the wait period (4 weeks) required for Group B participants made them more eager to begin the poetry writing intervention and influenced instrument ratings at Time 3. For example, one group B participant thanked the researcher for “making me do this” and simultaneously chastised her for “making me wait four weeks to get started.” This participant demonstrated markedly lower self-transcendence (-8) and resilience scores (-
14) and higher depressive symptoms (+15) and burden scores (+7) than baseline at Time 2, with substantial improvement in all outcomes Time 3 (STS +11; RS +23; CES-D -25; ZBI -4). It was as though waiting to write poetry was a very negative experience for this participant, and the experience of writing poems provided a huge release.

Although the data displayed above demonstrated mixed results that were sometimes opposite of what hoped for and expected, interpretation of group means may be misleading. In a small sample (n=10), large or even small variations in scores can alter group means. Therefore, it was more informative to examine trends on individual scores for the participants in Group A and Group B and compare outcomes that also consider demographic variables such as age, gender, and race (Appendix Q).

**Interpretation and Discussion of Trends Post-Intervention**

Scores on the measures of the four study outcomes did vary by group, age, and gender. Following the intervention (Time 2 for Group A and Time 3 for Group B), the total results expressed as percentages were: higher resilience in 45% of participants; higher self-transcendence in 30% of participants; lower depressive symptoms in 40% of participants; and lower burden in 55% of participants. In addition, 25% stayed the same on self-transcendence, 5% on depressive symptoms, and 5% on burden. Intuitively then, these results indicate that a high or larger percentage of participants moved in the direction not desired than in the direction desired (or the opposite of the anticipated direction in which variable scores would move). In other words, following the intervention, 55% of participants scored lower resilience, 45% lower self-transcendence, 55% higher depressive symptoms, and 40% greater burden.
Examination of results by group indicated that Group B participants displayed more movement in the expected direction than did Group A participants. Group B participants had a 4-week waiting period before beginning the intervention. While resilience was higher in 60% of Group B participants immediately post-intervention, it was higher in only 30% of Group A participants. Similarly, self-transcendence was higher or remained the same in 70% of Group B participants compared to 40% of Group A participants. Depressive symptoms scores for Group B also moved more in the direction anticipated than Group A (50% were lower, while 40% of Group A scores were lower or stayed the same); finally, burden scores for Group B were lower in 80% of participants compared with only 40% of Group A participants that were lower or unchanged.

There are several explanations for the trend of greater movement in the desired direction in Group B than Group A. One explanation is that Group B participants had a waiting period; thus, by the time they wrote poetry, they had been in the study for 8 weeks compared to only 4 weeks for Group A participants. This waiting period may have allowed for additional contemplation or mental preparation, perhaps making some participants more eager to begin the intervention. One Group B participant noted at Time 2 interview that she was more than ready to begin and accused the PI of being “cruel” because “you made me wait to start writing poems!” (Field notes, 5/09).

Another explanation for the difference in outcomes may be that Group B had more male participants (30% of total sample) as well as more older adult (over 60) participants (50% of total sample). In general, scores of males and older adults trended
more in the expected direction in this study. The impact of gender and age is discussed in the section below.

Interpretation of Mean Trends Based on Gender, Age, and Race

Findings on all the study variables for the men were consistent with published research in which a propensity for female caregivers to experience more depression and burden than male caregivers (Rose-Rego, Strauss & Smyth, 1998; Gallachio, Siddiqi, Langenberg, & Baumgarten, 2005; Campbell et al., 2008). In this study, men were found to be more resilient (142.5 compared to 128), more self-transcendent (53.4 compared to 49.7), have fewer depressive symptoms (5.1 compared to 16.4), and perceived less caregiver burden (10.7 compared to 18.3) than the women. However, these results must be interpreted with caution, as only 15% of the total caregiver sample (n=3) were male.

When examining the effect of age on means, those over age 60 (n=8) were more resilient (136.1 compared to 126.3), more self-transcendent (52.8 compared to 48.5), had fewer depressive symptoms (10.3 compared to 17.8), and perceived less caregiver burden (14.4 compared to 18.9) than caregivers under age 60. Previous researchers have noted increased self-transcendence in older adults (Young & Reed, 1998; Stinson & Kirk, 2006). It is not disingenuous to suspect that middle aged adults may experience more burden as a function of multiple life roles (i.e. still caring for children, working, etc.) than older adults.

Differences by race cannot be determined for this study, as 19 of 20 caregivers were white, with only one African American caregiver. This caregiver’s baseline scores were high in self-transcendence and resilience and low in depressive symptoms and caregiver burden. This finding of fewer depressive symptoms and caregiver burden for
African Americans compared to Caucasian caregivers has been supported by previous research (Janevic & Connell, 2001), although other studies have suggested that African American caregivers may experience similar caregiver burden, but express it differently (Hale et al., 2004).

**Interpretation of Qualitative Data from Interviews**

Qualitative data may also be interpreted to answer Research Question 3. Post-intervention interviews revealed that participants perceived benefit from writing poetry. Table 4 displays dominant themes that emerged from interviews juxtaposed with participant characteristics such as gender, amount of time spent giving care and type of care required by care recipient.

*Table 4 Themes from Interviews and Characteristics of Participants Suscribing to Themes*

<table>
<thead>
<tr>
<th>Theme</th>
<th>Frequency ((n &amp; % participants reporting))</th>
<th>Key Words</th>
<th>Exemplars of Participants Suscribing to Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Achievement</td>
<td>12 (60%)</td>
<td>“I did it” (wrote poems)…”proud of self” (for writing poems)</td>
<td>70 yr. old female spouse caregiver concerned about ability to write poems due to lack of education (↑ST; ↓ depression)</td>
</tr>
<tr>
<td>Catharsis</td>
<td>11 (55%)</td>
<td>“relieve”…”cleanse”…”helped get stress out”…”purges”…”get your feelings out”…”venting”</td>
<td>56 yr old female child caregiver sl. dissatisfied with caregiving—plans to write poems with</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
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<tr>
<td>---------------------</td>
<td>--------</td>
<td>-----------------------------------------------------------------</td>
<td>-----------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Increased acceptance</strong></td>
<td>5 (25%)</td>
<td>“accept”…“acceptance”…“clarify things”…“things are just what they are”</td>
<td>59 yr old female spouse caregiver with profoundly demented husband who verbalized great relief from poetry writing (↑ ST &amp; resilience; ↓ depression)</td>
</tr>
<tr>
<td><strong>Greater empathy</strong></td>
<td>7 (35%)</td>
<td>“more sympathetic”… “more thoughtful of others”… “empathy (for care recipient)”</td>
<td>58 yr old female child caregiver with parent in facility initially hesitant to write poems (↑ ST &amp; resilience; ↓ depression &amp; burden)</td>
</tr>
<tr>
<td><strong>Reflection</strong></td>
<td>7 (35%)</td>
<td>“reflect”…“reflection”…“time to sit and think it through”… “it made you think”</td>
<td>53 yr old female spouse caregiver who reframed poems in a positive way (↑ ST &amp; resilience; ↓ depressive symptoms &amp; burden)</td>
</tr>
<tr>
<td><strong>Greater self-awareness</strong></td>
<td>10 (50%)</td>
<td>“learning a little about me”… “label own feelings”… “more tuned in”… “get in touch with (feelings)”</td>
<td>53 yr old female child caregiver who “felt better” after writing poems &amp; said it increased</td>
</tr>
</tbody>
</table>
Further discussion of themes identified follows discussion of Research Question 6 later in this chapter.

Analysis of participant characteristics related to the caregiving context was also performed to identify any patterns for those scoring high or low on outcome variables (Table 5).

Table 5. Participant Characteristics/Caregiving Context and High and Low Scores

<table>
<thead>
<tr>
<th>Gender</th>
<th>Age</th>
<th>Living with care recipient</th>
<th># hrs. care</th>
<th># years care</th>
<th>Type care (lower LB Score needs more)</th>
<th>Caregiver Satis.</th>
<th>High or low scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Age</td>
<td>Caregiving</td>
<td>IADLs &amp; ADLs</td>
<td>LB Score</td>
<td>ADLs &amp; IADLs Status</td>
<td>Mental Health</td>
<td>Burden &amp; Depression</td>
</tr>
<tr>
<td>--------</td>
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<td>---------------</td>
<td>---------</td>
<td>---------------------</td>
<td>---------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>Female</td>
<td>58</td>
<td>No</td>
<td>1+</td>
<td>3</td>
<td>IADLS &amp; toileting (LB Score 3)</td>
<td>Very dissatis</td>
<td>High depression; high burden; low ST; low resilience</td>
</tr>
<tr>
<td>Female</td>
<td>66</td>
<td>Yes</td>
<td>168</td>
<td>5</td>
<td>ADLs and IADLs (LB Score 1)</td>
<td>Mod. Satis.</td>
<td>High ST; low depression; low-normal burden</td>
</tr>
<tr>
<td>Female</td>
<td>54</td>
<td>No</td>
<td>1+</td>
<td>2.5-3</td>
<td>ADLs &amp; IADLs (LB Score 1)</td>
<td>Mod. Satis.</td>
<td>High ST; high resilience; low depression; low burden</td>
</tr>
<tr>
<td>Male</td>
<td>75</td>
<td>Yes</td>
<td>168</td>
<td>4</td>
<td>ADLs &amp; IADLs (LB Score 1)</td>
<td>Very Satis.</td>
<td>Low depression; low-normal burden</td>
</tr>
<tr>
<td>Female</td>
<td>80</td>
<td>Yes</td>
<td>112 (sleep)</td>
<td>4</td>
<td>IADLs (LB Score 1)</td>
<td>Very Satis.</td>
<td>High ST; high resilience; low-normal burden</td>
</tr>
<tr>
<td>Male</td>
<td>69</td>
<td>No</td>
<td>4</td>
<td>5</td>
<td>ADLs &amp; IADLs (LB Score 0)</td>
<td>Very Satis.</td>
<td>High ST; high resilience; low-normal burden</td>
</tr>
<tr>
<td>Female</td>
<td>58</td>
<td>No</td>
<td>14</td>
<td>8</td>
<td>ADLs &amp; IADLs (LB Score 2)</td>
<td>Very Dissatis.</td>
<td>High ST; high resilience; high burden &amp; depression</td>
</tr>
<tr>
<td>Gender</td>
<td>Age</td>
<td>Caregiver</td>
<td>ADLs</td>
<td>IADLs</td>
<td>ADLs &amp; IADLs (LB Score)</td>
<td>ADLs &amp; IADLs (LB Score) (T2 only)</td>
<td></td>
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<tr>
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<td></td>
</tr>
<tr>
<td>Female</td>
<td>47</td>
<td>No</td>
<td>2</td>
<td>1</td>
<td>Mod. satis.</td>
<td>Low ST; low resilience; high depression; high burden (T2 only)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>70</td>
<td>Yes</td>
<td>144</td>
<td>6</td>
<td>Mod. Satis.</td>
<td>High ST; high burden (T2 only)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>59</td>
<td>Yes</td>
<td>168</td>
<td>4</td>
<td>Mod. Satis.</td>
<td>High depression; high burden</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>64</td>
<td>Yes</td>
<td>168</td>
<td>5</td>
<td>Mod. Satis.</td>
<td>High resilience; low depression; low-normal burden</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>53</td>
<td>Yes</td>
<td>80</td>
<td>3</td>
<td>Mod. Satis.</td>
<td>High ST; high resilience; high depression (T1 only); high burden</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>54</td>
<td>Yes</td>
<td>168</td>
<td>3.5-4</td>
<td>Very satis.</td>
<td>High ST; low depression (T1 &amp; T2); low-normal burden</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>56</td>
<td>Yes</td>
<td>128</td>
<td>2</td>
<td>Slightly dissatis.</td>
<td>High depression (T1 &amp; T2); high burden</td>
<td></td>
</tr>
</tbody>
</table>
The 14 participants listed above demonstrated the highest and lowest scores on the outcome variables. It was difficult to identify consistent patterns that could be attributed to caregiver characteristics. Isolating the characteristic “living with care recipient” is an example.

Those scoring highest on self-transcendence lived with the care recipient 2/3 of the time; those scoring lowest on self-transcendence lived with the care recipient 1/3 of the time. While 50% of those scoring highest on resilience lived with the care recipient, none of those scoring lowest in resilience did. To complicate matters, however, while 75% (3 of 4) of participants having the highest depression scores lived with care recipients, 80% (5 of 6) of those having lowest depression scores lived with care recipients. Similarly, three-fourths of those with highest burden lived with the care recipient, while three-fourths of those with lowest burden also lived with the care recipient.

One pattern that could be identified is that all those scoring lowest on self-transcendence and resilience were middle-aged (under 60). These scores fit with previous research noting lower scores on these outcomes in this age group. Half of those scoring lowest on depression were male, and it is important to note that there were only 3 males in the study; thus, two of the three males had notably low depression scores. This was also supported by the literature. Another consistent pattern identified was that of relationships between outcomes. High self-transcendence and resilience were directly related in participants, as was high depression and burden. Likewise, low scores on self-transcendence and resilience were directly related, as was low depression and burden. In
only one instance, that of a middle-aged caregiver living with her care recipient, were high resilience and depressive symptoms inversely related. This relationship has been previously noted in the literature (Tusaie & Dyer, 2004).

Number of years of care or type of care required didn’t seem to significantly impact scores; however, caregiver satisfaction seemed to be associated with scores on instruments. Those who were very satisfied trended towards higher scores on positive resources such as self-transcendence and resilience or lower scores on depressive symptoms and burden, while those who were very or slightly dissatisfied had more negative outcomes.

Research Question Four Results

Research Question Four asked what common themes would be identified in the poetry of family caregivers of older adults with dementia, with its hypothesis postulating that common themes would indeed be identified. Seventy-nine poems were written by twenty family caregivers during the study. Although the study protocol was open-ended and did not mandate that caregivers write about their family member (care recipient) or their caregiving situation, 53 or 67% of all poems written were about the care recipient or the life situation/caregiving situation of the caregiver. Other poems were about nature or retrospectives on life and time passages.

Two readers independently reviewed Poems 1 and 3 of all twenty participants (n=40), particularly noting whether themes of self-transcendence, resilience, depressive symptoms, or caregiver burden (also measured as variables in this study) were present in their content. Readers used the definitions of the study variables to assist them in identifying themes in the poems (see Chapter Two). In cases where more than three
poems were written, the last poem written was analyzed for content. The rationale for selecting these poems was that it was believed that the first poem written would likely be cathartic or reflective of the emotions and themes most needing to be expressed by the caregiver; in a sense, being the most “genuine” voice. The third or last poem would show maturity or growth by the poet in the poetry writing experience. As caregivers became more comfortable in expressing themselves through the format of poetry, they would possibly feel more free to expand their reflections and experiment.

Reader 1 noted 66 times in which the four study variables were reflected as themes in participant poetry; Reader 2 noted 58 times. Two iterations were conducted, with readers meeting to discuss their rationale for selecting themes. Percent agreement on themes between the two readers was 80.4% (41/51) in the first iteration and 89.66% (52/58) in the second iteration. Almost 90% inter-rater reliability is considered a high level of agreement (Krippendorff, 1980), lending support for validity of the study variables. Other themes of note included grief, loss, and bereavement; however, one could reasonably bracket these emotional responses under the broader category of depressive symptoms, one of the major study outcomes.

Discussion of Research Question Four Results

Self-transcendence

Self-transcendence was the theme that appeared most frequently in caregiver poems, or was most often identified by both readers. It was identified a total of 36 times by the readers or in 20/40 poems (50%). Self-transcendence was defined as “the ability to rise above or go beyond oneself toward others in a caring relationship or toward the advancement of social causes” (Das, 1998, p. 7)
and the expansion of self boundaries inward, outward, temporally, or transpersonally (Coward, 2006). Self-transcendence was agreed upon as a theme by both readers sixteen times (30.1% of all reader agreement). Self-transcendence was noted as a theme by both readers when poems focused on spiritual matters, demonstrating overcoming hardship with assistance of a higher power, through nature, or by expanding boundaries to include friends, family, and others into a helping circle. Participants may also have written their gratitude for the blessings they perceived in their lives. Word choices included “God,” “peace,” “beauty,” and “privileged.”

One spouse caregiver entitled her poem “God’s Care” and wrote about her personal awareness of the presence of a higher power:

…each day when I wake, I know that you care,
   I talk to you and have no doubts that you’re there
…Your sovereignty and love is what keeps me afloat,
   Without you I’d feel more pain, like being lost in a boat.
…You’ve been my guide through all of my years,
   You’ve held me and loved me through laughter and tears...

Another spouse caregiver expressed his love and gratitude towards nature:

…I watch two deer frolic near the far side of the lake,
   How privileged am I to view such graceful creatures.
   A black squirrel scolds from a nearby oak
   I wonder what has upset it so?
   Perhaps a fox, a cat, a snake, or a hawk,
   How privileged am I to hear such wonders…

A third participant also wrote about nature and suggested one should:

…Leave your troubles at home and really open your eyes
   to the things God has provided
…The peace of God’s work just entralls you…

Another participant expressed her life philosophy and faith through her
poem “Creator:”

…To love and not to hate
To give and not to receive
To live life in its fulness
To have gratitude for all things
To humbly go in submission relying totally on your will
To understand that letting go of myself
Gives you complete control…

Resilience

Resilience was the second most frequently noted theme. Resilience was identified 34 times or in 19/40 poems (47.5%); both readers concurred in its identification fifteen times (28.8% of agreement). Resilience was defined previously as a complex interaction between personality characteristics of an individual and his or her larger environment influencing the individual’s recovery from a traumatic or stressful event (McCubbin & McCubbin, 1996). Characteristics of resilience considered by the readers included: strong self-esteem; independence of thought and action but ability to rely on others when needed; give and take in interactions and a well-established personal social network; well-developed personal discipline and responsibility; ability to recognize and develop personal talents; open-minded reception of new ideas; willing to dream; diverse interests; sharp sense of humor; insight into the feelings of self and others, as well as the ability to communicate these insights; significant tolerance of discomfort or distress; focus; commitment; and a philosophy of life that enables interpretation of life experiences as hopeful and meaningful (Flach, 1988).

Along with self-transcendence, resilience was considered a positive psychological resource, so one could conclude that caregivers in this study either possessed positive psychological resources to a higher degree or chose to reflect their striving for such
resources in their poetry. The poem below was judged by the readers as reflective of the theme of resilience:

…Bright sun, warm days
  Hearts swell sending glad rays
  Hope and cheer
  Courage without care
  Knowing deep inside
  Love resides there.

This spouse caregiver stated in interview that she wrote a poem to deliberately try to elevate her mood. Resilient persons use personal characteristics and their environment to make meaning from experience and move toward recovery in a goal-directed manner (Flach, 1988; McCubbin & McCubbin, 1996). The last poem written by one participant demonstrated resilience in its repetition of the words “I want.” This assertive stance taken by the poet reflected positive change and growth from previous poems in which she questioned why she was treated badly by her loved one and grieved traumatic childhood memories.

One participant wrote of her determination to persevere despite obstacles:

…Rivers you can’t cross
  Mountains you can’t climb
  Just keep trying your best
  God will take care of the rest.

A third caregiver found herself stressed by an aging parent and growing teenagers. She wrote hopefully about surviving beyond current parenting stress:

…We were their heroes, their everything.
  How does that change, so subtly?
  Will it reverse somewhat
  And make us feel needed again?

  Appreciation will hopefully come one day.
  For now, we need to try our best
and enjoy the moments. 
There will be a time to look back and take it all in.

This poem reflected resilience in that efforts were made by the participant to make meaning out of stressful life experiences and to rise above current adverse circumstances, hoping for a better future.

*Depressive symptoms*

Depressive symptoms were identified a total of 26 times or in 16/40 poems (40%); the theme was noted by both readers 10 times (or 19.2% of total theme agreement). Depressive symptoms were identified according to the definition of the American Psychological Association, DSM-IV-TR (2000). Depressive symptoms was identified as a theme when word choice was associated with feelings of sadness, hopelessness and helplessness, and guilt, as well as other negative emotions. Two participants shared the desire to “escape” or “run away.” As one participant wrote:

> …Run away, run away where?  
> Run anywhere away from here.  
> Can’t move, heavy, stuck like glue…

Grieving the loss of relationship was a major component of poetry written by some spouse caregivers:

> …Fifty years of wedded bliss  
> Who knew it would come to this?  
> For better or worse the vows were said  
> We’ve had the better and now the worse  
> We mourn  
> We cry  
> We question  
> Why us?  
> Why not us?

An adult child caregiver caring for her mother mixed self-pity with anger in her first poem:
...It’s hard Sometimes
   Not to whine
   Not to think how hard I’ve got it
   No partner
   No help
   No one to love me…

...I just want to whine
   To cry
   To shout to the Stars
   I am SOMEONE
   God damn it!

*Caregiver burden*

Caregiver burden was identified as a theme 28 times or in 15/40 poems (42.5%). Both readers concurred that content reflected caregiver burden eleven times (21.2% of agreement). Subjective burden was previously defined in this study as the caregiver’s personal appraisal of stress, anxiety, or other negative feelings related to the caregiving situation (Faison, Faria, & Frank, 1999); thus, burden was deemed to be present in poetry when stress, anxiety and other negative emotions related to the caregiving situation were reflected. The last poem cited as an example of depressive symptoms also reflected subjective caregiver burden. This is an example of the co-existence of themes depressive symptoms and burden, as discussed previously in this paper and consistent with the published research using the themes as outcome variables.

Caregivers struggled with managing symptoms of dementia:

   ...I don’t know what you remember
   I’m afraid to say Dad, remember this?

   ...It hurts when I know you did but you say you don’t recall.
   ...I hate difficult conversation.
They yearned for the person they once knew and tried to understand the one they now care for:

…The blank looks, the sadness in her eyes  
   We reflect on how she must feel  
…This disease has made her another person we do not know  
…It is hard to see her when she is feeling so low  
   This is a terrible disease that attacks the ones we love  
   There seems to be no cure in sight  
…Please bring back my Mom and make her right.

Another finding was the co-existence of resilience and depression; self-transcendence and burden. All themes were identified by both readers in at least 40 percent of poems, with positive themes of self-transcendence and resilience being identified more frequently. The co-existence of resilience and depression has been noted by researchers Tusaie and Dyer (2004). Similarly, positive psychological resources or personality traits such as self-transcendence can exist along with negative outcomes, such as burden. One participant’s poem provided an example of the co-existence of burden and self-transcendence:

…Alone—so alone  
   As I sob in despair  
   Wait-no-not alone  
   God is always with me  
    Holding me.  
   No longer alone.

Caregiver burden was rarely the sole theme in a poem. When burden could be identified in a poem, the participant often reframed his or her emotions in a more positive way as the poem progressed. For instance, one spouse caregiver whose husband was experiencing cognitive decline began her poem weighed down by burden, but acknowledged the ability to rise above her circumstances and joyfully shoulder her burden, demonstrating simultaneous burden and resilience:
…Run away, far away from here
   Nothing will move, stuck like glue
Float, float away from here
   Free, Free and happy always to
   Stay right here.

Feedback about poem content and themes was requested from 10 participants
(five from Group A, five from Group B) chosen randomly by drawing paper slips with all
participant ID numbers written on them. This step was important to validate
“confirmability” of findings (Miles & Huberman, 1994). Participants were mailed copies
of their poems in advance of a telephone call from the principal investigator. During the
phone call, they were asked if they agreed or disagreed with the poem themes identified
by the two readers and if they would suggest any additional themes. All participants
(n=10, 100% agreement) agreed with the themes identified by the readers. One
participant in Group A agreed with the theme of depressive symptoms, but stated she
would also use themes of “frustration,” “irritation,” and “cheated.” A Group B
participant thought depressive symptoms should have been identified as an additional
theme in one of his poems (in which self-transcendence and resilience had been noted); a
third participant wasn’t sure she agreed with the words “self-transcendence” but verified
that the meaning was correct as interpreted by the readers. In summary, the study
participants verified the themes identified by the two readers.

In addition, the poem content findings were verified by comparing themes
identified with quantitative scores on measures of the four study outcomes. Scores of 14
of 22 total themes (or 63.6%) reflected high levels of the variable (i.e. scores of 59 and
59 for Participant 8 reflected high self-transcendence) as identified by the readers. Table
5 illustrates results of the ten randomly selected participants, themes identified in their
poems, and pre- and post-intervention scores of study variables (at Times 1 and 2 for Group A, at Times 2 and 3 for Group B). The asterisk indicates high scores of the variable validating interpretation of the readers.

Table 6. Validating Themes and Scores of Randomly Selected Participants

<table>
<thead>
<tr>
<th>Participant ID #</th>
<th>Group</th>
<th>Themes Identified</th>
<th>Scores T1 &amp; T2</th>
<th>Score T2 &amp; T3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>A</td>
<td>Resilience; Depressive symptoms; Burden</td>
<td>72 &amp; 67</td>
<td>39 &amp; 39*</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>39 &amp; 39*</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>A</td>
<td>Burden</td>
<td>14 &amp; 17</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>A</td>
<td>Self-transcendence; Resilience</td>
<td>59 &amp; 59*</td>
<td>140 &amp; 152*</td>
</tr>
<tr>
<td>12</td>
<td>A</td>
<td>Resilience; Burden</td>
<td>158 &amp; 148*</td>
<td>12 &amp; 14</td>
</tr>
<tr>
<td>16</td>
<td>A</td>
<td>Self-transcendence; Resilience; Burden</td>
<td>48 &amp; 47*</td>
<td>134 &amp; 112</td>
</tr>
<tr>
<td>9</td>
<td>B</td>
<td>Self-transcendence; Resilience; Burden</td>
<td></td>
<td>48 &amp; 48*</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
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<td>--------------------------------</td>
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<td></td>
</tr>
<tr>
<td>13</td>
<td>B</td>
<td>Depressive symptoms</td>
<td>20 &amp; 11*</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>B</td>
<td>Resilience;</td>
<td>108 &amp; 102</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Depressive symptoms</td>
<td>22 &amp; 17*</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>B</td>
<td>Self-transcendence;</td>
<td>54 &amp; 55*</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Resilience;</td>
<td>123 &amp; 138*</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Burden</td>
<td>20 &amp; 16</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>B</td>
<td>Self-transcendence;</td>
<td>54 &amp; 54*</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Resilience</td>
<td>146 &amp; 147*</td>
<td></td>
</tr>
</tbody>
</table>

Of the remaining ten participants, 14 of 24 variables (58.3%) were identified as themes by both readers and had accompanying high scores on those variables. For all 20 participants, scores on the measures of the four study outcomes validated the themes the readers identified in approximately 60% of the poems. In addition, participant validation by verbal feedback was 100%. Subjective or qualitative reports often differ from numerical scores. It is interesting to note that of 27 themes identified in the poems that matched scores on measures of respective outcomes, 13 or 48% were on self-transcendence. It seemed to have been easier for the readers and the study participants to identify self-transcendence. One may conclude that, although it is difficult to ascribe significance to quantification of poem content, qualitative analysis demonstrated solid corroboration of the quantitative findings on the four study outcomes.
Research Question Five Results

Research Question Five asked whether Group A participants who wrote poetry in the first 4 weeks of the study would continue to write poems in the second 4 weeks of the study without being required to do so, or if they would verbalize intent to continue to write poetry after the study was concluded. The expected outcome was that a majority of participants in Group A (writing between Time 1 and Time 2) would continue to write poetry without being required to do so (between Time 2 and Time 3). In fact, 6 of 10 participants (60%) in Group A wrote at least one additional poem (n=7) between Time 2 and Time 3. These six participants verbally indicated that they would continue to write poems from time to time, as they found it beneficial. Of the additional four participants in this group, three said they would probably or definitely continue to write poems as another outlet or resource for their caregiver burden and stress. Thus, 9 of 10 (90%) participants in Group A either continued to write poems between Times 2 and 3 or verbalized intent to continue writing poetry. This was a large majority, helping to support the effectiveness of the poetry writing intervention.

Additional analysis of participants in Group B (writing poetry between Time 2 and Time 3) was completed. Although Group B caregivers did not have the opportunity to write additional poems before the end of the study, six of the ten participants expressed a likelihood of continuing to write poetry after the study ended. Three others in this group stated they weren’t sure about writing poetry, but would perhaps include a poem as part of journaling, or would find expressing themselves through journaling beneficial. In summary, 18 of 20 (90%) participants expressed benefit from poetry
writing demonstrated either through writing additional poems, or verbalizing the desire to continue writing poems or engage in other forms of expressive writing.

**Discussion of Research Question Five Results**

An adventitious finding in interview that emerged from the interview was that four of the study participants (20% of sample) commented that they enjoyed completing the study instruments. Several participants stated that the questions on the study instruments made them ponder their situation as a caregiver; two persons felt “proud” of how they were handling their caregiving duties and themselves after reviewing the questions. One participant noted that completing the instruments was what she most enjoyed in the study. Another participant stated that her high initial score on the baseline measure of depressive symptoms alerted her to the fact that she was probably more depressed than she realized and that she needed to attend to her feelings of depression. This participant stated that she also deliberately tried to write poems that would elevate her mood, and did demonstrate improvements in scores measuring depressive symptoms at subsequent testing times.

**Research Question Six Results**

Research Question Six addressed the feasibility of conducting a larger clinical trial. Data were gathered regarding the number of poems written, amount of time involved in study participation, amount of financial compensation, number of scales/instruments completed, and difficulty of forms completed (Appendix H). Three choices designated that time required for study participation and similar questions was too much, just the right amount, or more would be ok. Table 13 below illustrates results.
Table 7. Data Feasibility Questionnaire Results

<table>
<thead>
<tr>
<th>N=20</th>
<th>Number of poems</th>
<th>Amount of time</th>
<th>Amount of compensation</th>
<th>Number of forms</th>
<th>Difficulty of forms</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Response</td>
<td>More would be ok</td>
<td>More would be ok</td>
<td>Too much</td>
<td>More would be ok</td>
</tr>
<tr>
<td>#</td>
<td>%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>.45</td>
<td>7</td>
<td>6</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>%</td>
<td>%</td>
<td>%.35</td>
<td>%.30</td>
<td>%.15</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Response</td>
<td>About right</td>
<td>About right</td>
<td>About right</td>
<td>About right</td>
</tr>
<tr>
<td>#</td>
<td>%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>.55</td>
<td>13</td>
<td>14</td>
<td>17</td>
<td>20</td>
</tr>
<tr>
<td>%</td>
<td>%</td>
<td>%.65</td>
<td>%.70</td>
<td>%.85</td>
<td>100</td>
</tr>
</tbody>
</table>

One can see that appropriateness of number of poems, time spent to participate, amount of compensation, number of forms (questionnaires) and difficulty of questionnaires was supported by participant feedback. One hundred percent of participants agreed that poems, questionnaires, time, and compensation were acceptable or even that they would have written more poems, spent more time, or received less compensation. Forty-five percent of participants selected that they could have written more poems than the required three and six participants (30%) stated they didn’t need so much money or felt guilty for receiving the amount of compensation they received.

Discussion of Research Question Six Results

The feasibility of a full clinical trial (Research Question Six) was therefore supported in terms of the research design elements; however, a feasibility issue not addressed by this data was participant recruitment. It took 11 months to recruit the 20 caregivers who participated in this pilot study; thus, it may not be feasible to recruit the
number of participants needed for a full clinical trial. As calculated previously (see chapter 3), a moderate effect size of 0.6 would require a minimum of 45 participants in each group or a total of 90 study participants. Perhaps other recruitment methods would be more effective, but substantial restructuring of the methods would be required to enroll this large number of participants in a reasonable time frame.

**Additional Analysis**

Some caregivers received substantial benefit from participation in the study, with their scores on the instruments reflecting these benefits. An example is a middle-aged female participant caring for and living with her older parent. Eager to try an intervention that would provide some relief, she expressed frustration with being on the Group B waiting list. Her Time 2 scores worsened from baseline and indicated increased depression (18 to 33), caregiver burden (30 to 37), and decreased resilience (134 to 117) and self-transcendence (49 to 41). In interview, she spoke several times of poetry writing as “freeing” and providing “release.” She was able to get “things out that needed to come out.” She was pleased with completing the task of writing the poems, and also pleased that she “created something beautiful in the process” (of releasing feelings). She summarized the experience by saying that she felt poetry writing had helped me “see that I’m up to the challenge.” After poetry writing for 4 weeks, her Time 3 scores demonstrated increased self-transcendence (41 to 52) and resilience (117 to 140) and decreased depression (33 to 8) and caregiver burden (37 to 33).

There were also times when participant scores did not significantly improve, or perhaps even worsened, yet benefit of the intervention was perceived by the participants. An example was the middle-aged female providing weekly care and visits to her parent.
This participant was also dealing with a major medical issue of her own throughout the duration of the study, and stated that worsened scores Time 2 could be a reflection of those personal struggles. After writing poetry for four weeks, her Time 2 scores did not reflect any benefit from the intervention (self-transcendence from 58 to 53; depressive symptoms from 7 to 20; caregiver burden from 8 to 23; and resilience from 152 to 149). However, she spoke in interview of poetry writing helping her to develop a new skill, and providing a way to clarify and accept her situation with her loved one. She found catharsis in putting her emotions down on paper (“by writing about it …I was able to move from it…got past some of the anger issues.”). She spoke of poetry writing as another “tool” to add to her “toolkit.”

To demonstrate the value of poetry writing not fully captured by the analyses of questions in this study, the following brief section will discuss additional analysis of qualitative data obtained from open-ended interviews with participants.

Themes Emerging from Participant Interviews

A number of themes emerged from the participant interviews when asked about the experience of writing poetry. Perhaps most frequently noted was the theme of achievement. Twelve of twenty participants (60%) experienced a sense of accomplishment (“I did it”) and were proud of themselves for writing poems. Three participants were proud of how they provided care for a family member, and the overall positive attitude they were able to maintain.

Another common theme was catharsis. Seven participants spoke of the emotional release experienced from writing a poem. Two participants, including one who had experienced emotional conflict with her loved one as a child, referred to it as “cleansing,”
while others spoke of feeling a sense of “relief” or “release.” They noted that putting their emotions down on paper enabled them to move on. An older spouse caregiver stated that it was “a good way for me to release the feelings that I’m suppressing.” A middle-aged child caregiver stated that writing poems was stressful for her, but also noted that it enabled her to shift her mood and gain a different perspective—it provided “something tangible to attach the intangible emotion” to. One child caregiver who had experienced conflict with other family members related to caring for her loved one said that she got past “anger issues…so I was freed.” Another participant said that there was a “build up” of emotion on days she didn’t write poetry, but that writing poems allowed her to get “things out that needed to come out” and “create something beautiful in the process.” Still others spoke of poetry as a method to reduce stress.

*Increased acceptance* was also described by participants. One participant said she felt writing poems helped her to “accept the situation better”; another spoke of gaining greater clarity, leading to the ability to “accept it a little bit more…understand it a little bit more.” A middle-aged caregiver providing full-time care for a profoundly demented spouse stated that it helped her realize that “things are just what they are.” Another spouse caregiver stated that the questionnaires helped her reach a greater acceptance of things as they were.

Increased acceptance sometimes took the form of *greater empathy* for the loved one for whom they were giving care. One participant spoke of feeling “more sympathetic” towards her family member; another was less “irritated.” A child caregiver noted that writing poems helped her to realize how embroiled she had become in the mundane tasks of providing care to her parent and reminded her that “this is somebody
that I love.” She said it brought her back to “dealing with it on a personal level.” Several participants wrote affirmation of their caregiving in their poems or interpreted their poems as affirmation of “doing a good job” and “done the right thing” for their family member.

Caregivers commented that writing poetry provided them with an opportunity for reflection. Some appreciated the time to pause provided by writing poetry. As a spouse caregiver stated “I never had time to sit and think it through.” or Another participant said “It made you think...(have to) slow down and smell the roses.” For some, this reflection took the form of reliving happier days and memories with the care recipient. One child caregiver wrote a poem about a pleasant memory and referred to “capturing the moment”; another to taking a “snapshot” through short haiku poems. One participant described receiving benefit from reflecting on the study questionnaires.

Participants also verbalized gaining greater self-awareness through poetry writing. One caregiver noted that “I’m learning a little bit about me” throughout the study; another spoke of getting “in touch with some of my more intimate feelings” through poetry writing. Yet a third stated that poetry writing helped her “consolidate…capsulate…label my own feelings”. Caregivers experienced increased self-esteem when they were able to accomplish the task of writing poems and felt good about themselves. One child caregiver simply stated it “made me feel good about myself.” A spouse caregiver who expressed initial anxiety about her ability to write due to having only a high school education enjoyed the experience of preparing to write and said poems “kept me more upbeat.” She also noted that they “kept my mind occupied…helped me be more focused and attentive…more tuned in.”
Participants often found their assigned task fun and creative. Two male participants whose careers had been in scientific fields that required mathematical and logical analysis stated that they liked “thinking outside the box” or using a different part of (their) brains. They described it as “relaxing”. Two participants viewed the experience as learning and developing a new skill—one planned to work with serious intent on becoming a better poet.

A final significant theme was that of challenge. Although a number of participants found the experience of composing poems stressful to some degree, the majority found it to be “positive stress.” They verbalized that they enjoyed the challenge. Some seemed to view the poetry writing task as a welcome distraction, “something that I knew I had to be thinking about” or “something that occupied my mind completely.” Another caregiver noted that it kept her from dwelling on more negative events in her daily life. While the majority referred to enjoying the challenge of writing poetry, others reflected on growth in other ways. A middle aged child caregiver who had begun the study with high depressive symptom and burden scores summarized “This whole experience helped me see that I’m up to the challenge” (of caregiving).
CHAPTER FIVE

Introduction

In this chapter, a summary of the study of a poetry writing intervention for dementia family caregivers will be presented. Pertinent findings related to the research questions will be summarized. Limitations of the study related to sampling method, protocol implementation and design will be discussed. Next, implications for nursing theory development, future nursing research, nursing education, clinical nursing practice, and health policy development will be reviewed. Finally, recommendations for future implementation will be offered.

Summary

This pilot study tested the effectiveness of a poetry writing intervention on outcome variables self-transcendence, resilience, depressive symptoms, and subjective caregiver burden in a sample of twenty caregivers of older adults with dementia.

The study was guided by a synthesis of Reed’s Theory of Self-transcendence and the individual personality development theories of Adler and Frankl. Reed (2003) stated that nurses can directly intervene to influence inner resources such as self-transcendence in individuals. The theories of Frankl (1969) and Adler (1956) helped support the identification of specific nursing interventions that would promote the ability to transcend and create meaning from experiences, encourage consistency of thought, feeling, and goal-directed action, and choose attitudes such as resilience. Poetry writing was hypothesized as a specific nursing intervention that would help family caregivers transcend stresses, affirm meaning, and achieve positive outcomes by encouraging
caregiver expression of emotion, offering distraction or redirection from unpleasant
caring tasks, or enhancing positive feelings about the care recipient.

A mixed methods, longitudinal, crossover design with three points of data
collection over an 8-week period was used. A convenience sample of twenty adults were
randomly assigned to two groups (n=10). Study instruments were administered to both
groups to obtain baseline scores. Then the first group, Group A, participated in the
intervention and wrote at least three poems over a 4-week period. At four weeks,
instruments were administered again to all participants, then the second group, Group B,
wrote at least three poems over the next 4-week period. Group A participants could
continue to write poems if they so chose. All participants again completed study
instruments at the end of eight weeks (Time 3).

A semi structured interview format was used to collect data. Four instruments
were administered: The Self-transcendence Scale, the Resilience Scale, the Center for
Epidemiologic Studies- Depression (CES-D) and the Zarit Burden Interview (short form).
Participants in both groups were also interviewed about their poetry writing experiences.
Demographic data were collected and used to describe both groups. Analysis was
descriptive and involved the examination of trends in the data relative to outcome
variables. In addition, thematic analysis of poem content with “member checks” of
randomly chosen participants was conducted. The feasibility of the research protocol and
of conducting a larger clinical trial was assessed during the final interviews.

Research questions investigated in the study were:

1) Are there differences on self-transcendence, resilience, depressive symptoms,
and caregiver burden between family caregivers of older adults with dementia who write
poetry (Group A) and family caregivers not writing poetry (Group B) from Time 1 (before poetry writing) to Time 2 (after four weeks of poetry writing)?

2) Are higher positive psychological resources (self-transcendence, resilience) associated with lower negative psychological outcomes (depressive symptoms, subjective caregiver burden) over time with continued poetry writing?

3) Will there be differences in mean scores on study instruments in Group A from Time 1 to Time 2 and Group B from Time 2 (before poetry writing) to Time 3 (after four weeks of poetry writing)?

4) What common themes emerge from the poetry written by family caregivers of older adults with dementia?

5) Will family caregivers (Group A) who participate in poetry writing continue to write poetry or verbalize intent to write poetry after they are no longer required to do so?

6) What is the feasibility of conducting a larger clinical trial on poetry writing in dementia family caregivers?

Pertinent findings

Analysis of demographic data revealed some differences in age and gender between Groups A and B. Group A was slightly younger (58.8 years compared to 61.6 years) and contained more female caregivers (100% compared to 70% of Group B). Previous analysis of age and gender (see Chapter 4) indicated that these variables may have affected mean outcomes by group. Groups A and B were similar on marital status, education, and employment status; however, the mean income in Group B ($57,600) was 28.3% higher than Group A ($41,300). It should be noted that one participant in Group
A declined to report income; thus, Group A income mean was derived from only nine participants. It is unknown what impact income may have had on study outcomes.

In this study, female caregivers had lower scores on measures of self-transcendence and resilience, and higher scores on measures of depressive symptoms and caregiver burden than male caregivers. Older caregivers (age 60 and above) had higher self-transcendence and resilience scores and lower depressive symptoms and caregiver burden scores than younger caregivers (under age 60). Nineteen of twenty participants were caucasian; therefore, race did not influence outcomes in this study.

The two groups were similar on measures of self-transcendence, resilience, depressive symptoms, and caregiver burden following the poetry writing intervention (Research Question 1). Group A had lower mean scores on all variable measures than Group B at baseline; mean scores changed in the opposite direction from what was expected at Time 2 data collection. Post-intervention mean scores in Group B moved in the expected direction for the outcomes of self-transcendence, resilience and caregiver burden. The anticipated and actual direction of mean score changes following the intervention (Research Question 3) are summarized in Table 14.

**Table 8. Expected and Actual Mean Score Changes Following Intervention**

<table>
<thead>
<tr>
<th>Variables</th>
<th>Expected</th>
<th>Actual Group A (Time 2)</th>
<th>Actual Group B (Time 3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-transcendence</td>
<td>↑</td>
<td>↓</td>
<td>↑</td>
</tr>
<tr>
<td>Resilience</td>
<td>↑</td>
<td>↓</td>
<td>↑</td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>↓</td>
<td>↑</td>
<td>↑</td>
</tr>
<tr>
<td>Caregiver burden</td>
<td>↓</td>
<td>↑</td>
<td>↓</td>
</tr>
</tbody>
</table>
There was no sustained effect of the intervention at Time 3 for Group A participants who wrote poetry first (Research Question 2), as self-transcendence and resilience means remained lower than baseline and depressive symptoms and caregiver burden means remained higher than baseline; however, all mean scores changed in the direction anticipated from Time 2 to Time 3, possibly indicating that: 1) allowing more time to elapse after the intervention may have enhanced its effectiveness; or 2) scores of participants who continued to write poems between Time 2 and Time 3 may have influences the change in group mean. In Group B, mean scores on three measures changed in the predicted direction following the intervention between Time 2 and Time 3 (higher self-transcendence and resilience, lower caregiver burden); however, overall changes from baseline (Time 1) to Time 3 (end of study) were either not present or opposite of the direction predicted (Research Question 3). Table 14 summarizes expected and actual mean score changes from baseline to end of study in both groups.

Table 9. Expected and Actual Mean Score Changes from Baseline (Time 1) to End of Study (Time 3)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Hypothesized</th>
<th>Actual Group A (T1 to T3)</th>
<th>Actual Group B (T1 to T3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-transcendence</td>
<td>↑</td>
<td>↓</td>
<td>=</td>
</tr>
<tr>
<td>Resilience</td>
<td>↑</td>
<td>↓</td>
<td>=</td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>↓</td>
<td>↑</td>
<td>↑</td>
</tr>
<tr>
<td>Caregiver burden</td>
<td>↓</td>
<td>↑</td>
<td>↑</td>
</tr>
</tbody>
</table>

Poem content analysis (Research Question 4) revealed the presence of the study outcome variables (self-transcendence, resilience, depressive symptoms, and caregiver burden) as themes in the majority of participant poems. Two readers conducted two iterations of analysis of the poems, with percent agreement of 80.4% in the first iteration and 89.66% in the second iteration. Self-transcendence was identified most frequently as
a theme, followed by resilience, caregiver burden, and depressive symptoms. Participant phone interviews validated themes identified by readers.

The majority of the study participants wrote poetry between Time 2 and Time 3 (six or 60% of Group A participants), or indicated at the end of the study that they would consider continuing to write poetry (eighteen or 90%). In addition, the usefulness of the poetry writing intervention was supported by qualitative data obtained in open-ended interviews conducted with participants about the experience of writing poetry (Research Question 5). In the interviews, helpful outcomes of poetry writing such as achievement, catharsis, increased acceptance of illness and loved one, greater empathy, reflection, greater self-awareness, fun, and (positive) challenge were described by participants.

Feasibility of conducting a larger clinical trial (Research Question 6) based on design elements of the study (number of poems written, amount of time involved in participation in study, amount of financial compensation, number of questionnaires completed, and difficulty of questionnaires) was supported by participants responses to a feasibility questionnaire (see Table 12)

Limitations

This research study contained several limitations. One major limitation was sampling method. Convenience sampling introduced bias, as participants were self selected. Although some participants expressed initial reservations about writing poetry, all who participated in the study were willing to try something that they may have perceived as being difficult or challenging. Thus, the caregivers who volunteered for this study may have already possessed traits such as a more adventurous spirit, the willingness to take risks, and to try new things. In other words, their baseline measures
of study outcomes such as self-transcendence and resilience may have already been higher than that of participants who would not volunteer for the study. Higher baseline measures of variables would reduce the degree of change noted in subsequent outcome measures; ultimately, it would be more difficult to detect any intervention effect.

The sample was also biased towards white, middle class females and/or males. Participants were of higher socioeconomic status than the U.S population in general (i.e. mean income for participants from both groups in this study was over $49,000 while median income for those providing care to persons over age 50 nationwide was just over $38,000 (NAC/AARP, 2004)). This was largely due to the fact that recruitment sites for the study were primarily drawn from suburban and rural areas through Alzheimer’s Association. Although dementia caregivers are more likely to participate in support groups than other types of caregivers, only 7% of all caregivers seek assistance of support groups (NAC/AARP, 2004); thus, the majority of dementia caregivers may not be able to be recruited through support groups. Different recruitment methods might be helpful in future studies.

Further, although flyers were posted in certain Alzheimer’s Association offices with the potential to reach more lower income and urban participants, the fourteen participants who volunteered for the study from these offices were of middle to upper middle income levels. Requirements for this study included eighth grade reading level and sixth grade writing level. Urban dwellers with limited education or discomfort with verbal and writing skills would have been much less likely to volunteer for this study.

In addition, there was little cultural diversity in the sample. There were several possible reasons for this disparity. One reason is that there may be lack of use of services
(i.e. Alzheimer’s Association support groups) by persons of racial and ethnic diversity. Part of this may have been geographic in origin, as the geographic area used for study recruitment contained more racially homogenous individuals who would thus have access to the services. Furthermore, differences exist in cultural expression. For instance, some African American teens feel more comfortable reciting poetry for peers at the current popular “poetry slams”; other groups such as Native Americans may pass along traditions of oral storytelling. Prayers can be poems. These alternative methods of expression may not be viewed by participants as poetry writing, however; thus, they would not be inclined to volunteer for the study.

Another limitation of the study sample may be that some caregivers feel burdened to the point of immobilization. They do not seek out services; thus, some of the most burdened caregivers do not receive the services they need. Racial and ethnic subgroups in particular may report unmet needs. In the National Alliance for Caregiving/American Association for Retired Persons survey (2004), more than one unmet need was reported by 80% of Hispanic caregivers, 75% of African American caregivers, 73% Asian caregivers, and 64% White caregivers. In the study reported here, certain caregivers who made an investigational phone call to the researcher spoke at length of the great burden they were experiencing, but declined to participate in the study, stating that they believed this particular intervention would increase their stress.

Another possibility is that certain caregivers may not identify themselves as caregivers. They may perceive their duties towards a loved one as normal responsibilities of family, responsibilities for which they would not ask for or seek outside assistance or intervention. African American caregivers, for example, are more likely to live in urban
areas, spend more money to support care recipients (thus reporting greater financial hardship), perform more IADLs, and cope by talking to professional or spiritual counselors. Again, unfortunately, racial and ethnic subgroups were not reached by this pilot study.

Another significant limitation was the difficulty in recruiting participants. This study was a pilot study, requiring only 20 participants. Nonetheless, despite inclusion of a number of recruitment sites and venues, completion of data collection lasted 11 months (approximately 9 months in recruitment phase). Initial interest on the part of a number of participants seemed to dissapear after they understood that poetry writing was integral to the study. Some clearly expressed their disinterest in writing poetry; one potential recruit stated emphatically that writing poetry would increase, not decrease her stress as a caregiver. One participant asked “Can you call it something besides poetry?” Reactions of other potential recruits were similarly negative, with some participants noting that they hadn’t written poetry since high school. Others simply failed to respond to mailed informed consent documents, so the PI cannot say with certainty the reason for lack of follow-up; however, perception of the intervention as unpalatable is high on the list of likely reasons for nonparticipation.

Another concern was that the study was designed so that both groups (A and B) were given information about the poetry writing intervention at Time 1, although Group B participants were not requested to write poems until after Time 2. In fact, they were asked not to write poems for 4 weeks. It is possible that some participants in Group B could have written poems between Time 1 and Time 2 because they wanted to be prepared early or because they misunderstood directions. They may also have looked up
information on their own about poetry writing or prepared themselves psychologically in other ways. Any amount of advance preparation on the part of Group B participants could have affected outcomes on study measures at Time 2. It is also possible that Group A participants could have prepared themselves in the interim from telephone arrangement of an interview date for Time 1 until the actual time of the appointment. Advance preparation could confound outcomes in regards to the intervention, and make it more difficult to determine how much effect the intervention had.

The PI chose to provide poetry writing information to all participants before Time 1 interview due to her belief that the intervention itself might seem threatening to some participants. She believed that the poetry writing information sheet—describing elements of poetry, providing examples, and offering tips on how to begin writing poems—provided with informed consent would be persuasive in encouraging participants to volunteer for the study. In this way, the poetry writing information sheet was viewed as being helpful in recruiting participants and discouraging dropout at the start of the study. Verbal feedback from participants about the poetry writing sheet validated that many were relieved or reassured that they would be able to complete the intervention after reading the information. A number stated that the examples and the tips (i.e. a poem doesn’t have to rhyme) were very helpful in persuading them that they could write the poems. It would be illuminating, however, to replicate the study changing the timing of the delivery of the poetry writing information sheet from before Time 1 for all participants to after Time 1 for Group A and after Time 2 for Group B participants. This change would provide more data on whether advance preparation was a confounding factor in the study.
A change in original study protocol was also a questionable limitation. The PI had originally planned to contact participants by phone on a weekly basis while they were writing poetry. This contact was planned to help decrease attrition by encouraging participants as needed in their poetry writing task. However, after the first four participants had been called several times during their month of poetry writing, the PI noted that participant response to the phone calls was either puzzlement or irritation. Two participants wondered why the PI was calling, as they were working on their poetry writing task and were not experiencing major difficulties; a third participant seemed annoyed at receiving the weekly calls from the PI. The PI also noted that participants began to discuss stressors they were experiencing with the family member they were caring for, or personal health issues, and became concerned that the weekly telephone calls would become an intervention in themselves. Introducing a second intervention of providing social support over the phone in addition to the poetry writing intervention would clearly confound the study findings; thus, weekly phone calls to participants were dropped from the study protocol.

Following the first four participants, the PI called each participant one time between Time 1 and Time 2 and one time between Time 2 and Time 3. It is difficult to determine what effect this alteration in study protocol had on study outcomes. Although changing the protocol may have prevented the introduction of a confounding variable, it is also possible that dropping the phone calls affected study outcomes in a negative way. Participants may have benefited from verbal encouragement about their poetry writing task. Perhaps scores on study measures would have been affected had participants received the additional support from the PI.
Further, since this study was a pilot study, there were too few participants to analyze data using parametric statistics. Any conclusions based on quantitative data would not have been considered reliable findings. It was only possible to analyze data using descriptive statistics and to note data trends. An avenue of future exploration would thus be a larger sample size for a clinical trial. In a future clinical trial, t-tests could be used to assess statistical significance of group mean differences. Another recommendation would be to design the entire study as more qualitative, perhaps assessing the lived experience of caregivers writing poetry. Qualitative findings might prove to be of greater merit. Although statistical significance may not be achieved with a larger sample, the results of this pilot study suggested that clinical significance might be demonstrated through indepth participant interviews even with a smaller sample.

Plans for Dissemination

Dissemination of research findings to stakeholders--those persons and groups with vested interest in results and who will most benefit from application of findings—is crucial. Findings of this study will be reported back to the study participants through a written summary; some support groups will be revisited by the researcher to verbally present her findings. Gatekeepers at the Alzheimer’s Association regional offices who assisted in recruitment will also receive written reports, as well as those from the Area Agency on Aging.

Study results will be published in professional journals, either professional nursing journals or interdisciplinary journals reporting qualitative research or poetry therapy. The study findings will also be discussed as part of a chapter about caregiver stress and burden in an upcoming gerontological nursing education textbook targeting a
wide audience. The researcher has already presented preliminary findings at a regional
and international conference, and will attempt to present complete study findings at other
professional nursing conferences.

Implications

Nursing theory development

Nursing “research links theory, education, and practice” (LoBiondo-Wood &
Haber, 2002, p. 7). Evolution of nursing science mandates expansion of a theory base
that helps distinguish evidence-driven formulations for a practice profession. Theories
outside the nursing discipline may be useful (i.e. Frankl, Adler) as well as nursing
theories. Further development of middle-range nursing theories are testable, yet specific
enough to be helpful in general research and practice settings (Walker & Avant, 2005).

Poetry writing is a creative endeavor. Flood and Phillips (2006) suggested that
the outcome of the creative process is a novel product, and as such, can be an end as well
as a means. In other words, the process of creation can be of benefit to older adults. As
one writes a poem, gains self-understanding or pushes oneself beyond previous concepts
of self-boundaries, the poet is able to transcend normal limits. He or she may find the
achievement personally fulfilling, growth producing, or merely fun. The creative process
of writing a poem may be thought of as a means of problem-solving, as one may have to
experiment with words, cadences, and symbols. Old and new skills may be brought to
bear to express an idea or emotion. For older adults in particular, creativity may help
temper functional or financial limitations (Flood & Phillips, 2006).

Enhancement of creativity may be an outcome of poetry writing. One of the
major attributes of self-transcendence is creative energy. Indeed, the presence of creative
energy may be necessary in order for one to transcend (Teixeira, 2008). Participants in this study recognized that they were using creative energy and producing something new. One participant stated that she enjoyed the creativity, the ability to express feelings and “create something beautiful in the process”. Another participant felt that she was learning or developing a new skill; another planned to further develop her poetry writing abilities after the study was concluded. Other participants used words such as “fun,” “relaxing,” and “enjoyed it” in reference to poetry writing. Others felt that it was a change from their everyday experiences and thus encouraged them to “think outside the box.” Others found poetry writing “challenging,” but in a positive way. Promoting creative energy in persons of all ages could enhance growth and be beneficial. A variety of disciplines could help older adults or other persons in vulnerable life situations tap into their creative energy.

A possible innovative finding of this study is that there may be mediating variables by which poetry writing increases self-transcendence or decreases depressive symptoms and caregiver burden. These mediating variables could be those benefits such as catharsis, empathy, reflection, and increased self-awareness reported by participants. Perhaps reflection, for example, acts as the mechanism by which poetry writing produces a positive effect for the dementia caregiver. Future research should control for the impact of intervening variables falling into the space between the intervention and the outcomes. The impact of contextual and environmental influences that act as mediators or moderators (Reed, 1993) should also be examined in future research involving caregivers and their ability to self-transcend and achieve other positive mental health outcomes.
If there is indeed a connection between self-transcendence and creative energy, the creative act of poetry writing could enhance self-transcendence in these individuals. High self-transcendence scores have already been noted in older adults. Poetry writing could also help individuals find meaning in their experiences and personal fulfillment (Frankl, 1969). As Reed (1993) noted in her Theory of Self-transcendence, intrapersonal interventions that bolster internal resources can promote self-transcendence. In this study, some participants demonstrated an increase in their self-transcendence scores from Time 1 to Time 3 and stated that poetry writing was a useful and positive experience for them; thus, an intervention promoting their internal resources. Future research testing poetry writing as a nursing intervention would thus contribute to nursing knowledge through further development of Reed’s Theory of Self-transcendence.

Frankl’s concept of Will to Meaning also holds implications for future theory testing. Frankl (1969) noted the critical importance of an outside focus for those achieving or enhancing self-transcendence. Benefits cited by study participants included focusing on something besides caregiving duties, or having their attention diverted. In addition, participants felt that they were creating something new and positive through their poetry, perhaps giving to the world through their creations (Frankl, 1969). In line with Frankl’s theory, participants were able to reflect on and reframe their situations and allow openness to new meanings (Das, 1998). A poignant example was the spouse caregiver annoyed by the constant meaningless laugh of her demented husband. After writing a poem about her feelings, she realized that his laugh was the only sound he made; suddenly, the laugh became something valuable to preserve and hold onto.
As the trajectory of dementia caregiving may wax and wane with the peaks, plateaus and valleys experienced by the family member receiving care, so attitudinal choices of the caregiver will fluctuate. Vulnerability will be increased during times of loss and setback (Reed, 1993); opportunity for enhanced self-transcendence and resilience is one potential outcome of choosing positive meaning in caregiving experiences. Poetry writing is one creative choice dementia caregivers may make to impose new meaning on experiences of pain and suffering (Frankl, 1969).

Clinical nursing practice

Poetry writing is a useful addition to the spectrum of available interventions for dementia caregivers. In their meta analysis of dementia caregiver burden studies, Etters, Goodall & Harrison (2008) noted that only studies with more than one interventional component reduced burden to a significant degree. Evidence suggests that outcomes improve when interventions have multiple components as opposed to a single intervention (Farcnik & Persyk, 2002; Schulz, 2002). A finding of another meta-analysis (Sorenson et al., 2002) was that care recipient characteristics have a major impact on the effectiveness of an intervention. The researchers noted that dementia caregivers do not appear to receive as much benefit from interventions as other caregivers, perhaps because of the unpredictability of stressors such as care recipient personality changes and behaviors (Sorenson et al., 2002).

Caregiver burden was lower following poetry writing in some participants; in addition, caregiver burden mean scores for Group B were lower after the intervention in this study. As effective intervention with this challenging population of caregivers requires more than one intervention strategy, all interventions demonstrating
effectiveness should be implemented. Reducing burden in dementia caregivers would be a useful application of poetry writing research to clinical nursing practice. In the words of one study participant, poetry writing could be a useful addition to a “toolbox” that helps reduce burden and stress.

Promoting positive psychological resources is one way that nurses can intervene to assist dementia caregivers. Some participants experienced increases in study outcomes of self-transcendence and resilience following poetry writing. Nurses working closely with dementia caregivers can encourage them to try new and different methods of reinforcing their strengths; poetry writing is one such example of such a method.

Caregivers in this study found poetry writing affirming of their strengths as caregivers and the good work they were doing; they also deliberately used poems to elevate their mood or redirect negative thoughts and feelings.

Another clinical nursing application for this study is related to cognitive function in older adults. As a number of the caregivers were older adults themselves, maintenance of optimum cognitive function in this population is a desirable outcome. Caregivers spoke of the challenge of writing poetry. One caregiver spoke of poetry writing “occupying” her mind and “giving her something to be thinking about.” The mental exercise of arranging language into a poetical framework would provide helpful cognitive stimulation for aging caregivers.

Health policy development and nursing education

Caring for the caregiver has become a popular phrase in the health care arena. As twenty-one percent of all households provide care for an older adult (NAC/AARP, 2004) and thirty-six percent of Hispanic households provide care for an older adult (Evercare
Study, 2008). Thus, maintaining health of caregivers becomes a priority. Loss of informal caregivers creates additional strain and adds cost to an overburdened formal caregiving system. Development and funding of initiatives or strategies that maintain physical and mental health in caregivers is therefore critical.

Financial barriers are often the root cause of lack of access to health care in the U.S. (Bodenheimer & Grumbach, 2002). Indeed, those providing the highest level of care also report the lowest level of income (NAC/AARP, 2004). As health care costs spiral out of control, contributing to development of cost-effective interventions for caregivers is incumbent upon the profession of nursing. Interventions that promote caregiver coping may extend to management of care recipient behaviors, decrease caregiver burden, improve quality of life, and reduce financial costs of care (Nichols et al., 2008).

Reaching racial and ethnic subgroups should also be a health policy priority. While similar percentages of African American and Hispanic families provide care for family members, these groups are more likely to report lower incomes than white and Asian groups. For example, 42% of white caregivers and 53% of Asian caregivers reported incomes over $50,000; only 33% of African American and 37% of Hispanic caregivers reported such high incomes (NAC/AARP, 2004).

Poetry writing is an informal, cost effective intervention for dementia caregivers. It requires minimal face to face contact between caregivers and health care professionals, and little training is required to instruct caregivers about how to write poems. Caregivers can choose when and how to write poems. However, caregivers must be made aware of the advantages and the option of writing poetry to decrease negative outcomes and
promote positive psychological resources. This awareness requires education by nursing professionals who interface with caregivers on a daily basis.

The intervention of poetry writing must be brought to caregivers in the communities in which they reside. Creative methods to promote use of poetry writing should be encouraged in the public health arena. As public health nurses present self-care educational offerings at health fairs, drop in centers and senior centers in underserved neighborhoods, the benefits of poetry writing could be incorporated into these health care offerings. The definition of poetry writing can be expanded to suit the needs of the individuals in the community (i.e. written or oral). The use of expressive therapies should be taught in nursing programs across the country. Health care policy initiatives relating to nursing education should provide incentives to promote nursing education requiring incorporation of curricula about reflective practice and encouragement of expressive therapies such as poetry writing in individuals, groups, and communities that nurses serve.

Recommendations for future research

Finally, recommendations for future nursing research that may be implemented are reviewed. Recommendations for future nursing research include:

1) Examine changes in self-transcendence and well-being following a poetry writing intervention using Reed’s Theory of Self-transcendence model.

2) Compare the effectiveness of a poetry writing intervention in a group of dementia caregivers and a group of other caregivers.

3) Examine outcomes of self-transcendence, resilience, depressive symptoms, and caregiver burden in samples of varying ages and types of caregivers.
4) Add a measure of caregiver satisfaction pre- and post- a poetry writing intervention to future studies.

5) Replicate study with protocol changes. Increase duration of poetry writing task to eight weeks for first group that writes and compare to group writing only four weeks at time points 4, 8, 12, and 24 weeks.

6) Replicate study, implementing weekly phone calls to offer more support during poetry writing intervention period.

7) Replicate study, withholding advance information on poetry writing. Provide information at Time 1 for Group A and Time 2 for Group B.

8) Examine outcomes of self-transcendence, resilience, depressive symptoms, and caregiver burden in two different intervention groups—poetry writing and poetry reading.

9) Examine effectiveness of a poetry writing intervention over a longer time interval. Add two additional data collection time points—12 weeks and 24 weeks. Assess changes in measures of self-transcendence, resilience, depressive symptoms, and caregiver burden. Assess percent of participants continuing to write poetry at six months to determine sustainability and long term effectiveness of intervention.

10) Examine poetry writing as an emotion-focused coping strategy using Lazarus and Folkman’s Stress and Coping model as a theoretical framework.

11) Examine outcome variable of caregiver satisfaction at Time 1 and Time 3 to determine if any differences that may be attributed to the intervention exist. Continue to ask participants about other confounding factors such as changes in family member health status or personal health.
12) Change sampling strategy to insure representation of racial and ethnic subgroups.

Expand definition of poetry writing intervention to facilitate participation of culturally diverse groups (i.e. oral poetry recitations, internet chat rooms).
Appendix A: Demographic Questionnaire

Group _____ ID # ____________

Directions: Please complete the following items

Age: ________________
Sex: Male Female

Education: Put an X next to all years completed (if did not complete, indicate how many years completed)

Elementary _________ College ______
High School _________ Graduate School ______

Race: Caucasian _________ African American _______
Asian American _________ Hispanic _________
Other _________________

Marital Status: Single _________ Married _________
Divorced _________ Widowed _________
Other _______________

Employment Status: Full-time _________ Part-time _________
Retired _________ Unemployed _________
Disabled _________ Other _________

Annual Income: _____________________

Religion: Protestant _________ Catholic _________
Lutheran _________ Methodist _________
Baptist _________ Jewish _________
Religion (con’t)

Presbyterian ______________  Episcopalian ______________

Jehovah Witness ____________  Mormon _________________

Other _________________

Do you provide care for a family member with Alzheimer’s or another type of dementia?

Yes ___________   No ____________

Relationship of this person to you ______________

How many hours/week do you provide care? ______________

Do you live with the person you are helping to care for? Yes _________  No ________

Please use the attached Katz ADL* (1963) and Lawton-Brody IADL (1969)* forms to tell me about the type of care your family member needs and that you assist them with (at least part of the time): SEE NEXT PAGE—PLEASE PUT AN X in the BOX or CIRCLE THE ITEM

Other support (call on phone, check on safety, etc.) _________________

How long have you been caring for this family member? (number of years) ______

How satisfied are you with your caregiving role:

Very satisfied _______  Moderately satisfied_______________

Slightly satisfied _____  Moderately dissatisfied_______________

Slightly dissatisfied _____  Very dissatisfied ___________
**Katz Basic Activities of Daily Living (ADL) Scale**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Independent</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Bathing (shower, bath, tub bath, or shower)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Receives only no assistance or assistance in bathing only one part of</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>body</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Dressing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gets clothes and dresses without any assistance except for tying shoes.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Toileting</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Goes to toilet room, uses toilet, arranges clothes, and returns without</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>any assistance (may use cane or walker for support and may use bedpan/</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>urinal at night)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Transferring</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moves in and out of bed and chair without assistance (may use a walker)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Continence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Controls bowel and bladder completely by self (without occasional</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;accidents&quot;)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Feeding</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeds self without assistance (except for help with cutting meat or</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>buttering bread)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Lawton-Brody Instrumental Activities of Daily Living Scale (I.A.D.L.)**

<table>
<thead>
<tr>
<th>Activity</th>
<th>A. Ability to Use Telephone</th>
<th>E. Laundry</th>
<th>F. Mode of Transportation</th>
<th>G. Responsibility for Own Medication</th>
<th>H. Ability to Handle Finances</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Operates telephone on own initiative looks up and dial numbers, etc.</td>
<td>1</td>
<td>1. Does personal laundry completely</td>
<td>1</td>
<td>1. Is responsible for taking medication in correct dosage at correct time</td>
<td>1</td>
</tr>
<tr>
<td>2. Dials a few well known numbers</td>
<td>1</td>
<td>2. Arranges own travel as tax, but does not otherwise use public</td>
<td>0</td>
<td>2. Takes responsibility for medication in advance in separate dosage</td>
<td>1</td>
</tr>
<tr>
<td>3. Answers telephone but does not dial</td>
<td>0</td>
<td>3. Travels on public transportation when accompanied by another</td>
<td>0</td>
<td>3. Is not capable of dispensing own medication</td>
<td>0</td>
</tr>
<tr>
<td>4. Does not use telephone at all</td>
<td>0</td>
<td>4. Travels limited to taxi or automobile with assistance of another</td>
<td>0</td>
<td>4. Does not travel at all</td>
<td>0</td>
</tr>
<tr>
<td>5. Shopping</td>
<td>1</td>
<td>1. Travels independently on public transportation or drives own car</td>
<td>1</td>
<td>5. Does not travel at all</td>
<td>0</td>
</tr>
<tr>
<td>6. Shopping independently for small purchases</td>
<td>1</td>
<td>2. Arranges own travel as tax, but does not otherwise use public</td>
<td>1</td>
<td>6. Does not travel at all</td>
<td>0</td>
</tr>
<tr>
<td>7. Needs to be accompanied on shopping trips</td>
<td>0</td>
<td>3. Travels on public transportation when accompanied by another</td>
<td>1</td>
<td>7. Does not travel at all</td>
<td>0</td>
</tr>
<tr>
<td>8. Completely unable to shop</td>
<td>0</td>
<td>4. Travels limited to taxi or automobile with assistance of another</td>
<td>0</td>
<td>8. Does not travel at all</td>
<td>0</td>
</tr>
<tr>
<td>9. Food Preparation</td>
<td>1</td>
<td>1. Is responsible for taking medication in correct dosage at correct time</td>
<td>1</td>
<td>9. Does not travel at all</td>
<td>0</td>
</tr>
<tr>
<td>10. Preparers meal and serves adequate meals independently</td>
<td>0</td>
<td>2. Takes responsibility for medication in advance in separate dosage</td>
<td>0</td>
<td>10. Does not travel at all</td>
<td>0</td>
</tr>
<tr>
<td>11. Preparers adequate meal if supplied with ingredients</td>
<td>0</td>
<td>3. Is not capable of dispensing own medication</td>
<td>0</td>
<td>11. Does not travel at all</td>
<td>0</td>
</tr>
<tr>
<td>12. Hears, serves and prepares meal, or prepares meals, or</td>
<td>0</td>
<td>4. Does not travel at all</td>
<td>0</td>
<td>12. Does not travel at all</td>
<td>0</td>
</tr>
<tr>
<td>13. Preparers adequate meal if supplied with ingredients</td>
<td>0</td>
<td>5. Does not travel at all</td>
<td>0</td>
<td>13. Does not travel at all</td>
<td>0</td>
</tr>
<tr>
<td>14. Needs to have meals prepared and served</td>
<td>0</td>
<td>6. Does not travel at all</td>
<td>0</td>
<td>14. Does not travel at all</td>
<td>0</td>
</tr>
<tr>
<td>15. Housekeeping</td>
<td>1</td>
<td>1. Manages financial matters independently (budgets, written checks)</td>
<td>1</td>
<td>15. Does not travel at all</td>
<td>0</td>
</tr>
<tr>
<td>16. Performs light daily tasks such as dish washing, bed</td>
<td>1</td>
<td>2. Manages day-to-day purchases, but needs help with banking, major</td>
<td>1</td>
<td>16. Does not travel at all</td>
<td>0</td>
</tr>
<tr>
<td>making</td>
<td>1</td>
<td>purchase, etc.</td>
<td>1</td>
<td>17. Does not travel at all</td>
<td>0</td>
</tr>
<tr>
<td>17. Performs light daily tasks but cannot maintain adequate level of</td>
<td>1</td>
<td>3. Is incapable of handling money</td>
<td>0</td>
<td>18. Does not travel at all</td>
<td>0</td>
</tr>
<tr>
<td>cleanliness</td>
<td>0</td>
<td></td>
<td></td>
<td>19. Does not travel at all</td>
<td>0</td>
</tr>
<tr>
<td>18. Needs help with all home maintenance tasks</td>
<td>1</td>
<td></td>
<td></td>
<td>20. Does not travel at all</td>
<td>0</td>
</tr>
<tr>
<td>19. Does not participate in any household cleaning tasks</td>
<td>1</td>
<td></td>
<td></td>
<td>21. Does not travel at all</td>
<td>0</td>
</tr>
</tbody>
</table>


Appendix B: Self-Transcendence Scale

**Directions:** Please indicate the extent to which each item below describes you. There are no right or wrong answers. I am interested in your frank opinion. As you respond to each item, think of how you see yourself at this time of your life. Circle the number that is the best response for you.

<table>
<thead>
<tr>
<th>At this time of my life, I see myself as:</th>
<th>Not At All</th>
<th>Very little</th>
<th>Somewhat</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having hobbies or interests I can enjoy</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Accepting myself as I grow older.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Being involved with other people or my community when possible.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Adjusting well to my present life situation.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Adjusting to changes in my physical abilities.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Sharing my wisdom or experience with others.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Finding meaning in my past experiences.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Helping others in some way.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Having an ongoing interest in learning.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Able to move beyond some things that once seemed so important.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Accepting death as a part of life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Finding meaning in my spiritual beliefs.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Letting others help me when I need it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Enjoying my pace of life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Dwelling on my past issues.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Appendix C: Resilience Scale (RS)

**Directions:** Please answer the following questions about yourself by indicating the extent of your agreement or disagreement using the following scale:

<table>
<thead>
<tr>
<th>Agree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. When I make plans, I follow through with them.</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>2. I usually manage one way or another.</td>
<td></td>
</tr>
<tr>
<td>3. I am able to depend on myself more than anyone else.</td>
<td></td>
</tr>
<tr>
<td>4. Keeping interested in things is important to me.</td>
<td></td>
</tr>
<tr>
<td>5. I can be happy on my own if I have to.</td>
<td></td>
</tr>
<tr>
<td>6. I feel proud that I have accomplished things in my life.</td>
<td></td>
</tr>
<tr>
<td>7. I usually take things in stride.</td>
<td></td>
</tr>
<tr>
<td>8. I am friends with myself.</td>
<td></td>
</tr>
<tr>
<td>9. I feel that I can handle many things at a time.</td>
<td></td>
</tr>
<tr>
<td>10. I am determined.</td>
<td></td>
</tr>
<tr>
<td>11. I seldom wonder what the point of it all is.</td>
<td></td>
</tr>
<tr>
<td>12. I take things one day at a time.</td>
<td></td>
</tr>
<tr>
<td>13. I can get through difficult times because I’ve experienced difficulty before.</td>
<td></td>
</tr>
<tr>
<td>15. I keep interested in things.</td>
<td></td>
</tr>
<tr>
<td>16. I can usually find something to laugh about.</td>
<td></td>
</tr>
<tr>
<td>17. My belief in myself gets me through hard times.</td>
<td></td>
</tr>
<tr>
<td>18. In an emergency, I’m someone people generally can rely on.</td>
<td></td>
</tr>
<tr>
<td>Agree</td>
<td>Disagree</td>
</tr>
<tr>
<td>--------------------</td>
<td>----------</td>
</tr>
<tr>
<td>20. Sometimes I make myself do things whether I want to or not.</td>
<td></td>
</tr>
<tr>
<td>21. My life has meaning.</td>
<td></td>
</tr>
<tr>
<td>22. I do not dwell on things that I can’t do anything about.</td>
<td></td>
</tr>
<tr>
<td>23. When I’m in a difficult situation, I can usually find my way out of it.</td>
<td></td>
</tr>
<tr>
<td>24. I have enough energy to do what I have to do.</td>
<td></td>
</tr>
<tr>
<td>25. It’s okay if there are people who don’t like me.</td>
<td></td>
</tr>
</tbody>
</table>
Appendix D: CESD

**Directions:** Please choose the response that best describes how often you have felt this way *during the past week*. The responses are None of the time, Some of the time, A lot of the time, and Most of the time.

<table>
<thead>
<tr>
<th>[CIRCLE ONE]</th>
<th>None of the time</th>
<th>Some of the time</th>
<th>A lot of the time</th>
<th>Most of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I was bothered by things that usually don’t bother me.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. I did not feel like eating; my appetite was poor.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. I felt that I could not shake off the blues even with help from my family or friends.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. I felt that I was just as good as other people.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. I had trouble keeping my mind on what I was doing.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. I felt depressed.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. I felt that everything I did was an effort.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8. I felt hopeful about the future.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9. I thought my life had been a failure.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10. I felt tearful.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11. My sleep was restless.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12. I was happy.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>13. I talked less than usual.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>14. I felt lonely.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>None of the time</td>
<td>Some of the time</td>
<td>A lot of the time</td>
<td>Most of the time</td>
</tr>
<tr>
<td>---</td>
<td>-----------------</td>
<td>------------------</td>
<td>-------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>15. People were unfriendly.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>16. I enjoyed life.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>17. I had crying spells.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>18. I felt sad.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>19. I felt that people dislike me.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>20. I could not get “going.”</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Appendix E: Zarit Burden Interview (Short Scale)

**Directions:** Please choose the response that best describes how you feel at this moment. The responses are Never, Rarely, Sometimes, Quite frequently, and Nearly always.

**DO YOU FEEL:**

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite frequently</th>
<th>Nearly always</th>
</tr>
</thead>
<tbody>
<tr>
<td>That because of the time you spend with your relative that you don’t have enough time for yourself?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Stressed between caring for your relative and trying to meet other responsibilities (work/family?)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Angry when you are around your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>That your relative currently affects your relationship with family members or friends in a negative way?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Strained when you are around your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>That your health has suffered because of your involvement with your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>That you don’t have as much privacy as you would like because of your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>That your social life has suffered because you are caring for your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>That you have lost control of your life since your relative’s illness?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
**DO YOU FEEL:**

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite frequently</th>
<th>Nearly always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uncertain about what to do for your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>You should be doing more for your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>You could do a better job in caring for your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Appendix F: Informed Consent Document

The Effect of a Poetry Writing Intervention on Self-transcendence, Resilience, Depressive symptoms, and Subjective Burden in Family Caregivers of Older Adults with Dementia

You are being asked to take part in a research study. This study tests whether poetry writing helps decrease feelings of sadness or burden that come from caregiving. The study also tests whether poetry writing helps caregivers rise above and bounce back from stress. You were asked to take part in this study because you care for a family member with memory problems. You also responded to the flyer or printed materials you got in your Alzheimer’s support group, your nursing home, or your church. Please read this form and ask any questions you have before you agree to be in the study.

Researchers at Case Western Reserve University are conducting this study.

Background Information
The purpose of this research is to test whether poetry writing helps caregivers taking care of family members with memory problems. The researchers are asking if poetry writing helps care givers rise above life stresses. They are asking if poetry writing will help them bounce back from disturbing events. The researchers want to know if poetry writing helps lessen feelings of sadness in caregivers. They want to know if caregivers may feel less burdened by their role as care giver through writing poetry.

Procedures
If you agree to take part in this research, we would ask you to do the following things:

1) Take part in a research study that is at least eight weeks long. During the eight weeks, you will be asked to take part in three or four face-to-face interviews with lead investigator Lori Kidd. It is also possible that the interviews will be with research assistants from Case Western Reserve University. These interviews should last between 60-90 minutes. They will be set up at a convenient time for you over about 2-4 months. You will decide where to meet. You are asked to choose a location that you believe to be a safe place such as your home. Another idea is a public place like a restaurant or library. In the first three interviews, you will be asked to fill out four scales that measure self-transcendence, resilience, depressive symptoms, and subjective caregiver burden. Self-transcendence helps someone rise above difficult life situations. Resilience helps you bounce back from stressful life events. Depressive symptoms make you feel sad or tired or unhappy. Caregiver burden is the sense that your life has been affected in a negative way by care giving. You may be asked to take part in a fourth interview (not all persons who finish the first three interviews will be asked to take part in the fourth interview). In this interview, you will be asked to talk about the poetry writing you did in some detail. You will also be asked to share what it’s like for you to be a caregiver, including things that help you stay positive. You will be asked to answer a few questions about time involved and how hard it was to take part in this study. Last, you may be asked to take part in a brief (5 minutes or less) phone interview that will not require a face-to-face meeting. The purpose of the phone call will be to determine your agreement with poem
themes stated by investigators. There will be no additional compensation for this brief interview.

2) Take part for at least four of the eight weeks of the study. You will be asked to write at least 3 poems during a 4-week period. Information about what poetry is and how it is different from other types of writing are in this information packet. There are also examples of poems. You will be asked to write poetry either during the first 4 weeks of the study, or during the second 4 weeks of the study. If you are asked to write poetry during the first 4 weeks of the study, and find it helpful, you may continue to write poems during the second 4-week period. If you are asked to write poetry during the second 4-week period, you are asked not to write poetry during the first 4 weeks of the study.

3) Give consent for digital voice recording of all interviews. This will help the researchers review content more easily. It will help researchers decide what helped you most in your caregiver role. It will also provide useful information for others caring for family members with memory problems. If you don’t want to be recorded, we ask your consent to take written or typed notes during interviews.

4) Give consent to publish poems or parts of poems. Your poem may be published in a professional journal. If your poem is published or used in a journal, your name will not be given.

5) Give written consent to take part in this study by signing this form. Getting this form in the mail before the first interview will allow you to fully consider the risks and benefits of being in the study. No other persons need to be asked whether you may take part in the study. Only your cooperation and permission is needed. You may come to the first meeting with this consent form already signed. You may also sign it in my presence at the start of the interview. At the first meeting, you will be asked to give some demographic data (ex. age, race, gender) and to complete two questionnaires. One questionnaire looks at your ability to think and concentrate. The other asks about symptoms of depression. If your scores on either tool indicate, the researcher(s) may ask you not to take part in the study. Instead, she may give you information about further health evaluations. After you fill out the screening questionnaires, the researcher(s) will ask for you to give signed consent. Giving signed consent means that you do not feel forced or pressured by any person or organizations to take part against your wishes. Refusing to take part in this study will not in any way affect care provided to you by your physician’s office or support provided to you by the Alzheimer’s Association.

**Risks and Benefits to Being in the Study**

This research has the following risks: There is very little risk to you for taking part in this study. You may feel some mental distress or anxiety when you talk about being a care giver or when you write poetry. If this happens, you may choose to leave the study at any time. Also, you will be urged to seek any professional support (ex. counseling) you think you need during the study. You will also be asked to follow up with your usual health care providers. If you do not have a current provider, a referral for psychological counseling will be suggested to you by Lori Kidd or her research assistants. If the
investigators notice that you seem very stressed and upset and think that continuing in the study could have bad results for you, we may ask you to leave the study. We may do this even without your direct consent. We will then refer you to professional psychological support. There are no other foreseeable risks of taking part in this study.

There are no direct benefits of taking part in this study. Please be aware that your personal details will not be given out to anyone else. Findings will be reported together so that you will remain anonymous and not able to be identified. The investigator will share overall study findings with you if you wish. These results may be presented through your support group. Findings may also be published in professional nursing journals or other journals.

**Compensation**
You will receive $15.00 cash at the end of each interview. You will receive this amount after you are enrolled in the study. The total amount you will receive when you have finished all three interviews and poems will be $45.00 cash. If you take part in the fourth interview, you will receive another $15.00 cash (total $60.00). You may choose to receive gift cards instead of cash.

**Confidentiality**
The records of this research will be kept private. In any sort of report we might publish, we will not include any information that will make it possible to identify you as an individual. Research records will be kept in a locked file. Access will be limited to the researchers and the University review board responsible for protecting human participants. Regulatory agencies or any research funder(s) will also have access. Digital voice recordings will be protected and kept confidential. Only the study investigators will have access to them. Any published material of recording content will be referred to with made up names or no names to protect your identity. Records will be kept on computer discs and will be password protected. Records will be erased or destroyed three years after the end of the study. If the researcher(s) suspect that elder abuse or neglect is happening to any of the participants (or those they care for) aged 65 or above, this will be reported. Reporting is required by law. Also, if the researcher(s) suspect that any participant is suicidally depressed or is a danger to themselves or others at any time during the study, we will contact family members or crisis resources for you immediately. No other violations of confidentiality will take place.

**Voluntary Nature of the Study**
Your taking part is voluntary. If you choose not to take part, it will not affect your current or future relationships with the University. It will not affect care provided by any health care organization that may have referred you. There is no penalty or loss of benefits for not taking part or for leaving the study. If you take part in the fourth interview, you will be asked to review the researchers’ findings and give them feedback. You will be asked whether you agree or disagree with their understanding of poems written. You will also be provided with any significant new findings that result from the research after all information is collected. You will be given this information in the public forums discussed previously in this consent form.
Contacts and Questions
The researchers conducting this study are Jaclene A. Zausniewski, PhD and Lori I. Kidd, MSN, PhD candidate. You may ask any questions you have now. If you have any more questions, concerns or complaints about the study, you may contact them at 330-612-4077, 330-670-6509 or 216-368-3612. If the researchers cannot be reached, or if you would like to talk to someone other than the researcher(s) about; (1) questions, concerns or complaints about this study, (2) research participant rights, (3) research-related injuries, or (4) other human subjects issues, please contact Case Western Reserve University's Institutional Review Board at (216) 368-6925 or write: Case Western Reserve University; Institutional Review Board; 10900 Euclid Ave.; Cleveland, OH 44106-7230.

You will be given a copy of this form for your records.

Statement of Consent
I have read the above information. I have received answers to the questions I have asked. I consent to participate in this research. I am at least 18 years of age.

☐ YES, I CONSENT to being digital voice recorded.
   I also understand that I have the right to change my mind.

☐ NO, I DO NOT CONSENT to being digital voice recorded. However, I DO consent to being interviewed and allowing notes of my interview to be taken and used in the study.

Print Name of Participant: ________________________________

Signature of Participant: ________________________________ Date: ______

Signature of Person Obtaining Consent: _____________ Date: ______________
Appendix G: Information about Writing Poetry

Writing poetry does not need to be complicated or mysterious—each poem is as unique as the poet. If you take part in this study, you will be asked to write at least 3 poems in four weeks. There are no special directions for the content or the length of poems.

Study directions: Over the next four weeks, you are asked to try to write poetry at least two times per week. We ask that you write at least three poems over the four week time period, and we will remind you weekly with a phone call or postcard to keep writing. Please record the date and time on each poem that you write. The researchers in this study will read your poems. They may interview you about your experience of writing poetry and ask you to discuss certain poems you have written. They may also ask for your consent to publish your poems or pieces of your poems.

The following pages of this handout are meant to provide information about basic parts of poetry. This information may help you if you are new to or uncomfortable about writing poetry. It may simply remind you of things you already know about writing poetry. You should use whatever you find useful in this guide, but you do not have to follow any of the advice given here. The poetry you will write will not be criticized or judged by professional poets or by anyone else. Poems simply express your thoughts, feelings, perceptions, and experiences in a way that is probably different from your usual way of expressing yourself.

In these pages, a few basic elements common to poems will be described, and a few examples of poems will be given to help you in your poetry writing.
A Brief Overview of Poetry

Poetry is different from prose or the everyday language we use in four main ways: **Imagery, language or word choice, rhythm, and poetic devices** that include metaphor, simile, and personification.

1) Imagery—words that give clear descriptions and involve the senses and emotions are important. This is the most important part of a poem—it speaks to others and gives a real voice to the poet’s experience. For example, haikus are short, quick poems that give powerful images:

A tethered horse,  
Snow  
In both stirrups  
Washing the hoe—  
Ripples on the water;  
Far off, wild ducks (Buson)

Neither of the above haikus is limited by syllable length, but both are brief and full of imagery. What images describe what you want others to understand?

2) Language—words you choose should feel natural and real to you. They should connect to what you are trying to express, but stand apart from the way you would speak the words in everyday conversation. Here is a poem by Theodore Roethke:

**My Papa’s Waltz**

The whiskey on your breath  
Could make a little boy dizzy;  
But I hung on like death;  
Such waltzing was not easy.

We romped until the pans  
Slid from the kitchen shelf;  
My mother’s countenance  
Could not unfrown itself.

The hand that held my wrist  
Was battered on one knuckle.  
At every step you missed  
My right ear scraped a buckle.

You beat time on my head  
With a palm caked hard by dirt,  
Then waltzed me off to bed  
Still clinging to your shirt.
Notice how Roethke uses words such as “countenance” instead of “face” and makes up the word “unfrown.” Words like “waltzed” and “romped” create a sense of playfulness, but this is in contrast to other images such as hanging on “like death”. Words like “clinging” make us think that the little boy’s feelings of love for his father war with fear. Our senses are involved by words like “dizzy”, “scraped”, “beat time” and the smell of “whisky on your breath.” The poem uses language and images that stir strong emotions. It is also a natural poem, from the poet’s personal experience—this is his genuine voice.

3) Rhythm—The above poem is rhythmical. In fact, the first and third lines of each verse rhyme, as do the second and fourth. But poetry does not have to rhyme to be rhythmical. The thought of rhyming scares off many would-be poets. Rhythm may seem like breathing in a poem and may be emphasized by line breaks. For example:

busy place and bright
flashing silver
chopping vegetables
pressing tofu
loud talking
one hundred pounds of salmon
(Elisa Weiner, in Fox, 1997)

the cat sleeping on the fence is famous to the birds
watching him from the birdhouse (Naomi Shibab Nye, in Fox, 1997)

In the first example, the rapid fire lines and word choices remind one of chopping vegetables in a busy kitchen. It has its own rhythm. The second poem has a more natural conversational tone; however, its line break helps provide its rhythm or sense of movement.

4) Metaphor—words that compare two different things not usually compared. Think about these examples:

Music—My rage is a cloud of flame
A naked woman (Marge Piercy, in Fox, 1997)
Running mad through the pure night!
(Juan Ramon Jimenez, in Fox, 1997)

Metaphor is a symbol of an unusual connection. It asks us to use our senses to make a leap we wouldn’t usually make. Music is not usually compared to a naked woman running mad, but this metaphor helps us understand the wild abandon or freedom of the music described by the poet. Rage that is compared to a cloud of flame helps us to understand how hot and angry it really is!

Simile draws comparisons between two different things using the words “like” or “as.” For example, “There is no Frigate like a Book to take us Lands away” (Emily Dickinson, in Fox, 1997) or “They bow shyly as wet swans” (James Wright, in Fox, 1997).
Finally, Personification gives human characteristics to animals, ideas, or inanimate object. Read this brief, but powerful Langston Hughes poem:

**Suicide’s Note**  
The calm,  
Cool face of the river  
Asked me for a kiss

In this poem, the river becomes almost human; a lover with whom the writer wants to be united.

In his poem “Out, Out--“ Robert Frost wrote about a real tragedy in which a young boy lost his hand and his life in a sawmill accident. He gives the saw human, evil motives when he writes:

“The saw,  
As if to prove saws knew what supper meant,  
Leaped out at the boy’s hand, or seemed to leap—“

These four elements of poetry just touch the surface. Many volumes of poetry analysis and criticism have been written. Again, the poetry you write will not be “judged” by professional poets or the suggestions offered here. Your poetry will express your own thoughts, feelings, perceptions, and experiences.

If you find yourself feeling “stuck” and are having trouble writing a poem, consider trying the following:

1. Keep a notebook. Write down words or phrases that come into your head during the day. Use things that you notice or see around the house, on a drive, etc. to start.
2. Try “random writing.” Put down a first phrase, then keep going! Use free association, or just any words that pop into your head—like talking to yourself on paper! This could be the beginning of a poem.
3. Find a poem you really like and try to imitate it. Try to replace some of the words of a written poem with your own words. Deliberately try to sound like that poet. Or try a parody (an exaggerated, mocking version of another’s poem)

Please ask the researcher any questions or concerns you have about poetry or writing poetry during your first interview. Thank you!
Appendix H:  Semi-structured Interview Guide (with feasibility questions)

**Directions to co-investigators:** Please make every attempt to ask these questions of participants; if not word for word, please stay close to the intent of the question.

**Grand Tour Question**

**Tell me what it was like for you to write poetry during this study.**

- What was it like in the beginning?
- What was it like after a while?
- What did you like best about writing poetry?
- What did you like least about writing poetry? OR what was most challenging or troubling for you about writing poetry?
- How helpful was the poetry information sheet? What would have been more helpful?
- Tell me about your favorite poem. What made it your favorite?
- What are you most proud of about the poems you have written?
- Did poetry writing affect the performance of your caregiver duties in any way? If yes—In what way? Please tell me more about that.
- Did poetry writing change your feelings about caregiving in any way? If yes—In what way? Please tell me more about that.
- Did poetry writing change your feelings about the person you are caring for in any way? If yes—In what way? Please tell me more about that.
- Did poetry writing change your feelings about yourself in any way? If yes—please explain.
- Will you consider continuing to write poetry now that the study is concluded? Why or why not?
- What helps you cope with the stresses of caregiving?
- Please tell me about any other events that have taken place during the course of the study that have affected your feelings about yourself, caregiving, or the person you are caring for.
For Group A interviewees (those who wrote poetry during first four weeks):

- Did you write any poems on your during the second four weeks of the study? If yes—tell me what prompted you to continue to write poetry.

Attachment N: Semi-structured Interview Guide (con’t)

Please circle the answer that best describes your opinion:

1. The number of poems I was asked to write during the 4-week time period

   TOO MUCH/MANY       ABOUT RIGHT       MORE WOULD BE OK

2. The amount of my time the interviews took

   TOO MUCH/MANY       ABOUT RIGHT       MORE WOULD BE OK

3. The amount of money provided for my time

   TOO MUCH/MANY       ABOUT RIGHT       MORE WOULD BE OK

4. The number of forms/questionnaires I had to complete

   TOO MUCH/MANY       ABOUT RIGHT       MORE WOULD BE OK

5. The difficulty of the forms/questionnaires I had to complete

   TOO HARD       ABOUT RIGHT       TOO EASY
CAREGIVER POETRY WRITING STUDY

IF YOU ARE A FAMILY CAREGIVER OF AN OLDER ADULT WITH DEMENTIA, YOUR HELP IS NEEDED!!

RESEARCHERS AT CASE WESTERN RESERVE UNIVERSITY ASK YOU TO HELP US FIND OUT IF WRITING POEMS IS A HELPFUL WAY TO REDUCE STRESS, DECREASE NEGATIVE FEELINGS YOU MAY BE HAVING, INCREASE POSITIVE FEELINGS, AND HELP YOU FEEL BETTER IN YOUR CAREGIVER ROLE.

We want to help family caregivers of dementia patients to feel less stress and less sad and to rise above such feelings when they occur. We believe that writing poems may be very helpful. If you take part in the study, you will help us find out whether writing poems helps family caregivers. And, writing poems may help you to feel better in your caregiver role.

This study involves three or four interviews that will take place in a private place. The study takes about five hours of your time plus the time you will need to write three poems over an 8-week period. Those who take part in the study will receive $15 per interview for their time.

IF YOU WANT TO BE IN THE STUDY, PLEASE NOTE THE NAME AND PHONE NUMBER OF THE STUDY LEAD INVESTIGATOR BELOW. PLEASE CALL—THANK YOU!

LORI KIDD  330-670-6509
Appendix J: Cover Letter to Participants

Date

Betsy Ross
195 Independence Way
Philadelphia, PA 17766

Dear Ms. Ross:

Thank you for your interest in participating in a nursing research study entitled “The Effect of a Poetry Writing Intervention on Self-transcendence, Resilience, Depressive Symptoms, and Subjective Burden in Family Caregivers of Older Adults with Dementia.” I have enclosed a Consent Form for the study, as well as a handout of information about poetry writing. Please review these forms. I will contact you in 2-3 weeks after you have had time to review them and set up an appointment for us to meet. I will ask you to bring these forms with you to your first interview. We will discuss them at that time and you may ask any questions you have. I will ask you to sign the consent form if you meet all criteria for this study. In the first interview, I will also ask you to complete a demographic questionnaire, a brief oral questionnaire, and four written instruments. The first interview should take approximately 60-90 minutes and will be the longest interview.

Two more interviews will be set up in four weeks and again at eight weeks, and you will be asked to complete the four instruments again. You will also be asked to give any poems you have written to the researcher. At the end of eight weeks, you may or may not be asked to participate in a fourth interview with the researcher, when you will be asked what this entire experience was like. You will receive financial compensation for your time and participation. Please contact Lori Kidd at 330-972-6703 if you have any questions after receiving this letter and materials.

Sincerely,

Lori I. Kidd, PhD (c), MSN, CNS
Frances Payne Bolton School of Nursing
Case Western Reserve University
APPENDIX K: Short Portable Mental Status Questionnaire (SPMSQ)

THE SHORT PORTABLE MENTAL STATUS QUESTIONNAIRE (SPMSQ)

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
<th>Incorrect Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What are the date, month, and year?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. What is the day of the week?</td>
<td></td>
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<tr>
<td>3. What is the name of this place?</td>
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<tr>
<td>4. What is your phone number?</td>
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<tr>
<td>5. How old are you?</td>
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<tr>
<td>6. When were you born?</td>
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<td></td>
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<tr>
<td>7. Who is the current president?</td>
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<tr>
<td>8. Who was the president before him?</td>
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<tr>
<td>9. What was your mother's maiden name?</td>
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<td></td>
</tr>
<tr>
<td>10. Can you count backward from 20 by 3's?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**SCORING:**

0-2 errors: normal mental functioning  
3-4 errors: mild cognitive impairment  
5-7 errors: moderate cognitive impairment  
8 or more errors: severe cognitive impairment

*One more error is allowed in the scoring if a patient has had a grade school education or less.  
*One less error is allowed if the patient has had education beyond the high school level.

Appendix L: Pre-study Profile of Family Caregivers Sample

The following information was obtained from the Education/Support Group Coordinator of the Alzheimer’s Association, Greater East Ohio Chapter as of April, 2008:

There are 33 listed support group meetings in the Greater East Ohio Chapter at present. Data is not collected on age, gender, race/ethnicity, living with or separate from care recipient, or spousal or other family caregiver; however, the following information was available:

- Meetings are monthly. Average attendance is 5-8. Groups with high attendance include: Canton Day, Cuyahoga Falls, Green, Millersburg, Canfield, East Liverpool, Medina, Ravenna, Alliance, and Massillon.
- In 2007, there were 342 meetings attended by 1777 caregivers
- Gender: Observation is that more women attend than men
- Age: Observation is that age ranges from 40-80, depending upon support group
- Race/ethnicity: Varies depending upon support group, but unable to determine
- Spousal or family caregivers: An estimate is that approx. 75% of support group attendees are spousal caregivers. They typically attend day time meetings. The remaining 25% are children, friends, or other relatives
- Living with or separate from care recipients: Data not collected, but an estimate is 50% live together, 50% separate. Some group members have placed their loved one in an extended care facility.
Appendix M: Telephone Script to Arrange Initial Interview with Participants

Thank you for calling me about taking part in the study “The Effect of a Poetry Writing Intervention on Self-transcendence, Resilience, Depressive Symptoms, and Subjective Burden in Family Caregivers of Older Adults with Dementia.” First, I’d like to ask you—are you at least age 18? If yes: Now I would like to review with you the main points about being in the study and ask if you have any questions.

1. This study lasts at least eight weeks. During that time, I (or another researcher) will ask to meet with you at least three times—now, at 4 weeks, and at 8 weeks. We will also ask you to write at least 3 poems during a four week period. You may be asked for a fourth interview at the end of 8 weeks in which you will be asked what it was like to write poems and how you felt while writing them. Finally, you may be asked for a brief phone interview to give your opinion on researchers’ findings about common themes of poems.

2. During the first interview, I will ask you to fill out a brief form that screens your memory and your ability to focus and concentrate. I will also ask you to fill out a questionnaire that asks about age, race, income, etc. Finally, I will ask you to complete four other questionnaires that look at characteristics I want to find out about. I will ask you to complete these same four questionnaires during the second and third interview. You will receive $15 or a $15 gift card at the end of each face-to-face interview for a total of $45-$60.

3. Before our first meeting, I will mail to you information about giving informed consent. You can bring this signed to our first meeting or sign it in my presence. I will also mail you general information about writing poetry.

Do you have any questions or concerns? If no…..Are you interested in taking part in the study?
If yes…..May I have your mailing address to send you information about the study? I will only contact you at this address. Later, if you are eligible to be in the study, I will also ask you to volunteer a phone number where I may contact you.
I’d like to set up a time and a place for us to meet in 1-2 weeks after you’ve received the information. Can we do that now?
If yes…What would be a good date and time for you? Where would you like to meet (in a place that is private and we won’t be interrupted)? (If inappropriate place or doesn’t know where to meet, say….May I suggest…{various places, starting with local library}). Please contact me if you do not receive the information, if you have any questions, or if you change your mind about being in the study after reading the information. My name is Lori Kidd. I am the lead investigator in the study, and you may contact me at 330-612-4077 or 330-972-6703. Thank you very much for your interest in being in the study. I look forward to meeting with you.
Hello, my name is Lori Kidd. I am a nursing doctoral student at Case Western Reserve University. Nurses know that giving care to a family member with dementia is very stressful and can have negative consequences. I am interested in finding new ways to help reduce those feelings of stress and negative outcomes. I and my colleagues are conducting a study about whether poetry writing helps reduce negative feelings and increase positive feelings in family caregivers of older adults with dementia. Specifically, we are interested in finding out if poetry writing can help reduce feelings of depression and caregiver burden, and increase feelings of optimism, resilience, and self-transcendence (the ability to rise above situations and stressors). Your participation will help us decide if poetry writing is useful for family caregivers. It may also result in positive outcomes for you.

If you decide to participate, I ask you to contact me at one of these phone numbers. The study would involve 3 or 4 interviews and will last 8 weeks. Each private and confidential interview will last approximately 60-90 minutes. During the interviews, you will be asked to complete five paper and pencil questionnaires yourself, your feelings and coping and your emotional status. The researchers will assist you and answer any questions you have. Your total time commitment would be approximately 4-6 hours, plus time needed to write at least 3 poems over an 8 week period. If you qualify to participate, you will receive financial compensation for your time following each interview. All information collected is confidential, and anything that is published would be anonymous. You would not be named and your identity would be protected. I will answer any more specific questions you may have as time permits today. Thank you for your attention.
Appendix O: Contact List of County Community Agencies and Web Sites

**Summit and Portage Counties**

**ABUSE**
- Adult Protective Services 330-643-7217 (Summit) 330-296-2273 (Portage)
- Battered Women’s Shelter 330-374-1111 Toll free 1-888-395-4357
- Rape Crisis Center (Akron)--24 hours 330-434-RAPE
- Rape Crisis Center (general) 1-877-906-7273

**SUMMIT COUNTY CHILDREN’S SERVICES**
- 330-379-1880

**SUMMIT COUNTY ELDER ABUSE PREVENTION COALITION**
- 330-374-0333

**CAREGIVERS**
- Area Agency on Aging 330-896-9172

**COUNSELING**
- Catholic Social Services of Summit County 330-762-7481
- Family Services of Summit County 330-376-9494
- Portage Path Behavioral Health 330-253-4118

**GERIATRICS**
- American Association of Retired Persons www.aarp.org
- Centers for Medicare & Medicaid www.cms.hhs.gov
- Community Services and Programs for Older Adults in Summit County 330-344-7650
- National Council on Aging 1-800-424-9046 www.ncoa.org
- National Institute on Aging Resource Directory for the Elderly 301-496-1752

**HOME HEALTH CARE**
- Gentiva Health Services 330-644-4447
- Praxair Healthcare 330-929-7563
- Medline
- Medina 330-745-1601
- Portage 1-800-225-4994
- Summit-Stark 330-745-1601

**MENTAL HEALTH**
- Community Support Services, Inc. 330-253-9388
- Mental Health Association of Summit County 330-923-0688
- National Alliance for the Mentally Ill 1-800-950-6264 www.NAMI.ORG
Ohio
Support Hotline of Summit County 1-800-686-2646
Portage Path Behavioral Health 330-434-9144
Portage Path Emergency Services 24 Hour Emergency 330-253-4118
330-762-6110

Carroll County
Community Mental Health Center 330-627-4313
Cornerstone Support Services (Addictions) 330-627-3954
Visiting Nurse Association 1-877-627-7625
Area Agency on Aging 1-800-945-4520

Columbiana County
Columbiana County Mental Health Center 330-424-9573
Crisis Hotline 330-424-7767

Coshocton County
Counseling Center of Coshocton County 740-622-3404
Emergency Hotline 1-800-344-5818
Area Agency on Aging 1-800-945-4520

Guernsey County
Guernsey Counseling Center 740-439-4428
Crisis Hotline 1-800-273-8255
Area Agency on Aging 1-800-945-4520

Holmes County
Counseling Center of Wayne & Holmes Counties 330-264-9029
(Wooster) 330-264-9029
Crisis Hotline 330-674-6697
Millersburg 330-683-5106
Orrville 1-800-421-7277
Area Agency on Aging 330-896-9172
Adult Protective Services (Wayne County) 330-287-5800

Mahoning County
Mahoning County Mental Health Board 330-746-2959

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Catholic Charities Regional Agency 330-744-3320
Crisis Hotline 330-747-2696

**Medina County**

Alternative Paths, Inc. 330-725-9195
(Crisis Hotline) 330-725-9195
Catholic Charities Community Services of Medina Co. 330-723-9615

**Muskingum County**

Muskingum Behavioral Health 740-454-1266
Crisis Hotline 1-800-344-5818
740-453-5818
Area Agency on Aging 1-800-945-4250

**Stark County**

The Crisis Center 330-452-9812
Crisis Hotline 330-452-6000
Trillium Family Solutions (Adult Protective Services division) 330-454-7066
1-888-269-0672
Trillium Family Solutions (Massillon Office) 330-832-2427
Area Agency on Aging 1-800-421-7277
330-451-8998

**Trumbull County**

Trumbull Lifeline AOL & Mental Health Network 330-675-2765
Crisis Hotline 330-393-1175
Adult Mental Health at Forum Health 330-841-9942
Geropsychiatry Program at Forum Health 330-841-9914

**Tuscarawas County**

Community Mental Health Center 330-343-6631
Area Agency on Aging
Tuscarawas County Dept. of Job & Family Services 1-800-431-2347
(Adult Protective Services) 330-339-7791
Area Agency on Aging 1-800-945-4250

**Cuyahoga County**

ABUSE
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<tr>
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</thead>
<tbody>
<tr>
<td>Department of Senior &amp; Adult Services</td>
<td>216-420-6750</td>
</tr>
<tr>
<td>(Adult Protective Services)</td>
<td></td>
</tr>
<tr>
<td>Children and Family Services (child abuse)</td>
<td>216-696-KIDS</td>
</tr>
<tr>
<td>Rape Crisis Center (Cleveland)—24 hour hotline</td>
<td>216-619-6192</td>
</tr>
<tr>
<td>Bellflower Center</td>
<td>216-229-3400</td>
</tr>
<tr>
<td><strong>CAREGIVERS</strong></td>
<td></td>
</tr>
<tr>
<td>Eldercare Services Institute (Benjamin Rose Institute)</td>
<td>216-791-8000</td>
</tr>
<tr>
<td>Warren Reserve Area Agency on Aging</td>
<td>216-621-8010</td>
</tr>
<tr>
<td>Alzheimers Association, Cleveland Chapter</td>
<td>216-721-8457</td>
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<tr>
<td><strong>COUNSELING</strong></td>
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</tr>
<tr>
<td>Berea Children’s Home and Family Services</td>
<td>440-234-2006</td>
</tr>
<tr>
<td>Center for Families and Children (main office)</td>
<td>216-432-7200</td>
</tr>
<tr>
<td>Catholic Charities Services of Cuyahoga County</td>
<td>216-631-3499</td>
</tr>
<tr>
<td><strong>GERIATRICS</strong></td>
<td></td>
</tr>
<tr>
<td>American Association of Retired Persons</td>
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</tr>
<tr>
<td>National Institute on Aging Resource Directory for the Elderly</td>
<td>301-496-1752</td>
</tr>
<tr>
<td>St. Vincent Charity Geropsychiatry</td>
<td>1-800-810-7294</td>
</tr>
<tr>
<td><strong>MENTAL HEALTH</strong></td>
<td></td>
</tr>
<tr>
<td>24 hour Mental Health crisis, info, &amp; referral hotline</td>
<td>216-623-6888</td>
</tr>
<tr>
<td>Cuyahoga County Community Mental Health Board</td>
<td>216-241-3400</td>
</tr>
<tr>
<td>St. Vincent Charity Psychiatric Emergency Dept.</td>
<td>216-363-2538</td>
</tr>
<tr>
<td>National Alliance for the Mentally Ill (NAMI) of Greater Cleveland</td>
<td>216-875-7776</td>
</tr>
<tr>
<td>Office of Homeless Services (shelters for men and Women)</td>
<td>216-420-6844</td>
</tr>
</tbody>
</table>
Appendix P: Script for Ineligible Participants

Thank you for your interest in taking part in the nursing research study called “The Effect of a Poetry Writing Intervention on Self-transcendence, Resilience, Depressive Symptoms, and Subjective Burden in Family Caregivers of Older Adults with Dementia.” I am sorry to tell you that you will not be eligible to take part in the study. You were not able to meet certain criteria that would qualify you to be in the study. I would like to thank you very much for your willingness to participate.

If ineligible related to cognitive deficits (SPMSQ), state:

I would like to give you referral information. I encourage you to call to talk to someone about the memory and concentration problems you are having (provide contact list for county).

If ineligible related to journaling or other method expressive writing, state:

I am pleased that you are already using journaling/expressive writing to help you deal with care giver stress. But this means that you cannot take part in this study at this time. I encourage you to continue doing this if you find this helpful.

If ineligible related to suicidal depression:

I am concerned about your mental health, especially what you shared with me about thoughts of death and suicide. I need to tell you that I must report what you told me because this is my ethical responsibility. I would ask you to make a phone call with me right now for emergency mental health help.
Appendix Q: Individual Data Display of Pre-and Post-intervention Scores with Demographic Variables

Trends on Resilience Scores for Group A – randomized to poetry-writing after baseline measures and followed over time.

<table>
<thead>
<tr>
<th>Age</th>
<th>Race</th>
<th>Gender</th>
<th>Baseline Score</th>
<th>Post-intervention Score</th>
<th>Cont. Poems (Y or N)</th>
<th>Final Score</th>
<th>Comment on trend observed</th>
</tr>
</thead>
<tbody>
<tr>
<td>56</td>
<td>White</td>
<td>Female</td>
<td>72</td>
<td>67</td>
<td>Y</td>
<td>64</td>
<td>Lower resilience, lower scores after intervention &amp; at Time 3—overall, lower resilience from baseline to end of study</td>
</tr>
<tr>
<td>66</td>
<td>White</td>
<td>Female</td>
<td>137</td>
<td>141</td>
<td>Y</td>
<td>142</td>
<td>Higher resilience after intervention &amp; even higher at Time 3—overall, higher resilience from baseline to end of study</td>
</tr>
<tr>
<td>53</td>
<td>White</td>
<td>Female</td>
<td>133</td>
<td>125</td>
<td>Y</td>
<td>129</td>
<td>Lower resilience after intervention, but increased by Time 3—still lower than baseline. Overall, lower resilience from baseline to end of study</td>
</tr>
<tr>
<td>58</td>
<td>White</td>
<td>Female</td>
<td>137</td>
<td>141</td>
<td>Y</td>
<td>154</td>
<td>Higher resilience after intervention &amp; much higher by Time 3—overall, higher resilience from baseline to end of study</td>
</tr>
<tr>
<td>72</td>
<td>White</td>
<td>Female</td>
<td>132</td>
<td>120</td>
<td>N</td>
<td>113</td>
<td>Lower resilience</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
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<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>43</td>
<td>White</td>
<td>Female</td>
<td>137</td>
<td>123</td>
<td>N</td>
<td>125</td>
<td>Lower resilience after intervention &amp; at Time 3—overall, lower resilience from baseline to end of study</td>
</tr>
<tr>
<td>80</td>
<td>White</td>
<td>Female</td>
<td>140</td>
<td>152</td>
<td>Y</td>
<td>139</td>
<td>Higher resilience after intervention, fell at Time 3 to baseline—overall, resilience remained same but higher after intervention</td>
</tr>
<tr>
<td>41</td>
<td>White</td>
<td>Female</td>
<td>130</td>
<td>120</td>
<td>N</td>
<td>112</td>
<td>Lower resilience after intervention &amp; even lower at Time 3; fell steadily—overall, lower resilience from baseline to end of study</td>
</tr>
<tr>
<td>58</td>
<td>White</td>
<td>Female</td>
<td>152</td>
<td>149</td>
<td>N</td>
<td>150</td>
<td>Lower resilience after intervention (slightly), remained same at Time 3—overall, resilience lower from baseline to end of study</td>
</tr>
<tr>
<td>59</td>
<td>White</td>
<td>Female</td>
<td>134</td>
<td>112</td>
<td>Y</td>
<td>126</td>
<td>Lower resilience after intervention, but returned closer to baseline by Time</td>
</tr>
</tbody>
</table>
Trends on Resilience Scores for Group B – randomized to waiting list control followed by poetry-writing

<table>
<thead>
<tr>
<th>Age</th>
<th>Race</th>
<th>Gender</th>
<th>Baseline Score</th>
<th>Pre-intervention Score</th>
<th>Post-intervention Score</th>
<th>Comment on trend observed</th>
</tr>
</thead>
<tbody>
<tr>
<td>75</td>
<td>White</td>
<td>Male</td>
<td>130</td>
<td>134</td>
<td>138</td>
<td>Higher resilience after intervention (also increased after waiting for intervention Time 2)</td>
</tr>
<tr>
<td>74</td>
<td>White</td>
<td>Female</td>
<td>127</td>
<td>123</td>
<td>117</td>
<td>Lower resilience each testing time—post intervention &amp; while waiting to begin intervention</td>
</tr>
<tr>
<td>54</td>
<td>White</td>
<td>Female</td>
<td>120</td>
<td>132</td>
<td>124</td>
<td>Lower resilience after intervention; higher than baseline, but lower than waiting testing time</td>
</tr>
<tr>
<td>69</td>
<td>White</td>
<td>Male</td>
<td>158</td>
<td>148</td>
<td>138</td>
<td>Lower resilience each testing time; much lower post-intervention than baseline</td>
</tr>
<tr>
<td>47</td>
<td>White</td>
<td>Female</td>
<td>95</td>
<td>108</td>
<td>102</td>
<td>Lower resilience after intervention, but higher than baseline</td>
</tr>
<tr>
<td>70</td>
<td>White</td>
<td>Female</td>
<td>141</td>
<td>123</td>
<td>138</td>
<td>Resilience highest at baseline, but large increase from waiting Time 2 to Time 3 after intervention</td>
</tr>
<tr>
<td>64</td>
<td>White</td>
<td>Male</td>
<td>145</td>
<td>146</td>
<td>147</td>
<td>Resilience increased slightly across testing times of study; higher after</td>
</tr>
</tbody>
</table>
### Trends on Self-transcendence Scores for Group A – randomized to poetry-writing after baseline measures and followed over time.

<table>
<thead>
<tr>
<th>Age</th>
<th>Race</th>
<th>Gender</th>
<th>Baseline Score</th>
<th>Post-intervention Score</th>
<th>Cont. Poems (Y or N)</th>
<th>Final Score</th>
<th>Comment on trend observed</th>
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<tbody>
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<td>Female</td>
<td>42</td>
<td>39</td>
<td>Y</td>
<td>36</td>
<td>Lower self-transcendence at end of study &amp; at each data collection time</td>
</tr>
<tr>
<td>66</td>
<td>White</td>
<td>Female</td>
<td>56</td>
<td>51</td>
<td>Y</td>
<td>46</td>
<td>Lower self-transcendence at end of study &amp; at each data collection time</td>
</tr>
<tr>
<td>53</td>
<td>White</td>
<td>Female</td>
<td>51</td>
<td>46</td>
<td>Y</td>
<td>48</td>
<td>Lower self-transcendence after intervention (Time 2), but increased by Time 3</td>
</tr>
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<td>58</td>
<td>White</td>
<td>Female</td>
<td>54</td>
<td>52</td>
<td>Y</td>
<td>55</td>
<td>Lower self-</td>
</tr>
<tr>
<td>Age</td>
<td>Race</td>
<td>Gender</td>
<td>Time 1</td>
<td>Time 2</td>
<td>Gender</td>
<td>Time 3</td>
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<tr>
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<td>White</td>
<td>Female</td>
<td>51</td>
<td>51</td>
<td>N</td>
<td>49</td>
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</tr>
<tr>
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<td>N</td>
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<td>59</td>
<td>Y</td>
<td>54</td>
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<td>Female</td>
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<td>N</td>
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</tr>
<tr>
<td>59</td>
<td>White</td>
<td>Female</td>
<td>48</td>
<td>47</td>
<td>Y</td>
<td>45</td>
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</tbody>
</table>
Trends on Self-transcendence Scores for Group B – randomized to waiting list control followed by poetry-writing

<table>
<thead>
<tr>
<th>Age</th>
<th>Race</th>
<th>Gender</th>
<th>Baseline Score</th>
<th>Pre-intervention Score</th>
<th>Post-intervention Score</th>
<th>Comment on trend observed</th>
</tr>
</thead>
<tbody>
<tr>
<td>75</td>
<td>White</td>
<td>Male</td>
<td>51</td>
<td>51</td>
<td>52</td>
<td>Higher self-transcendence after intervention (but essentially unchanged from baseline &amp; pre-intervention)</td>
</tr>
<tr>
<td>74</td>
<td>White</td>
<td>Female</td>
<td>53</td>
<td>48</td>
<td>48</td>
<td>Lower self-transcendence after intervention (same as pre-intervention decrease)</td>
</tr>
<tr>
<td>54</td>
<td>White</td>
<td>Female</td>
<td>53</td>
<td>49</td>
<td>51</td>
<td>Higher self-transcendence after intervention (but lower than baseline)</td>
</tr>
<tr>
<td>69</td>
<td>White</td>
<td>Male</td>
<td>54</td>
<td>59</td>
<td>54</td>
<td>Lower self-transcendence after intervention (but same as baseline)</td>
</tr>
<tr>
<td>47</td>
<td>White</td>
<td>Female</td>
<td>43</td>
<td>39</td>
<td>40</td>
<td>Self-transcendence lower than baseline, but same as pre-intervention score</td>
</tr>
<tr>
<td>70</td>
<td>White</td>
<td>Female</td>
<td>54</td>
<td>54</td>
<td>55</td>
<td>Self-transcendence unchanged (only one point higher than baseline &amp; pre-intervention)</td>
</tr>
<tr>
<td>64</td>
<td>White</td>
<td>Male</td>
<td>52</td>
<td>54</td>
<td>54</td>
<td>Higher self-transcendence after intervention (same as pre-intervention Time 2)</td>
</tr>
<tr>
<td>53</td>
<td>White</td>
<td>Female</td>
<td>54</td>
<td>55</td>
<td>56</td>
<td>Higher self-transcendence after intervention (and</td>
</tr>
<tr>
<td>Age</td>
<td>Race</td>
<td>Gender</td>
<td>Baseline Score</td>
<td>Post-intervention Score</td>
<td>Cont. Poems (Y or N)</td>
<td>Final Score</td>
</tr>
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<td>-----</td>
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</tr>
<tr>
<td>54</td>
<td>Af. Am</td>
<td>Female</td>
<td>57</td>
<td>56</td>
<td></td>
<td>57</td>
</tr>
<tr>
<td>56</td>
<td>White</td>
<td>Female</td>
<td>49</td>
<td>41</td>
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<td>52</td>
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</table>

Trends on Depressive Symptoms Scores for Group A – randomized to poetry writing after baseline measures and followed over time.

<table>
<thead>
<tr>
<th>Age</th>
<th>Race</th>
<th>Gender</th>
<th>Baseline Score</th>
<th>Post-intervention Score</th>
<th>Cont. Poems (Y or N)</th>
<th>Final Score</th>
<th>Comment on trend observed</th>
</tr>
</thead>
<tbody>
<tr>
<td>56</td>
<td>White</td>
<td>Female</td>
<td>39</td>
<td>39</td>
<td>Y</td>
<td>40</td>
<td>Depressive symptoms unchanged after intervention &amp; essentially unchanged at end of study</td>
</tr>
<tr>
<td>66</td>
<td>White</td>
<td>Female</td>
<td>5</td>
<td>4</td>
<td>Y</td>
<td>8</td>
<td>Lower depressive symptoms after intervention, but higher depressive symptoms at end of study than baseline &amp; post-intervention (Time 2)</td>
</tr>
<tr>
<td>53</td>
<td>White</td>
<td>Female</td>
<td>8</td>
<td>14</td>
<td>Y</td>
<td>6</td>
<td>Higher depressive symptoms after intervention; lower depressive symptoms by end of study than</td>
</tr>
<tr>
<td></td>
<td>Ethnicity</td>
<td>Sex</td>
<td>Age</td>
<td>Depression Score</td>
<td>Time</td>
<td>Baseline Depression Status</td>
<td>Notes</td>
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</tr>
<tr>
<td>58</td>
<td>White</td>
<td>Female</td>
<td>9</td>
<td>7</td>
<td>Y</td>
<td>1</td>
<td>Lower depressive symptoms after intervention; substantially lower depressive symptoms by end of study than baseline &amp; post-intervention (Time 2)</td>
</tr>
<tr>
<td>72</td>
<td>White</td>
<td>Female</td>
<td>8</td>
<td>13</td>
<td>N</td>
<td>16</td>
<td>Higher depressive symptoms after intervention &amp; even higher by end of study than baseline</td>
</tr>
<tr>
<td>43</td>
<td>White</td>
<td>Female</td>
<td>21</td>
<td>23</td>
<td>N</td>
<td>22</td>
<td>Higher depressive symptoms after intervention; slightly lower depressive symptoms by end of study (Time 3) than baseline, but remained essentially the same level throughout study</td>
</tr>
<tr>
<td>80</td>
<td>White</td>
<td>Female</td>
<td>7</td>
<td>14</td>
<td>Y</td>
<td>17</td>
<td>Higher depressive symptoms after intervention &amp; even higher by end of study than baseline</td>
</tr>
<tr>
<td>41</td>
<td>White</td>
<td>Female</td>
<td>23</td>
<td>17</td>
<td>N</td>
<td>13</td>
<td>Lower depressive symptoms after intervention &amp; even lower by end of study than baseline</td>
</tr>
<tr>
<td>58</td>
<td>White</td>
<td>Female</td>
<td>7</td>
<td>20</td>
<td>N</td>
<td>11</td>
<td>Higher depressive</td>
</tr>
<tr>
<td>Age</td>
<td>Race</td>
<td>Gender</td>
<td>Baseline Score</td>
<td>Pre-intervention Score</td>
<td>Post-intervention Score</td>
<td>Comment on trend observed</td>
<td></td>
</tr>
<tr>
<td>-----</td>
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<td></td>
</tr>
<tr>
<td>59</td>
<td>White</td>
<td>Female</td>
<td>19</td>
<td>21</td>
<td>Y</td>
<td>Higher depressive symptoms after intervention, but lower than baseline by end of study (Time 3)</td>
<td></td>
</tr>
<tr>
<td>59</td>
<td>White</td>
<td>Female</td>
<td>21</td>
<td>Y</td>
<td>18</td>
<td>Higher depressive symptoms after intervention, but lower than baseline by end of study (Time 3)</td>
<td></td>
</tr>
<tr>
<td>75</td>
<td>White</td>
<td>Male</td>
<td>4</td>
<td>1</td>
<td>3</td>
<td>Higher depressive symptoms after intervention, but lower than baseline</td>
<td></td>
</tr>
<tr>
<td>74</td>
<td>White</td>
<td>Female</td>
<td>21</td>
<td>24</td>
<td>31</td>
<td>Higher depressive symptoms after intervention &amp; higher than baseline</td>
<td></td>
</tr>
<tr>
<td>54</td>
<td>White</td>
<td>Female</td>
<td>16</td>
<td>21</td>
<td>17</td>
<td>Higher depressive symptoms after intervention, but lower than pre-intervention (Time 2)</td>
<td></td>
</tr>
<tr>
<td>69</td>
<td>White</td>
<td>Male</td>
<td>7</td>
<td>2</td>
<td>12</td>
<td>Higher depressive symptoms after intervention &amp; higher than baseline</td>
<td></td>
</tr>
<tr>
<td>47</td>
<td>White</td>
<td>Female</td>
<td>19</td>
<td>22</td>
<td>17</td>
<td>Lower depressive symptoms after intervention &amp;</td>
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</tr>
</tbody>
</table>

**Trends on Depressive Symptoms Scores for Group B – randomized to waiting list control followed by poetry-writing**
<table>
<thead>
<tr>
<th>Age</th>
<th>Race</th>
<th>Gender</th>
<th>Baseline Score</th>
<th>Post-intervention Score</th>
<th>Cont. Poems (Y or N)</th>
<th>Final Score</th>
<th>Comment on trend observed</th>
</tr>
</thead>
<tbody>
<tr>
<td>70</td>
<td>White</td>
<td>Female</td>
<td>15</td>
<td>9</td>
<td></td>
<td>10</td>
<td>Lower depressive symptoms after intervention; unchanged from pre-intervention (Time 2)</td>
</tr>
<tr>
<td>64</td>
<td>White</td>
<td>Male</td>
<td>8</td>
<td>6</td>
<td></td>
<td>3</td>
<td>Lower depressive symptoms after intervention &amp; lower than baseline</td>
</tr>
<tr>
<td>53</td>
<td>White</td>
<td>Female</td>
<td>35</td>
<td>11</td>
<td></td>
<td>12</td>
<td>Lower depressive symptoms after intervention, but unchanged from pre-intervention (Time 2)**</td>
</tr>
<tr>
<td>54</td>
<td>Af. Am</td>
<td>Female</td>
<td>8</td>
<td>7</td>
<td></td>
<td>14</td>
<td>Higher depressive symptoms after intervention &amp; higher than baseline</td>
</tr>
<tr>
<td>56</td>
<td>White</td>
<td>Female</td>
<td>18</td>
<td>33</td>
<td></td>
<td>8</td>
<td>Lower depressive symptoms after intervention &amp; lower than baseline</td>
</tr>
</tbody>
</table>

Trends on Caregiver Burden Scores for Group A – randomized to poetry-writing after baseline measures and followed over time.
<table>
<thead>
<tr>
<th>ID</th>
<th>Race</th>
<th>Gender</th>
<th>Age 1</th>
<th>Age 2</th>
<th>Gender Y</th>
<th>YN</th>
<th>Description</th>
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<tr>
<td>53</td>
<td>White</td>
<td>Female</td>
<td>14</td>
<td>17</td>
<td>Y</td>
<td>15</td>
<td>Higher burden after intervention; back to baseline by end of study</td>
</tr>
<tr>
<td>58</td>
<td>White</td>
<td>Female</td>
<td>5</td>
<td>2</td>
<td>Y</td>
<td>0</td>
<td>Lower burden after intervention &amp; lower burden at end of study than baseline &amp; post-intervention (Time 2)</td>
</tr>
<tr>
<td>72</td>
<td>White</td>
<td>Female</td>
<td>16</td>
<td>19</td>
<td>N</td>
<td>22</td>
<td>Higher burden after intervention; even higher burden by end of study than baseline &amp; post-intervention (Time 2)</td>
</tr>
<tr>
<td>43</td>
<td>White</td>
<td>Female</td>
<td>18</td>
<td>19</td>
<td>N</td>
<td>20</td>
<td>Higher burden after intervention &amp; higher burden by end of study than baseline &amp; post-intervention (Time 2)</td>
</tr>
<tr>
<td>80</td>
<td>White</td>
<td>Female</td>
<td>6</td>
<td>6</td>
<td>Y</td>
<td>7</td>
<td>Burden same after intervention; essentially unchanged at end of study from baseline</td>
</tr>
<tr>
<td>41</td>
<td>White</td>
<td>Female</td>
<td>18</td>
<td>17</td>
<td>N</td>
<td>14</td>
<td>Lower burden after intervention &amp; even lower burden by end of study than baseline &amp; post-intervention (Time 2)</td>
</tr>
<tr>
<td>58</td>
<td>White</td>
<td>Female</td>
<td>8</td>
<td>23</td>
<td>N</td>
<td>15</td>
<td>Higher burden</td>
</tr>
</tbody>
</table>
after intervention, but lower burden by end of study than post-intervention (Time 2); however, still higher than baseline

<table>
<thead>
<tr>
<th>Age</th>
<th>Race</th>
<th>Gender</th>
<th>Baseline Score</th>
<th>Pre-intervention Score</th>
<th>Post-intervention Score</th>
<th>Comment on trend observed</th>
</tr>
</thead>
<tbody>
<tr>
<td>59</td>
<td>White Female</td>
<td>21</td>
<td>23</td>
<td>Y</td>
<td>25</td>
<td>Higher burden after intervention &amp; still higher by end of study than baseline &amp; post-intervention (Time 2)</td>
</tr>
</tbody>
</table>

Trends on Caregiver Burden Scores for Group B – randomized to waiting list control followed by poetry-writing

<table>
<thead>
<tr>
<th>Age</th>
<th>Race</th>
<th>Gender</th>
<th>Baseline Score</th>
<th>Pre-intervention Score</th>
<th>Post-intervention Score</th>
<th>Comment on trend observed</th>
</tr>
</thead>
<tbody>
<tr>
<td>75</td>
<td>White Male</td>
<td>10</td>
<td>10</td>
<td>9</td>
<td>Lower burden after intervention, but essentially unchanged from pre-intervention (Time 2)</td>
<td></td>
</tr>
<tr>
<td>74</td>
<td>White Female</td>
<td>32</td>
<td>26</td>
<td>29</td>
<td>Higher burden after intervention than pre-intervention, but lower than baseline</td>
<td></td>
</tr>
<tr>
<td>54</td>
<td>White Female</td>
<td>14</td>
<td>29</td>
<td>25</td>
<td>Lower burden after intervention, but higher than baseline</td>
<td></td>
</tr>
<tr>
<td>69</td>
<td>White Male</td>
<td>12</td>
<td>14</td>
<td>9</td>
<td>Lower burden after intervention &amp; lower than baseline</td>
<td></td>
</tr>
<tr>
<td>47</td>
<td>White Female</td>
<td>16</td>
<td>19</td>
<td>15</td>
<td>Lower burden after intervention, but essentially unchanged from baseline</td>
<td></td>
</tr>
<tr>
<td>70</td>
<td>White Female</td>
<td>7</td>
<td>20</td>
<td>16</td>
<td>Lower burden after</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Race</td>
<td>Gender</td>
<td>Age</td>
<td>Score</td>
<td>Burden of Disease</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>--------</td>
<td>--------</td>
<td>------</td>
<td>-------</td>
<td>-------------------</td>
<td></td>
</tr>
<tr>
<td>64</td>
<td>White</td>
<td>Male</td>
<td>11</td>
<td>13</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Lower burden after intervention &amp; lower than baseline</td>
<td></td>
</tr>
<tr>
<td>53</td>
<td>White</td>
<td>Female</td>
<td>28</td>
<td>29</td>
<td>25</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Lower burden after intervention &amp; lower than baseline</td>
<td></td>
</tr>
<tr>
<td>54</td>
<td>Af. Am</td>
<td>Female</td>
<td>11</td>
<td>8</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Higher burden after intervention, but lower than or essentially unchanged from baseline</td>
<td></td>
</tr>
<tr>
<td>56</td>
<td>White</td>
<td>Female</td>
<td>30</td>
<td>37</td>
<td>33</td>
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<td></td>
<td></td>
<td></td>
<td>Lower burden after intervention, but higher than baseline</td>
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</table>
References


Writing Standards articulated by Grade Level, Grade 6—Strand 2: Writing

Components. Retrieved January 12, 2008 from

Barleben, S. (1993). Women over the edge--a challenge to care: A
phenomenological/hermeneutic inquiry on the experience of homelessness for
women with children. Unpublished Doctor of Philosophy. Denver, CO:
University of Colorado.


Baumgarten, M., Battista, R.N., Infante-Rivard, C., Hanley, J., Becker, R., & Gauthier, S.
(1992). The psychological and physical health of family members caring for an
elderly person with dementia. Journal of Clinical Epidemiology, 45, 61-70.

The Psychological Corporation.

Bedard, M., Mollowy, D.W., Squire, L., Dubois, S., Lever, J.A., & O’Donnell, M.
The Gerontologist, 41, 652-657.

and caregiver health-related quality of life in Alzheimer disease. Alzheimer
Disease and Associated Disorders, 15, 129-136.

Bergman-Evans, B. (1994). A health profile of spousal Alzheimer’s caregivers:
Depression and physical health characteristics. Journal of Psychosocial Nursing
and Mental Health Services, 32, 25-30.

Berkowitz, L. (Ed.). Advances in experimental social psychology, 22, 211-244.


stress disorder (PTSD) symptoms and abuse attribution in abused children.


statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods, 39*, 175-191.


Existentialist philosophy (pp. 329-337).


Howard, A.A. (1997). The effects of music and poetry therapy on the treatment of


Kidd, L. & Tusaie, K. (2004). Disconfirming beliefs: The use of poetry to know the lived


Development, 62, 600-616.


Retrieved January 26, 2008 from
http://nihseniorhealth.gov/alzheimersdisease/causes/01.html


Pelusi, J. (1997). The lived experience of surviving breast cancer. *Oncology Nursing*


stressful experiences on symptom reduction in patients with rheumatoid arthritis:
A randomized trial, *JAMA, 281*(14), 1304-1309.
Takahashi, M., Tanaka, K., & Miyaoka, H. (2005). Depression and associated factors of
informal caregivers versus professional caregivers of demented patients.


