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Distance Education and Dementia Caregivers: A Comparison of Three Methods

Mary Colleen Corrigan

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This is to certify that the dissertation prepared by Mary C. Corrigan entitled *Distance Education and Dementia Caregivers: A Comparison of Three Methods*, has been approved by his committee as satisfactory completion of the dissertation requirement for the degree Doctor of Philosophy.

[redacted]

Iris A. Parham, Ph.D., Dissertation Committee Chair
Department of Gerontology, School of Allied Health Professions

[redacted]

J. James Cotter, Ph.D., Dissertation Committee Member
Department of Gerontology, School of Allied Health Professions

[redacted]

E. Ayn Welleford, Ph.D., Dissertation Committee Member
Department of Gerontology, School of Allied Health Professions

[redacted]

Diane Dodd-McCue, Ph.D., Dissertation Committee Member
Office of the Dean, School of Allied Health Professions

[redacted]

Cecil B. Drain, Ph.D., Professor and Dean
School of Allied Health Professions

[redacted]

Albert T. Sneden, Ph.D., Interim Dean
School of Graduate Studies

4/29/02
Date

Distance Education and Dementia Caregivers:
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A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

by

Mary Colleen Corrigan,
Bachelor of Science, Kansas State University, 1973
Master of Arts, Wichita State University, 1978

Director: Iris A. Parham, Ph.D.
Professor and Chair, Department of Gerontology

Virginia Commonwealth University
Richmond, Virginia
April, 2002

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"May the road rise to meet you,
May the wind be always at your back,
May the sun shine warm upon your face,
May the rain fall soft upon your fields,
And until we meet again,
May God hold you in the palm of his hand."

Table of Contents

List of Tables

List of Figures

ABSTRACT

DISTANCE EDUCATION AND DEMENTIA CAREGIVERS: A COMPARISON OF THREE METHODS

Mary Colleen Corrigan
Doctor of Philosophy in Health Related Sciences – Gerontology Specialization

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

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Director: Iris A. Parham, Ph.D.
Professor and Chair, Department of Gerontology

The purpose of the research is to examine the family experience of dementia caregiving and design an educational intervention to assist family members in the caregiving role. Stress results when a caregiver confronts environmental demands (dementia behaviors) that threaten personal well-being. The perception of threat is the process of primary stress appraisal. Caregivers evaluate coping options, a process of secondary stress appraisal. Positive secondary appraisal (view the situation as amenable to change) has the potential to trigger re-appraisal of the primary threat, and to reduce overall stress.

Education is one way to affect secondary appraisal. Adult learners benefit from progressive (problem solving) approaches using self-directed learning principles. With self-directed learning, the educator facilitates the learner's access to the information. Distance education is a form of self-directed learning. Distance techniques include postal mail, facsimile, telephone, video, teleconferencing, satellite conferencing, and the Internet. The research question is: to what extent can distance education (by postal mail, passive Internet, and multimedia, interactive Internet) alter the primary and secondary stress appraisals of dementia caregivers?

A total of 189 caregivers participated in the study. The study design, Switching Replications, includes three waves of measurement over a two month period. With the design, some participants receive the intervention upon entry into the study, while others wait until after the second wave of measurement.

Three study hypotheses relate to the construct of primary appraisal and the dependent variable of threat perception. Analysis of Variance (ANOVA) results do not support hypotheses that posit the form of education affects threat perception. Four hypotheses address the construct of secondary appraisal and the dependent variable of home modifications. ANOVA results support hypotheses that posit the form of education affects home modifications. Active web education is statistically better than receiving no education or receiving information by postal mail.

Assuming no cure or effective treatment, the number of people diagnosed with dementia will increase to 8.6 million by 2040 (General Accounting Office, 1998). Despite the stress, families are and will likely remain the primary caregivers. Distance education merits further study as a way to reach and help family caregivers.

CHAPTER 1

Introduction

Preface

Providing home care to an adult family member with physical and/or cognitive impairments is a stressful experience. Three meta-analyses find general support for hypotheses that posit caregiving stress increases the risk for psychiatric morbidity (depression, anxiety, and negative affect) and physical morbidity (self-rated health declines, illness symptoms, health service utilization, and reduction in health promotion behaviors) (Yee & Schulz, 2000; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Schulz, Visintainer, & Williamson, 1990). Four years of longitudinal data from the Caregiver Health Effects Study document increased mortality risks as well. Spouses who report a sense of strain from the caregiving experience have mortality risks 63 percent higher than a non-caregiving control group (Schulz & Beach, 1999). Caregivers not experiencing strain have the same mortality rates as the control group.

When the reason for caregiving is dementia, unique disease-related factors influence caregiver stress. Dementia is an umbrella term used to describe over 70 illnesses that cause impairment in short and long-term memory, higher cortical function (such as abstract thinking and judgment), and the ability to complete activities of daily living (ranging from personal care and grooming, to meal preparation and home management) (Cohen, 1983). The most common forms of dementia are Alzheimer's Disease (50 to 60 percent of all cases) and vascular/multi-infarct dementia (10 to 20 percent of all cases (Zarit & Zarit, 1998; Katzman, 1995). The progressive physical and cognitive nature of dementia due to Alzheimer's Disease correlates with increased perceptions of caregiver burden over time (Vitaliano, Russo, Young, Teri, & Maiuro, 1991). The more sudden onset of vascular dementia correlates with higher burden and demands at the start of the caregiving process (Teel, Duncan, & Lai, 2001; Vetter, Krauss, Steiner, Kropp, Moller, Moises, & Koller, 1999).

Despite the stress of dementia caregiving, family members rise to the challenge and serve as the backbone of the long-term care system (Noelker, 2001). Seventy percent of individuals with dementia reside in the home setting (Alzheimer's Association 2001a). Most families, 72 percent, do not use any formal (paid) long-term care services (National Academy on an Aging Society, 2000b).

Family members want to provide effective dementia care (Schumacher, Stewart, & Archbold, 1998), but information deficits make the job difficult. An Alzheimer's Association study involving 376 caregivers and 500 primary care physicians documents education and communication problems (Roper Starch Worldwide, Inc., 2001). Approximately 58 percent of caregivers identify the physician as their main source of information and education. While 83 percent of physicians say they provide detailed information about the dementia diagnosis and future expectations, only 38 percent of caregivers report receiving such information. Many caregivers, 57 percent, indicated a desire for detailed information. Only 23 percent of caregivers said they received information on ways to cope with difficult dementia behaviors, although 81 percent of physicians reported providing such information. Most physicians, 73 percent, indicate they referred the family to support groups and other education resources, but only 24 percent of family members recalled receiving the information. An older study documented similar findings (Chenoweth & Spence, 1986). The problem is common in other countries as well (Commissaris, Jolles, Verhey, & Kok, 1995).

The information gap is not due to a lack of dementia knowledge by physicians. A stratified random study of 1,727 primary care physicians in the American Medical Association database found physicians to be well informed about the disease (Brown, Mutran, Sloane, & Long, 1998). Part of the problem may be the progressive, and therefore changing nature of most dementing illnesses (Mitnitski, Graham, Mogilner, & Rockwood, 1999). Information provided at one physician visit might not be useful to the caregiver at the time. The stress of caregiving may impair the subsequent recall of the information. Therefore, caregivers need easy access to pertinent information and education that applies to the challenges currently faced in the home setting.

Statement of Purpose and Aims of the Study

The purpose of this study is to examine the family experience of dementia caregiving and design an education intervention to assist family members with the caregiving role. To accomplish this task, several areas of literature require review. This chapter will examine the background and current experience of dementia caregiving, and document the social impact of caregiving.

Chapter 2 expands the discussion by framing the experience within a theoretical model of caregiving stress, with the aim to identify possible points of intervention. It is equally important to examine the strengths and weaknesses of previous caregiver intervention programs. Given the previously documented need of caregivers for information (Roper Starch Worldwide, Inc., 2001), it is necessary to examine adult education theories that can help guide the design of any intervention program. A general review of intervention results appears in this chapter, along with an overview of adult education perspectives.

The next step in accomplishing the study purpose is blending the theories on caregiver stress and adult education. This occurs in the last part of Chapter 2, along with the presentation of hypotheses specific to intervention research in this study. Chapter 3 reviews the methodology for the study, including the research design, procedures, and statistical analysis. Chapter 4 describes the study results, while Chapter 5 highlights implications and limitations of the study.

Background and Significance

This section addresses five related issues: the experience of dementia and caregiving over time, the current caregiving experience, the societal impact of caregiving, review of education intervention efforts, and future opportunities.

Dementia and Caregiving Over Time

The first recorded issue regarding dementia caregiving dates to a 500 BC Grecian law (Torack, 1983). If a family could show that "mental afflictions of old age" impaired judgment, the affected member could not deed property to a non-family member. More references to mental afflictions occurred during Greco-Roman time. The descriptions were derogatory; affected individuals were either possessed by the devil or childish and wanton in nature. Neither deserved help. Despite the recorded awareness, dementing illnesses were rare because few individuals lived long enough to develop the disorders. Dementia has an age correlation. Only 2.8 percent of persons between ages 65 and 74 have some form of dementia; by age 85 and older, the figure is 28 percent (Katzman, 1995). Even as "recently" as 1900, when average life expectancy at birth was 49.2 years (Federal Interagency Forum on Aging Related Statistics, 2000), dementia caregiving was not a major issue.

During the last century, the type and amount of dementia caregiving depended on family status (Mitchell, 1998; Bould, 1997). If the ill family member was "morally deserving" and the family had upper socioeconomic standing, the 19th Century Victorian morality dictated that the families provide home care. In reality, hired servants did the actual work. Most families with low socioeconomic status were unable to provide ongoing assistance. Many communities used charitable contributes to operate almshouses for these individuals. Services in most almshouses were minimal or nonexistent; health problems worsened and death occurred.

Though Alois Alzheimer first identified the disease named for him in 1906, it was not until the 1970s that it became recognized as the leading memory impairing illness (Cohen, 1983). Growth in the population age 85 and older is a contributing factor. Though biomedical research is examining stem cell treatments and pharmacotherapies to slow or prevent the progression of the disease, there is no cure. The same is true for multi-infarct/vascular dementia, and other forms of dementia. Therefore, the issues of dementia caregiving remain a personal and societal challenge.

Current Dementia Caregiving Experience: Descriptive Profile and Motivations

The precise definition of a family caregiver has been the subject of debate, though most agree it involves an interaction process between two people with a close relationship (Webb, 1996). In 1996, the National Alliance for Caregiving and the American Association of Retired Persons (1997) sponsored a national telephone survey to identify family caregivers. The following profile emerged. The typical dementia caregiver is a female (72.5 percent) with a mean age of 46.2 years; the mean tenure of caregiving is 5.1 years and involves 17.0 hours per week. Most caregivers are married (62.3 percent), employed outside the home (61.6 percent), and many still have children in the family home (43.5 percent). The caregiver is working with a parent or in-law (48.9 percent) with a mean age of 78.3 years. Spouses comprise 7.2 percent of caregivers; the remaining caregivers are siblings, grandchildren, nieces, nephews, or friends.

Caregiving affects daily life in many ways. Over half of all caregivers have given up vacations and hobbies; they also spend less time with other family members. The caregiver spends $104 of personal funds per month on the care recipient. Despite the sacrifices and stresses of caregiving (Yee & Schulz, 2000; Schulz, et. al., 1995; Schulz, et. al., 1990), the informal family system of caregiving is highly stable over time (Jette, Tennstedt, & Branch, 1992).

Caregiver Motivations

Motivations for caregiving are relevant to the planning of any intervention programs. Financial issues do not appear to influence motivation. The multi-year Medicare Alzheimer's Disease Demonstration Project provided up to $699 per month for community services and case management. Use of services did not significantly affect caregiver burden and depression levels compared to a control group (Newcomer, Yordi, DuNah, Fox, & Wilkinson, 1999). Further, the project did not significantly change outcomes related to nursing home placement (Miller, Newcomer, & Fox, 1999). Even though participants used more formal (paid) community services, there was no effect on the number of hours of care provided by family and no impact on the number of tasks that they performed (Newcomer, Spitalny, Fox, & Yordi, 1999; Yordi, DuNah, Bostrom, Fox, Wilkinson, & Newcomer, 1997). An analysis of the impact of Medicaid funding for home and community based services found different results, however. States that allocate more money to nursing home alternative services did significantly delay the time to nursing home admission (Miller, Prohaska, Furner, Freels, Brody, & Levy, 1998).

Batson and Coke (1983) propose two primary caregiving motives: egoistic and self-serving beliefs, and empathy and altruism feelings. Egoistic and self-serving motives look at the role of anticipated rewards and punishments. These range from receipt of praise, to avoidance of guilt, a sense of esteem from helping, and social approval. In a qualitative study of 10 caregivers, any decision to end home care resulted in ambivalence and conflict (Dellasega, 1998). Empathy and altruistic motives examine the impact of a desire to benefit others, not self, even though self-benefits may be a consequence of helping. Attachment and kinship influence these feelings. Motenko (1989) found higher levels of gratification among wife caregivers. Magai and Cohen (1998) did further analysis on the issue of relationship attachments. If secure attachments were present before the onset of dementia, caregivers coped better. If pre-morbid attachment styles are avoidant or ambivalent, caregiver burden increases. McCarty (1996) found similar results. In contrast, Nunley, Hall, and Rowles (2000) did not find the quality of the relationship to be predictive of stress and well being.

The social responsibility norm is a possible motive for caregiving (Schulz, Gallagher-Thompson, Haley, and Czaja, 2000). This explanation emphasizes concepts of reciprocity, equity, and social responsibility. There is evidence that caregiving expectations and responses different levels based upon racial and ethnic identity. In a meta-analysis of 21 studies examining racial and ethnic impacts on dementia caregiving (Janevic & Connell, 2001), Caucasians were found to be more stressed and depressed than African American caregivers. Latino and Asian American caregivers were more stressed and depressed than Caucasian or African American caregivers. However, Caucasians are the group most likely to elect nursing home placement for the family member.

Some research indicates family dynamics are more important motivators than patient or caregiver characteristics. Family characteristics that increase the likelihood of nursing home placement include high scores on emotional closeness (too much intensity), high scores on negative family feelings, and low scores on family efficiency (Fisher & Lieberman, 1999; Lieberman & Fisher, 1999). Families that use focused decision-making and positive conflict resolution are more likely to help with dementia care. Nursing home placement is less likely to occur when family members help with some overnight care and assist with activities of daily living (Gaugler, Edwards, Femia, Zarit, Stephens, Townsend, and Greene, 2000).

Often mentioned, but infrequently studied, are motivations based on the positive impacts of caregiving (Farran, 1997). In a qualitative study with 16 dementia caregivers, Bar-David (1999) analyzed and described a self-development journey taken by caregivers. The capacity for caring unfolds in three phases: development of caring capacity for the family member with dementia, development of capacity for self-care, and finally development of the capacity to care for others. Bar-David proposed that transcendence to the third stage result in development of the altruistic self, where there is selfless concern for the welfare of others. This is similar to the Erikson (1982) developmental task of generativity, considered the hallmark of middle adulthood. It is important to remember this is a small, qualitative study and the concept of transcendence would not apply to all, regardless of caregiver status.

Noonan and Tennstedt (1997) looked at a similar concept, the meaning of caregiving. Two dimensions of meaning were identified: a cognitive dimension related to the beliefs one holds about life experiences, and an emotional dimension related to the satisfaction one finds within the caregiving role, including rewards and benefits. A sense of meaning (on both dimensions) was negatively associated with depressive symptoms, and positively associated with self-esteem. The authors summarized the results as the ability of caregivers to hold positive beliefs about both the situation and the self as a caregiver. Though lacking the depth of the Noonan and Tennstedt work, Ganzer and England (1994) also found personal accounts of meaning to be important, especially in understanding which caregivers would use support services. In a somewhat lighter work, Beach (1997) found that meaning and positive impacts of caregiving also extend to secondary caregivers. Adolescents between 14 to 18 years of age reported increased sibling activity, greater empathy for older adults, significant parent-child bonding, and improved peer relationships because of their experiences.

Societal Impact of Caregiving

The prevalence of dementia victims will increase from the current 2.3 million, to 8.6 million by the year 2040 (General Accounting Office, 1998). Though based on less precise statistics, the national Alzheimer's Association estimates for the number of victims is nearly twice the General Accounting Office estimates (Alzheimer's Association, 2001a).

Data from the National Longitudinal Caregiver Study estimated the annual cost of informal (unpaid family) care to community dwelling veterans with dementia. In 1998 dollars, the amount was $18,385 per dementia victim; $6,295 represented the cost of the caregiver's time, and $10,709 represented the cost of lost earnings (Moore, Zhu, & Clipp, 2001). The cost of dementia also increases with the severity of the illness (Taylor, Schenkman, Zhou, & Sloan, 2001; Max, Webber, & Fox, 1995). Ernst and Hay (1994) estimate a lifetime cost of $174,000 per patient, making dementia the third most expensive American health problem after heart disease and cancer. Combining direct and indirect measures (lost earnings and productivity), the total national cost of dementia exceeds $1.75 trillion.

Nursing home expenditures account for a portion of the direct costs. Approximately 51 percent of all nursing home residents have some form of dementia (National Academy on an Aging Society, 2000b). Nursing homes are the third largest health care expenditure category, consuming $83 billion in 1997 (Federal Interagency Forum on Aging, 2000b). Three studies document that education interventions directed at family caregivers reduced costly, premature nursing home placements (Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996; Mittelman, Ferris, Steinberg, Shulman, Mackell, Ambinder, & Cohen, 1993; Toseland, Rossiter, Peak, & Smith, 1990). It therefore appears cost effective, at a societal level, to investigate ways that education interventions can help family caregivers.

Review of Intervention Efforts: Strengths and Weaknesses

Several meta-reviews of caregiver education interventions appear in gerontology literature (Opie, Rosewarne, & O'Connor, 1999; Biegel, Sales, & Schulz, 1991; Toseland & Rossiter, 1989). Opie and colleagues note that studies rigorously assessing pre and post education intervention impacts are lacking. Only 43 of 352 studies published between 1989 and 1998 offered pre and post intervention analyses; only five contained randomized control trials. Of the 43 studies reviewed, Opie and colleagues found general evidence to support the effectiveness of education programs, with effectiveness measured as reductions in caregiver stress (ranging from depression to subjective assessments of burden). The pre-1989 works reviewed by Toseland and Rossiter were less positive. Criticisms of early works include weak study designs, insensitive measurements, and lack of a theoretical basis for the interventions (Braithwaite, 2000; Kramer, 1997b).

Even the studies showing positive impacts of caregiver education programs are problematic. Resource intensity (intervention personnel and money) and narrow target populations (caregivers in larger cities with medical schools) make broader implementation difficult (Montgomery, 1996). Both problems occur because of a didactic (classroom lecture and discussion) approach to education. The didactic approach dominates the first two phases of educational life: initial education from ages to 16 or 21, and transitional (vocational) education from ages 16 to 21 (Atkin, 2000).

With the average age of dementia caregivers at 46.2 years (National Alliance for Caregiving & American Association of Retired Persons, 1997), the didactic approach is theoretically wrong. Adult learners are unique for many reasons, including the anxieties, experiences, and expectations they bring to the education experience (Lawler, 1991).

The third phase of educational life has many titles: continuing education, adult education, lifelong education, and lifelong learning (Aspin & Chapman, 2000; Titmus, 1999). The naming nuances stem from the early days of the adult movement when post-World War II emphasis was on training for the working classes and skill enhancements for parenting. Today, andragogy (art and science of helping adults learn) has several purposes: radical education to bring about fundamental and profound social change; humanistic education emphasizing creativity and human potential; behaviorist education addressing environmental manipulation for survival; liberal education for enhancement of intellectual powers and knowledge content; and progressive education to facilitate problem solving (Price, 1999; Donlevy & Donlevy, 1998). The philosophy taken by an educator is important and will shape the method of learning and learner success (Galbraith, 1999; Tisdell & Taylor, 1999).

The later category, progressive education to facilitate problem solving, has application for interventions with dementia caregivers. As the disease progresses, dementia caregivers must problem solve how to deal with a variety of noncognitive, psychiatric, and behavioral disturbances. In a two year longitudinal study, agitation and wandering occurred consistently for 54.5 percent of the study population, while depression declined; psychosis (including delusions and hallucinations) varied over time (Devanand, Jacobs, Tang, Castillo-Castaneda, Sano, Marder, Bell, Bylsma, Brandt, Albert, & Stern, 1997). In contrast, a curvilinear association between the severity of dementia and problem behaviors suggests forgetfulness, emotional reactions, and impulsive behaviors peak during the middle stages of dementia (McCarty, Roth, Goode, Owen, Harrell, Donovan, & Haley, 2000). Because individuals with dementia often have disrupted sleep patterns, 60 percent of family caregivers are sleep-interrupted three or more times per week (Wilcox & King, 1999). A cross sectional study found that psychiatric and behavioral disturbances are more common in men (Ott, Lapane, & Gambassi, 2000). Two Canadian studies predicted caregiver burden and stress when a higher than average frequency of disturbing behaviors occurred (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Meshefedjian, McCusker, Bellavance, & Baumgarten, 1998).

The changing nature of dementia symptoms suggests that education for dementia caregivers be flexible. Three possible models for progressive (problem solving) adult education are prominent in education literature: experiential learning, cooperative learning, and self-directed learning.

Experiential Learning and Dementia Caregiving

Kolb (1984) framed the four-stage experiential learning model. It begins by recognizing that the individual has concrete experiences in the real world. The individual observes and reflects on the experiences. Next the individual forms abstract concepts and generalizations about what occurred, and finally the individual tests or acts on the implications of the new concepts when faced with new concrete experiences in the real world. In academic settings, this philosophy supports academic credit for life experiences (such as having experienced a divorce) (Fenwick, 2000; Dinmore, 1997).

Applied to dementia caregivers, the perspective defines a "learn by doing" approach. The caregiver does not receive any type of formalized education content, and learns by trial and error. This appears to be the most common approach for dementia caregivers. Though national data are not available, a survey of one state (Kansas) conducted by this author in March 2000 found only 6.6 percent of family caregivers attend dementia support groups or education programs. The reasons for low participation range from lack of availability of programs, lack of time to attend programs, and transportation difficulties (Connell & Kole, 1999; Molinari, Nelson, Shekelle, & Crowthers, 1994). The "learn by doing" approach is not optimal for dementia caregivers given the high rates of physical and psychological distress, as well as elder abuse and neglect (National Center on Elder Abuse, 2001; Dyer, Pavlik, & Murphy, 2000).

Cooperative Learning and Dementia Caregiving

Using small groups, learners' work together to attain a common goal using positive interdependence and individual accountability (Johnson & Johnson, 1989). The cooperative learning perspective describes the dementia support group, the earliest intervention designed to assist caregivers (Collins, Stommel, Given, & King, 1991). Several themes concerning the efficacy of support groups emerge in the literature. Individuals attending groups led by professionals show more improvement in subjective well being compared with those in peer led groups; peer group well being does not differ significantly from well being scores from a control group (Toseland, Rossiter, Peak, & Smith, 1990; Toseland & Smith, 1990; Toseland, Rossiter, & Labrecque, 1989). Finding professional facilitators can be a challenge, especially in rural areas, making implementation difficult (Connell & Kole, 1999). One study correlates support group attendance with lower caregiving costs (Peak, Toseland, & Banks, 1995).

Some have argued that comparison of results is difficult because participants are caring for individuals with different levels of impairment (Farran & Keane-Hagerty, 1994; Gonyea, 1989). Molinari, et. al., (1994) found Alzheimer's Association support group members to be older (mean age 58.2 compared with mean age of non-attendees at 51.6), female, and white. They had also been caregiving for a longer time (52.6 months compared with 43.2 for non-attendees).

Self-Directed Learning and Dementia Caregiving

Posited by Knowles (1988), this perspective emphasizes the educator as a facilitator who helps the adult learner take an active role in the education process. With support, adult learners will take the initiative to diagnose their own information needs, formulate goals to meet those needs, identify resources to meet the needs, and implement the education process. Self-directed learning commonly involve asynchronous experiences. Distance education is asynchronous learning. It can involve a wide array of techniques, ranging from mail, to facsimile, radio, television, satellite broadcasts, videotapes, teleconferencing, and most recently, the Internet (Matthews, 1999; Wolf & Johnstone, 1999).

Perhaps the most common distance method is self-accessed, self-processed print materials (brochures) mailed to an individual, or given out for latter use. Only one study involving dementia caregivers appears in print. Mant, Carter, Wade, and Winner

(1998) found that receiving a strategy brochure at hospital dismissal statistically improved the mental health of stroke caregivers compared with a control group. In non-dementia studies, print materials were effective in providing education about appropriate responses to myocardial infarction symptoms (Meischke, Eisenberg, Schaeffer, & Henwood, 2000); weight loss (Kreuter, Oswald, Bull, & Clark, 2000); advance directives (Husted, Miller, & Brown, 1999); post-operative eye care (Higgins & Ambrose, 1995); and the roles and responsibilities of patients when they interact with physicians (Frederikson & Bull, 1995). Print materials were not effective in communicating information about arthritis medications (Pope, Stevens, & Rook, 1998), and were not effective in the long term for communicating asthma inhaler information (Rydman, Sonenthal, Tadimeti, Butki, & McDermott, 1999).

The education level and layout of print materials is a concern. Only brochures with less than an 8th grade level were effective for cancer caregivers (Butow, Brindle, McConnell, Boakes, & Tattersall, 1998). Lack of organization and clarity negatively impact comprehension in a diabetes study (Reid, Klachko, Kardash, Robinson, Scholes, & Howard, 1995) and a polio immunization study (Davis, Fredrickson, Arnold, Murphy, Herbst, & Bocchini, 1998). Many of these issues are not considered by health educators when purchasing print materials (Barnes, Neiger, Hanks, Lindman, & Trockel, 2000).

The effectiveness of print materials has been compared with independent use of instructional videos; independent use means that health professionals were not involved in helping the subject understand the material (Gagliano, 1988). Phillips (1994) posits that dynamic, audiovisual presentation should enhance comprehension and retention.

Videos were more effective than brochures in educating consumers about advance directives and cardiopulmonary resuscitation (Yamada, Galecki, Goold, & Hogikyan, 1999); diet and exercise after coronary bypass surgery (Mahler, Kulik, & Tarazi, 1999; Mahler & Kulik, 1998; Mahler & Kulik, 1995); and plaque removal with an electric toothbrush (Renton-Harper, Addy, Warren, & Newcombe, 1999).

Didactic critics argue that a lack of direction interaction harms the education process. A study with older adults compared classroom education with a home study intervention (videotapes and reading) (Rybarczyk, DeMarco, DeLaCrus, & Lapidos, 1999). Compared with a control group, both treatment groups showed statistically significant improvements in scores regarding sleep difficulties, depression, anxiety, and pain. The authors conclude that lower cost, more accessible home study can be an effective alternative to classroom instruction. As opposed to home study, video-teleconferencing from a central site was found to be well received for providing education about nutrition to dementia caregivers (Paul, Johnson, & Cranston, 2000); and family conferencing (Novotny, Seymour, & Stocker, 1995).

The telephone is also a tool for distance education. Goodman and Pynoos (1990) established peer networks of dementia caregivers to make and receive regular telephone calls for support. Participants also received recorded mini-lectures from staff. Results indicated participant gains in information, perception of social support, and satisfaction with social support. Steffen (2000) and Chang (1999) conducted studies that combined videos with follow up calls from nursing personnel. Caregivers viewing the videos and receiving the calls had statistically less depression and anxiety. The European ACTION (assisting carers using telematic interventions to meet older persons needs) consortium is taking telephone involvement to another level through design of a video telephone system to reach isolated caregivers (Folson, Tetley, & Clarke, 1999; Kraner, Emery, Cvetkovic, Procter, & Smythe, 1999). The consortium involves researchers from England, Ireland, Sweden, and Portugal. At the present time, the project is still under development, and no empirical data are available, as formal start up did not occur until April 2001 (Creedon, Heasly, & Rousseau, 2001).

Internet learning. The Internet is a form of self-directed learning (Ranwez, Leidig, & Crampes, 2000; Gray, 1999; Russell, 1999). Internet technology can combine the productive elements from the previously reviewed techniques (print materials and video presentations). It can also promote a level of active involvement as the user transitions through pages and linkages.

Lewis (1999) describes the effectiveness of interactive, multimedia computer-based approaches for patient education. Sixteen of 21 studies published between 1971 and 1998 showed statistically significant improvements in subject outcomes due to computer-based patient education. One study documented an impressive 54 percent reduction in hospital admissions for asthma patients, compared with patients receiving a conventional education booklet (Osman, Abdalla, Beattie, Ross, Russell, Friend, Legge, & Douglas, 1994). Several studies published since the meta-analysis provide interesting insights as well. Hospital stays were shorter for transplant patients who accessed computer-based education (Goedecke, Winsett, & Hathaway, 2001; Winsett & Hathaway, 2001). Older adults gained pertinent information advance directives using the Internet (Mercer, Chiribogna, & Sweeney, 1997). Positive results were cited for two nutrition education programs delivered by the Internet (Brug, Campbell, & van

Assema, 1999; Raats, Sparks, Geekie, & Shepherd, 1999). In a physician office-based study involving 50 patients, 77 percent indicated they would change a health behavior because of information gained (Helwig, Lovelle, Guse, & Gottlieb, 1999).

Internet learning and dementia caregivers. Gerontology literature encourages use of the Internet for research and information (Madan & Bodagh, 2002), and documents increased public interest in using the Internet for information gathering (Colantonio, Kositsky, Cohen, & Vernich, 2001). However, only four published articles examine dementia caregiving and Internet education. In what appears to be the first endeavor in the field, 51 caregivers of Alzheimer's Disease victims received a computer terminal and modem (Bass, McClendon, Brennan, & McCarthy, 1998). The applications program, ComputerLink, enabled caregivers to access a public bulletin board, private mail, and an on-line question feature facilitated by a nurse. An electronic encyclopedia on Alzheimer's Disease was also available. Assessment of the "computer" caregivers and a control group focused on reductions in physical, emotional, relationship, and activity restriction strains. Frequent use of the communication function correlated with significant reductions in strain for caregivers, especially for those who began with the highest stress levels. ComputerLink reduced stress levels significantly for non-spouse caregivers, as opposed to spousal caregivers. The service was more effective for caregivers that lived with the care receiver.

Mahoney, Tarlow, and Sandaire (1998) created a computer-mediated intervention for caregivers, Telephone Linked Care (TLC). TLC provides access to an electronic bulletin board for messages, discussion forums, and private chats. It also contains an encyclopedia of support information. Empirical studies are underway, and will last 3 years. TLC also includes a unique telephone-based education component. Caregivers access a prerecorded lecture via the telephone on a weekly basis. If interrupted, a cue function allows caregivers to redial and continue the lecture.

White and Dorman (2000) analyzed an on-line support group for Alzheimer's caregivers. Using a public mailgroup (listservs) created by Washington University, the authors examined a retrospective random sample of 11,076 messages posted during 1998. Results indicate that caregivers did access the service to find and to offer information, to share experiences and opinions, and to provide encouragement. The authors concluded that the supportive function of the on-line group was similar to that found with in-person support groups, but there was no attempt to assess the on-line caregivers for levels of stress.

Coulson (2000) is taking computer applications in a different direction by designing an on-line expert system for the management of disruptive behaviors. The expert system assists users in problem solving. Though not yet subjected to empirical testing, the system is for nursing home caregivers, not family members.

Thought not designed for dementia caregivers, Mundt, Ferber, Rizzo, and Greist (2001) tested a computer-automated dementia screening protocol implemented through touch-tone telephones. Mundt and colleagues hypothesize the tool may be of value to physicians who monitor patient progress. The authors conclude the system is feasible, although 16 of 155 dementia patients were unable to complete the telephone call assessment.

Future Opportunities: The Internet for Dementia Caregiver Education

The Internet holds intriguing possibilities for caregiver education. It has the potential to reach a large number of caregivers that currently learn only by experiential methods. As noted previously, the current system of "learn by doing" results in high levels of stress. Other positive potentials with Internet include: increased communication by exposing users to more and varied situations; time efficiency as learners use the medium at their convenience; learning enhancement when programs incorporate of both sound and video; allowances for individual differences in learning styles, strengths, and preferences; and an "unsurpassed" opportunity for perpetual archiving of the most up to date information (Mann, 2001; Malone, 2000; Oravec, 2000; Zucker, White, Fabri, & Kohnsari, 1998; Carlton, Ryan & Siktberg, 1998). The format can enhance understanding of complicated health and disease processes that cannot be adequately communicated in text alone (Ackerman, 1999). Properly designed with interactive choices and immediate feedback prompts, the Internet promotes practice of critical thinking skills without fear of patient harm (Weis & Guyton-Simmons, 1998; Bersky, Krawczak & Kumar, 1998). To the extent that programs are personalized and users can access the information most pertinent to their needs, efficacy of learning is enhanced (Dijkstra & DeVries, 1999; Marcus, Owen, Forsyth, Cavill, & Fridinger, 1998).

There are legitimate concerns about Internet education. Disadvantaged groups may lack access. Although 66 percent of American households will have Internet access by the year 2003, that still leaves a significant minority without access (Library of Congress, 2000). Early users of the Internet were white, college educated males, but use by women is increasing. For the first time ever, women outnumbered male users during the first quarter of 2000 (Rickert & Sacharow, 2000). Utilization by females age 55 and older increased by 109.5 percent between May 1999 and May 2000. While it clearly requires money to afford a personal computer and purchase Internet access, the average income of users has decreased, indicating that the technology is becoming more affordable (Thompson, 2000).

Quality of Internet materials is of concern as well. Currently, the average user searches the World Wide Web six times per week, spending slightly more than three hours and reviewing over 235 web pages (Romita, 2000). Health sites are increasingly popular. However, unlike print advertisements monitored and approved by the Food and Drug Administration, there is no oversight body for Internet information. One result is a high volume of often confusing information. In a small study done by this author in March 2000, over 30,300 site matches were found when Alzheimer's Disease was entered as the search phrase in the top six Internet search engines. Thought not related to dementia, a study sampling 50 Internet sites provided a caution about Internet education. Most of patient education materials rate at a 10th grade level, which is not comprehensible to the majority of patients (Graber, Roller, & Kaeble, 1999).

Specific concerns focus on older adults as potential users of Internet technology. The "digital divide" mentality states that older adults do not have an interest in or the ability to work with computers (SPRY Foundation, 2001). Thought reluctance to use the technology may be greater for older adults (Czaja & Sharit, 1998), older adults can learn computer skills and do reap social and health benefits from Internet experiences (Vastag, 2001; Morrell, Park, Mayhorn, & Kelley, 2000; White & Weatherall, 2000;

Kubeck, Miller-Albrecht, & Murphy, 1999; White, McConnell, Clipp, Bynum, Teague, Navas, Craven, & Halbrecht, 1999). Goal-oriented, computer instruction with older adults has been shown to be most effective (Hollis-Sawyer & Sterns, 1999). This is important in light of earlier discussion regarding caregiving motivations. In a sample of 144 older adults, Burgio, Cotter, Stevens, Hardin, Sinnott, and Hohman (1995) found caregivers would rather learn and use behavioral therapies for managing disturbing behaviors in place of pharmacotherapy solutions. Motivation, combined with user-friendly Internet programs, argues that older adults might be eager consumers.

Summary

This chapter examined the experience of dementia caregivers, documenting both the stresses experienced as well as the motivations. An overview of caregiver intervention programs demonstrates that education can attenuate the experience of stress. Data also demonstrate that many dementia caregivers are not receiving as much information and education as they need or want.

To design effective education interventions, it is important to recognize basic principles and options in the field of adult education. While didactic approaches generally show positive impacts, the resource intensity of such programs makes wide spread dissemination to millions of caregivers impossible. Cooperative learning through support groups has benefit but is not geographically accessible to many; for others, it is not time efficient. Therefore focus on progressive (problem solving) education philosophy, using self-directed learning strategies may have the greatest long-term impact. Distance education through the Internet is emerging as the newest tool for self-directed learning.

Chapter 2 takes a closer look at the process and factors that contribute to caregiver stress, and frames the dementia caregiving experience within the stress model developed by Cohen, Kessler, and Gordon (1995). After identifying each proposition from the model, data from caregiving illustrates the application to dementia caregiving. Key to the stress model is the concept of stress appraisal. Determining the potential threat of a situation and coping strategies to use is a multi-part process. The philosophy of self-directed learning argues that Internet education may be a way to positively enhance or change the appraisal process for dementia caregivers. Hypotheses for the research study emerge from the discussion.

Chapter 3 presents information about the study population: family caregivers recruited with assistance of the Sunflower Chapter of the Alzheimer's Association, Wichita, Kansas. The discussion also reviews principles of the study design, Switching Replications. Over time, the quasi-experimental design selected will allow all study participants to receive one of the three education interventions. Chapter 3 concludes with presentation of the study variables, their operationalization for measurement, and the plan for statistical analysis using Analysis of Variance (ANOVA) techniques. Chapter 4 reviews results of the statistical analysis, while Chapter 5 discusses implications and limitations.

CHAPTER 2

Literature Review and Theoretical Framework

Introduction

Upon learning that a loved one has dementia, most families begin a long journey that has physical, emotional, and financial implications. From the time of diagnosis, average life expectancy is seven more years (Ernst, 1997). There are over two million Americans already on this journey; the number will exceed 8.4 million by the year 2040 (General Accounting Office, 1998). Several meta-analyses document the negative physical and psychological consequences of dementia caregiving (Yee & Schulz, 2000; Schulz, et. al., 1995; Schulz, et. al., 1990).

Between 1989 and 1998, there were 352 published studies on caregiver intervention programs (Opie, et. al., 1999). While most studies show positive impacts (measured as reduction in caregiver stress), some experts express dismay that few studies show strong statistical correlation (Braithwaite, 2000; Montgomery & Kosloski, 2000; Switzer, Wisniewski, Belle, Burns, Winter, Thompson, & Schulz, 2000). One problem, identified by Richard Schulz, Ph.D., is inadequate theoretical perspectives for most studies. As a Professor of Psychiatry, Director of Gerontology, and Director of the University Center for Social and Urban Research at the University of Pittsburgh, Dr. Schulz has two decades of experience in carrying out research on caregivers. His seminal work, Handbook on Dementia Caregiving, argues that intervention studies be framed within a unified model of the stress-health process developed by Cohen, Kessler, and Gordon (1995).

The Cohen, Kessler, and Gordon model is strong because of its multi-step approach to understanding the stress process. Iterations within the model help identify possible targets for intervention strategies. The next section presents the Cohen, Kessler, and Gordon model. Discussion of each proposition examines two perspectives: literature from general stress research studies that support the claims of the model, and literature showing application of the claims to dementia caregiving experiences. The final section presents seven hypotheses derived from the stress model.

The Cohen, Kessler, and Gordon Stress-Health Process Model

At the invitation of the Chicago Fetzer Institute, and with partial funding from the National Institute of Mental Health, Cohen, et. al., (1995) undertook an analysis of stress related research. The definition of stress is the general process through which environmental demands result in outcomes deleterious to health. Five propositions mark the pathway from environmental demands to deleterious health impacts.

- "When confronted with environmental demands, the individual will evaluate the demands for potential threat and the adaptive capacities available for coping;
- stress perception results when environmental demands are appraised as threatening or taxing, and coping resources are viewed as inadequate;
- appraisal of a stress state results in negative emotional states for the individual;
- negative emotional states will trigger behavioral and/or physiological responses; and

- behavioral and/or physiological responses will place the person at risk for the development of physical and/or psychiatric disease" (Cohen, et. al., 1995, page 10).

The definition of essential constructs is important. Environmental demands include any environmental experience (internal or external) which requires adjustment on the part of the individual. Appraisal is the individual's interpretation of the meaning of an event. Threat involves a perception that harm has or will likely occur. If there is no perception of harm, then the appraisal of the environmental demand is benign. Coping resources include potential methods or means for elimination or reduction of the effects of the perceived threat. Negative emotional states involve the affective presentation of anger, anxiety, and/or depression. Behavioral responses are health or other practices employed by the individual. Physiological responses involve activation of the sympathetic-adrenocortical axis (increased secretion of epinephrine and norepinephrine resulting in increased blood pressure, heart rate, sweating, and constriction of peripheral blood vessels) and the hypothalmic-pituitary-adrenocortical axis (increased secretion of adrenocorticotrophic hormone and corticosteroids). Disease means structural change and impairment of body organs and organ systems that can be permanent and can result in death.

Figure 1 graphically depicts the heuristic model of the stress-health process. The strongest pathway from environmental demands to deleterious health impacts occurs in a straight-line. Nonetheless, the stress-health process model allows for some iteration. Specific emphasis is on the potential for behavioral and physiological responses (the fourth proposition) to trigger a reappraisal of the environmental

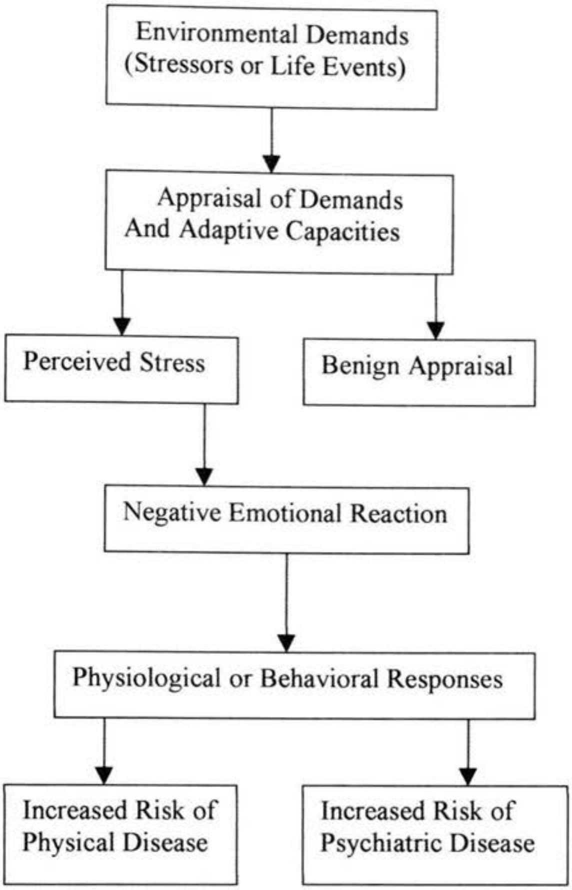


Figure 1. Cohen, Kessler, and Gordon stress-health process model

demands (the second proposition). It is possible for reappraisal to result in determination that the environmental demand is benign (non-threatening). Figure 2 illustrates the feedback loop, which involves the appraisal construct. The iteration involving the second proposition of the model (appraisal) is of particular interest in this study. Building upon information presented in Chapter 1, education interventions could play a role in triggering appraisal and reappraisal of a caregiving situation.

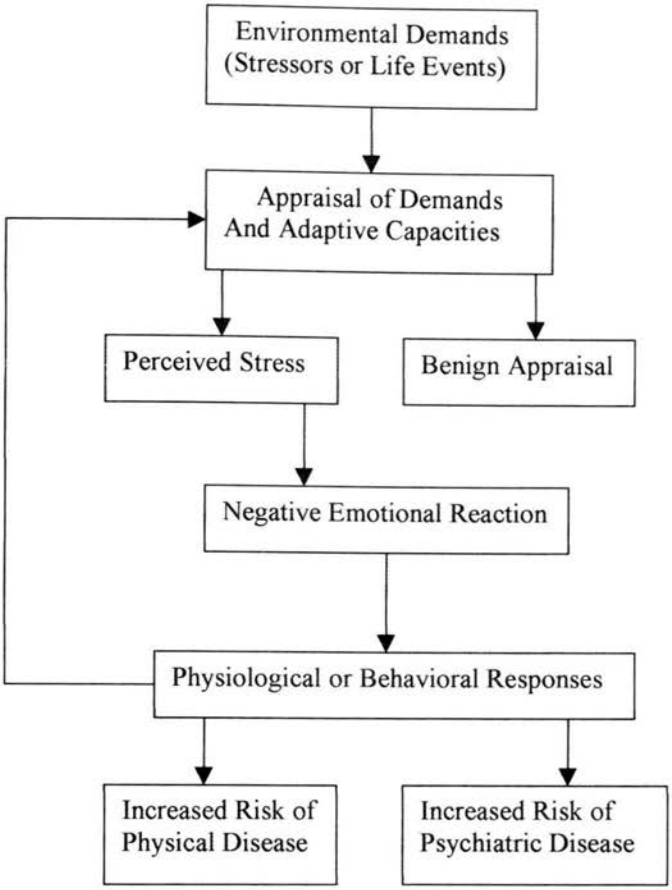


Figure 2. Stress-health process model with iterations

Theoretical and Empirical Support for and Caregiver Application of The Cohen, Kessler, and Gordon Stress-Health Process Model

Environmental Demands Construct

The first proposition in the Cohen, Kessler, and Gordon model highlights the important concept of environmental demands: when confronted with environmental demands, the individual will evaluate the demands for potential threat and the adaptive capacities available for coping.

Theoretical and empirical support for the environmental demands construct. The premise that environmental demands could negatively impact health captured the attention of psychologists and biologists during the early part of the 20th Century. By exposing laboratory animals to noxious stimuli (ranging from temperature extremes, to electric shock, forced swimming, sensory deprivation, and food deprivation), Cannon (1935) identified a differential effect on blood hormones. When stimuli exceeded critical thresholds, strained physiological adaptation resulted in illness and death. Selye (1975; 1950) expanded the work, identifying a universal, nonspecific stress response pattern involving secretions of adrenocorticotrophic hormones and corticosteroids. Psychology textbooks still report Selye's General Adaptation Syndrome.

The animal basis of the early stress research and the use of severe external stimuli made many researchers question the applicability of Cannon and Selye's work for human populations. Lazarus (1966) and Mason (1971) argued that psychological factors could mediate the physical effects of stress. Subsequent physiological responses might be smaller than would otherwise be anticipated or even move in the opposite direction. Elliott and Eisdorfer (1982) developed a conceptual framework for organization of stress research on humans. The X-Y-Z model acknowledged that something in the environment around an individual must serve as an activator (X). Individuals then experience a physical and/or psychological reaction (Y). The reaction results in a physical and/or psychological consequence.

Activators (X) include any internal and/or external event(s) or condition(s) that cause a change in the individual's current state. This is the basis for the Cohen, Kessler, and Gordon definition of environmental demands. Activators (X) must be sufficiently intense and/or frequent to trigger a reaction (Y). Elliott and Eisdorfer identified four categories of stressors: acute (any time limited or one time event such as waiting for surgery, or undergoing a surgical procedure); sequence (series of events that occur over an extended time, but are the result of a specific initiating event such as divorce); chronic intermittent (conflicts or difficulties that arise on a regular basis); and chronic (persist for a long period of time and may or may not be initiated by a discrete event such as a permanent disability or caregiving). The category of stressor does influence the long-term consequences (Lepore, 1995). Of particular interest is the category of chronic stressors. In a meta-analysis conducted by Herbert and Cohen (1993) findings indicate that the human body does not habituate to chronic stressors. Further, chronic stressors exacerbate the effects of any acute stressors the individual might experience.

Caregiver application of the environmental demands construct. The demands of dementia caregiving involve chronic stressors. The nature of the disease process means the individual with the dementia requires more assistance over time. Thus, the experience of caregiving requires a variety of ongoing adjustments. Levels of caregiver burden increase as functional impairments worsen (Whitlatch, Feinberg, & Sebesta, 1997; Vitaliano, et. al., 1991). Demands are greater in the early stages of vascular dementia, but increase over time with Alzheimer's Disease (Teel, et. al., 2001; Vetter, et. al., 1999).

Dementia caregiving also involves some acute stressors in the form of unique, disruptive or disturbing behaviors. As noted in the preceding section, chronic stress exacerbates the effect of acute stressors. Alzheimer's Disease and related dementias have been associated with a wide variety of noncognitive, psychiatric, and behavioral disturbances, ranging from agitation, to depression, psychosis, inappropriate sexual behavior, aggression, sleep disruption, and wandering. Behaviors of agitation and wandering were consistent over a two-year period for 54.5 percent of the study population, while psychosis, delusions, and hallucinations varied over time (Devanand, et. al., 1997). Problems such as forgetfulness, emotional reactions, and impulsive behaviors show a curvilinear pattern, peaking during the middle stages of the dementia process (McCarty, et. al., 2000). Individuals with dementia often have disrupted sleep patterns and 60 percent of family caregivers are sleep-interrupted three or more times per week (Wilcox & King, 1999). Psychiatric and behavioral disturbances are more common in men (Ott, Lapane, & Gambassi, 2000). Two Canadian studies predicted caregiver burden and stress when a higher than average frequency of "disturbing" behaviors occurred (Clyburn, et. al., 2000; Meshefedjian, et. al., 1998).

Environmental demands construct summary. Dementia caregiving involves many environmental demands. Some demands are chronic, while others are acute. The combination and range of demands does challenge caregivers. The next construct, focused on two types of stress appraisal, is critical in determining how or if the demands affect the caregiver.

Appraisal, Threat, and Coping Resource Constructs

The second proposition of the Cohen, et. al., (1995) model emphasizes cognition and an evaluative component: stress perception results when environmental demands threaten well-being, and coping resources seem inadequate.

Theoretical and empirical support for the appraisal, threat, and coping resource constructs. First identified by Grinker and Spiegel (1945) in the classic work Men Under Stress, appraisal is "mental activity involving judgment, discrimination, and choice of activity, based largely on past experience." While a number of other early stress researchers incorporated similar concepts of appraisal (Mandler, 1975; Arnold, 1960), they did so largely in informal, unsystematic ways (Cohen, et. al., 1985).

Empirical research by Lazarus (1977, 1981) and Lazarus and Folkman (1984) brought more focus to the concept of cognitive appraisal. Defined as "the process of categorizing an encounter, and its various facets, with respect to its significance for well-being," cognitive appraisal occurs in two distinct phases (primary and secondary), with an iterative dynamic between the two. Iteration modulates the degree of stress experienced by the individual.

Primary appraisal focuses on the potential of the environmental situation to affect the individual's well being. A situation must be cognitively evaluated to determine if it is irrelevant to personal well being, benign (non-threatening), or potentially stressful. Appraisal of a situation as stressful occurs if the individual determines the situation to be: harmful (some damage or loss to the person has occurred); threatening (anticipation that future damage or loss will likely occur); or challenging (assessment that the situation presents the possibility for growth or gain).

Secondary appraisal involves assessment of the coping options available and the perceived likelihood that a particular option is effective. Secondary appraisal does not involve the actual cognitive and/or behavioral efforts used to manage the situational demands. The actual efforts represent coping or coping resources (Lazarus & Folkman, 1984). Folkman, Lazarus, Dunkel-Schetter, DeLongis, and Gruen (1986) identified eight possible coping options that individuals evaluate during secondary appraisal.

1. Confrontive coping involves aggressive efforts to alter a situation. In the original work, Folkman and colleagues asked subjects if they were willing to "stand their ground and fight for what they wanted." Confrontive coping can involve a degree of hostility (expressions of anger) and/or risk taking (taking a chance to do something even if it did not work).

2. Distancing involves efforts to detach one's self from the situation. A person might "refuse" to think about the situation too much, or to make light of a situation and look for a "silver lining."

3. Self-controlling describes efforts to regulate one's own feelings about a situation by keeping others from knowing how bad things are. The action component is to avoid hasty action.

4. Seeking social support involves efforts to find information through talking to someone to find out more about a situation, or by seeking out someone who could help do something about the problem (tangible support). It may also involve emotional support in the form of acceptance of sympathy and understanding from someone.

5. Accepting responsibility acknowledges one's own role in the problem. This may involve self-criticism and promises to change in the future

6. Escape-avoidance uses wishful thinking strategies such as a hope that the situation will "just go away." It can also involve behavioral attempts to escape through eating, drinking, smoking, or use of drugs.

7. Planful problem solving describes deliberate efforts to alter a situation by increasing efforts to make things work, or by utilization of analytical approaches, such as making a plan of action with different solutions to a problem.

8. Positive reappraisal involves efforts to create positive meaning by focusing upon personal growth. This may lead the individual to identify their self as "changed" for the better. It may also involve religious tones, such as a sense that one has found a new faith.

Several of the coping options are "positive" or active strategies because they associate with reductions in stress levels (Shaw, 1999; Park, 1998; Webb, 1996; Aldwin & Revenson, 1987; Billings & Moos, 1981). Positive strategies include confrontive coping, seeking social support, planful problem solving, and positive reappraisal. The remaining strategies are less desired emotion-focused coping strategies. In addition, Lazarus and Folkman (1984) posit that the secondary appraisal process and the coping strategy used vary with the individual's perception of what is at stake (primary appraisal). They also suggest that characteristics of the person (including personality, locus of control, self-efficacy, and worldview), social support, socioeconomic status, physical health, and past experiences influence the coping strategy selected.

A path analysis involving 228 community residing adults with a mean age of 42 (range 18 to 78) found that appraisal of stress and subsequent attributions of control did affect coping strategies (Aldwin, 1991). Regardless of age, individuals who felt less control and responsibility were more likely to use escapism strategies, and less likely to use positive, instrumental coping actions. The authors hypothesize that prior experiences have shown elders that escapism is an ineffective technique for coping with stress. Downe-Wamboldt and Melanson (1998) found similar results in a study with arthritis patients. Age appears to have a unique influence on self-perception of problem-solving abilities (Haught, Hill, Nardi, & Walls, 2000). When controlling for level of education across age groups, older individuals perceived themselves as better problem solvers and were more confident in their problem solving abilities. Other studies contradict the finding (Spitzer, Bar-Tal, & Golander, 1995); younger adults with rheumatoid arthritis use more positive coping strategies than older adults. Scherer, Drumheller, and Owen (1993) found that the passage of time affects appraisal and coping as well. Coping strategies used vary depending on the proximity to the stress event. Lazarus and Folkman did not find gender to be an important predictor of coping strategies, but Stoke (2000) suggests that androgynous coping (use of both instrumental/active and expressive/emotional coping) correlates with better outcomes.

Caregiver application of the appraisal, threat, and coping resource constructs. Only a few dementia caregiver studies examine the concept of appraisal. Expanding on the Lazarus and Folkman concepts of primary and secondary appraisal, Lawton, Kleban, Moss, Rovine, and Glicksman (1989) attempted to develop a tool for specifically assessing the appraisal process of caregivers. Part of the motivation was to move beyond the late 1980s emphasis on objective burden, to a more full examination of subjective dynamics of caregiver stress. Lawton and colleagues believed that subjective assessments of burden, individual satisfaction, sense of mastery, and caregiving ideology (family tradition, religious principles, and role model function) affect appraisals and reappraisals. The authors were not impressed by their results and urged caution in the use of caregiving appraisal scales. In a latter work, a two-factor model of caregiving appraisal was established (Lawton, Moss, Kleban, Glicksman, and Rovine, 1991). The two elements of appraisal were operationalized as caregiving satisfaction (subjectively perceived gains from desirable aspects of caregiving) and caregiving burden (perception of psychological distress, anxiety, depression, demoralization, and general loss of personal freedom attributed to caregiving). With this model, Lawton and colleagues found that satisfaction did not relate to any aspects of dementia stressors for spousal caregivers, but it did determine positive affect. This was not the case for adult children caregivers.

Braithwaite (1996; 2000) reexamined the work of Lawton and colleagues, and attempted to redefine dimensions of caregiver appraisal. Six possible appraisal elements emerged as possible predictors of caregiver burden and psychiatric symptoms: perception of task load (provision of care and supervision with little support); perception of dysfunctional caregiver-received relationships; perception of social captivity (extensiveness of and support from social network); intimacy and love (reciprocity and appreciation in the relationship); resiliency (sense of inner strength, efficacy, mastery, and emotional stability); and social distance (degree of social independence). Using a sample of 144 Australian caregivers, Braithwaite found that the overall sense of burden was greater when the caregiver appraised resiliency as low, the relationship as conflict ridden, and social captivity as a possibility. A heavy task load did not correlate with burden. Appraising the relationship as intimate and loving was important to general well being, but not to caregiver burden. Because of the Australian database, Braithwaite (2000) concluded that cross validation is necessary before applying the constructs in American culture.

Researchers with the Amsterdam Study on the Elderly are examining caregiver appraisal (Pot, Deeg, & van Dyck, 2000; Pot, Deeg, van Dyck, & Jonker, 1998). Working with caregivers of dementia patients, the authors focused on caregiving appraisal, operationalized by a measure of pressure perceived by the caregiver. Using a self-created tool, comparison of objective demands and caregiver's personal interests (such as the need for non-care related thoughts, activities, and roles) took place. The extent of perceived pressure explained the association between stressors (behavioral problems) and psychological distress for non-spouse caregivers only. The authors conclude that interventions cannot merely focus on removal of stressor events; interventions must assist caregivers in changing their views about perceived pressure or appraisal of the stressor event.

Over a five-month period, Gignac and Gottlieb (1996) assessed 87 family caregivers providing home care for an individual with dementia. Findings indicated that even over the short period, appraisal of situations and coping change as dementia progresses and person-environment transactions change. In an older study, Long (1991) found that among 72 dementia caregivers, emotion focused coping increased as stress increased; problem focused coping was only used if a situation was appraised as being amendable to some type of action. Levesque, Cossett, and Lachance (1998) reported on a study of 280 caregivers in which appraisal of disturbance (threat) from problem behaviors increased negative caregiver outcomes. Similar results exist for nursing home personnel (Rodney, 2000). The general theme of the studies presented to this point is that caregivers do engage in primary appraisal processes. This does influence the secondary appraisal of the situation, and the subsequent selection of coping strategies. Lacking information on or belief in the ability to modify a situation results in less effective emotion focused and escapist strategies. A challenge faced by caregivers is reestablishing a new balance point (equilibrium with competing demands) as situations and stressors change. In a qualitative study with 15 caregivers, Shyu (2000) found that to maintain active coping, caregivers altered schedules, modified the environment, and emphasized teamwork.

As noted by Lazarus and Folkman, many background variables can affect the appraisal process. Despite the belief of Lazarus and Folkman, gender appears to have an effect for dementia caregivers. Rose-Rego, Strauss, and Smyth (1998) assessed 99 caregiving spouses and 113 non-caregiving controls. While caregiving increases stress for both genders, women report more negative emotions and use more emotion focused coping strategies. Kramer (1997a) assessed 74 husband caregivers and found that if they used emotion focused coping, it was associated with memory problems, behavioral problems, and appraisal of strain. Others have found that men are more likely to use strategies that involve formal (paid) assistance (Robinson, Adkisson, & Weinrich, 2001; Miller & Guo, 2000; Rose, Strauss, Neundorfer, Smyth, & Stuckey, 1997).

Bookwala and Schulz (1998) examined the mediating effects of personality attributes on a spouse caregivers' sense of strain and depression. Caregivers high on the trait of neuroticism and/or low on mastery reported more functional and behavioral problems in their disabled spouse. This correlated with greater levels of strain and depression. Yates, Tennstedt, and Chang (1999) also identified personal mastery as a critical variable.

Caregiver perceptions of social support are mediators of stress. In several early works, the amount of visits and social support provided by family members were more important than behavioral problems in predicting caregiver burden and coping responses (Zarit, Reever, & Bach-Peterson, 1980; Haley, Levine, Brown, & Bartoulucci, 1987). Role overload combined with a lack of support was as an important influence (Yates, Tennstedt, & Chang, 1999), as was the quality of the caregiver/care recipient relationship. An earlier work by Williamson and Schulz (1990) supported the Yates and colleagues finding regarding the quality of the caregiver/care recipient relationship. A study of 49 female caregivers in the home environment found that as perceptions of support increased, caregiver emotional reactivity decreased (Atienza, Collins, & King, 2001). Lieberman and Fisher (1999) found similar results in a decision-making and conflict resolution study of 211 caregivers, as did Smerglia and Deimling (1997) in a study of 244 caregivers.

A replication study by Miller, Townsend, Carpenter, Montgomery, Stull, and Young (2001) challenged the long held assumptions regarding the role of social support. In reassessing four community-based caregiving studies, only two of the four data sets showed an association between social support and caregiver distress in the expected direction (social support reducing distress). Behavior problems and caregiver health were more important in explaining caregiver distress. Part of the explanation may lie in the different definitions of social support; subjective measures of adequacy seem to be more germane than objective measures (Stuckey & Smyth, 1997).

As well, family dynamics differ in unique ways. Levesque, et. al., (1998) find an association with the incidence of conflicts between informal caregivers and the frequency of informal support. Perceptions of burden vary depending on whether a family was found to be in "high" or "low" agreement regarding caregiving (Pruchno, Burant, & Peters, 1997). Type and level of support vary with the type of illness (Straw, O'Bryant, & Meddaugh, 1991). Of all family caregivers, those providing assistance to Alzheimer's Disease victims received less informal support although they identified greater needs for support.

Appraisal and the potential influence of education interventions. As developed in Chapter 1, the progressive philosophy of adult education emphasizes enhancement of the learner's problem solving skills (Price, 1999; Donlevy & Donlevy, 1998). Secondary appraisal of positive coping strategies such as planful problem solving and seeking information are targets of opportunity for education intervention research with dementia caregivers.

Despite the large number (352) of caregiver education programs cited in gerontology literature (Opie, et. al., 1999; Biegel, et. al., 1991; Toseland & Rossiter, 1989), only four studies make a linkage between appraisal and intervention programs for dementia caregivers. Chang (1999) designed cognitive-behavioral intervention for caregivers that involved video education and reinforcing follow up calls from nursing personnel. Sixty-five caregivers participated in the study. Compared with a control group, intervention group members reduced their use of emotion-focused coping strategies. The results show statistical significance. In a qualitative study focused on the impact of a cognitive remediation intervention involving dyads (caregiver and care receiver), Quayhagen and Quayhagen (1996) felt the evidence supported enhancements in quality of life and emotional well being through more meaningful interactions. The small sample size (n = 10) was of concern. A subsequent LISREL analysis with a larger study sample (n = 87) found continued support for the benefit hypothesis. The remediation program increased the caregiver's use of problem-focused coping and positive reappraisal (Corbeil, Quayhagen, & Quayhagen, 1999). In contrast, an individually based problem solving counseling approach implemented with 77 caregivers did not identify any improvements in psychosocial adjustment, psychological distress, or caregiver burden (Roberts, Browne, Milne, Spooner, Gafni, Drummond-Young, LeGris, Watt, LeCalir, Beaumone, & Roberts, 1999).

While most education interventions address stress reduction, they do so in general ways using global measures. Understanding of and framing of efforts within a stress model has been lacking; as a result, most studies are atheoretical according to Kramer (1997b). Further, interpretation of results is confusing because interventions have combined an array of education techniques (didactic education, individual counseling, print materials, and support group interventions). Despite the criticism, a number of studies document significant stress reduction impacts due to caregiver education (Ostwald, Hepburn, Caron, Burns, & Mantell, 2000; Gallagher & Hagen, 1996; Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996; Monahan, Greene, & Coleman, 1992; and Toseland, Rossiter, Peak, & Smith, 1990). However a recent qualitative analysis questions the results (Martin-Cook, Trimmer, Svetlik, & Weiner, 2000). Using a case study approach, the authors found education efforts have little effect on reducing caregiver stress and improving outcomes. They suggest that broad measures of caregiver burden might be ineffective for assessing effectiveness of education programs.

Another problem in assessing the past literature is that intervention programs often address a wide array of caregiving issues. Some education programs cover all aspects of dementia and general skills for daily disease management (Ostwald, Hepburn, Caron, Burns, & Mantell, 1999; Mittelman, Ferris, Shulman, Steinberg, Ambinder, Mackell, & Cohen, 1995; Kahan, Kemp, Staples, Brummel-Smith, 1985). Other education endeavors took a focused approach: eating and dressing (Chang, 1999); wandering behaviors (Logsdon, Teri, McCurry, Gibbons, Kukull, & Larson, 1998); nonpharmacological sleep enhancements (McCurry, Logsdon, Vitiello, & Teri, 1998); pleasant events and problem solving (Teri, Logsdon, Uomoto, & McCurry, 1997); and difficult behavior interventions (Burgener, Bakas, Murray, Dunahee, & Tossey, 1998). Programs with a focused approach tend to show stronger results; Montgomery and Kosloski (2000) warn against "shotgun approaches" which lack specificity.

Chapter 1 addressed concerns that past interventions efforts were so resource intensive and geographically targeted that most dementia caregivers would not benefit from them. The self-directed learning model provides an alternative to didactic education. With self-directed learning, the educator need only serve as a facilitator, helping the adult learner take an active role in their own education process (Knowles, 1988). Active involvement of the learner is critical for comprehension and retention of information (Gagne, 1985). The self-directed model fits well with the growing phenomenon of distance education (Crowther, 2000; Kintzer, 1999). As previously noted, distance education is asynchronous learning that can involve a wide array of media (postal mail, facsimile, radio, television, satellite broadcasts, videotapes, teleconferencing, and the Internet) (Matthews, 1999; Wolf & Johnstone, 1999). Chapter 1 presented results from the few dementia caregiver studies that fit in the distance education modality.

The four published articles on dementia caregiving and distance education via the Internet education are intriguing (Coulson, 2000, White & Dorman, 2000; Bass, et. al., 1998; Mahoney, et. al., 1998). Though the dementia application has been limited, Internet education is becoming common in medical and nursing education. Empirical data from health professional studies indicate generally positive results. Student nurses with one year of prior computer experience effectively learned nursing theory and critical thinking skills using Internet technology (Weis & Guyton-Simmons, 1998). Medical students and physicians exposed to Internet programs significantly increased their level of knowledge about diabetes nutrition (Engel, Crandall, Basch, Zybert, & Wylie-Rosett, 1997). Cancer education presented to medical students over the Internet was as effective as information provided to a comparable group through didactic sessions (Mehta, Sinha, Kanwar, Inman, Albanese, & Fahl, 1998). Internet education was not able, however to impact IV therapy skill instruction to student nurses (DeAmicis, 1997). The available empirical studies are problematic for several reasons: small sample sizes, lack of rigorous scientific design, lack of control groups, and insufficient quantitative analysis.

Potential drawbacks to Internet education include: the impact of decreased human communication in the education process, a connection versus autonomy issue (Rose, 1999); liability, security, privacy, and cost of computers and Internet access

(Zucker, et. al., 1998); the ability to design simulations at an appropriate education level (Graber, Roller, & Kaeble, 1999); lack of explicit instructions for use and reflection of real life cases (Weis & Guyton-Simmons, 1998); and the lack of access for socially disadvantaged groups (Marcus, et. al., 1998). A meta-analysis of 23 studies by Piotrowski and Vodanovich (2000) found that while there are negative aspects to Internet instruction, there are many positive findings as well.

The potential benefits of active Internet education are numerous. It may increase communication by exposing users to more and varied situations; it can be time efficient as learners can use the medium at their convenience (asynchronous education); learning is enhanced by the potential for incorporation of both sound and video; it allows for individual differences in learning styles, strengths, and preferences; and it offers the user an "unsurpassed" opportunity for perpetual archiving of the most up to date information (Malone, 2000; Zucker, et. al., 1998; Carlton, Ryan & Siktberg, 1998). Ackerman (1999) feels the format will enhance understanding of complicated health and disease processes that cannot be adequately communicated in text alone. Properly designed with interactive choices for the user and immediate feedback prompts, critical thinking skills can be safely and independently practiced without fear of causing harm to a patient (Weis & Guyton-Simmons, 1998; Bersky, Krawczak & Kumar, 1998). Finally, if programs are personalized and users access the information most pertinent to their needs, efficacy of learning is greater (Marcus, Owen, Forsyth, et. al., 1998).

Measuring education outcomes. Researchers in the field of education continually debate how best to assess the effectiveness of education programs and interventions (Hayes, Lavender, Reisenberger, & Vorhaus, 2000; Sonner, 1999; Wade, 1999). Though many programs rely on retention rates and attendance records (if applicable), these are weak measures. Some studies of caregiver education programs identify and discuss dropout rates. However, this is due to the importance of being able to generalize the study results.

In education literature, emphasis is on assessing progress toward achievement of intended learning outcomes, such as acquisition and application of particular knowledge and/or skills. Hayes and colleagues believe that assessment of education outcomes is not an exact science. Instead, one may need to rely upon a "reasonable belief" that the education experience led to the desired outcome. As well, Hayes and colleagues indicate that "unintended outcomes" may be equally important. If a learner gains general self-confidence during the education experience, this is a legitimate benefit although it was not part of the original education intent.

Experts on dementia caregiving have expressed dismay that results of education intervention programs often do not show strong statistical correlation (Montgomery & Kosloski, 2000; Switzer, Wisniewski, Belle, Burns, Winter, Thompson, & Schulz, 2000). Braithwaite (2000) has argued that part of the problem may be due to selection of inappropriate measures, and argues that it may be best to assess both general outcomes as well as contextual outcomes. Caro (2001) suggest use of a "quality of circumstances" framework. This involves identification of objective measures to determine the adequacy of proposed solutions to the problems of everyday caregiving. For example, instead of a broad focus, such as the prevention of premature nursing home placement, the objective is to make the home safe so the individual can move throughout without significant risk of injury.

Appraisal construct summary. It is the cognitive process of appraisal that mediates an individual's experience of stress. Only when evaluation of an environmental demand determines it to be threatening does a stress response occur. Demands viewed as benign or challenging do not result in a stress response.

Because appraisal is a cognitive process, the potential exists that interventions can target important information that could change the appraisal process. The two step process of appraisal offers intervention options: primary appraisal (is the environmental demand threatening), and secondary appraisal (what coping options are available and what is the probability of success). Despite the commonalties of dementia caregiving, each caregiver is a unique individual. The unique features of personal characteristics, socioeconomic status, social support, physical health, and past experiences influence cognitive appraisal. Because of the similarities as well as the differences, education for dementia caregivers may be best when it is self-directed and flexible. Distance education via the Internet offers unique opportunities in this regard. Subsequent hypotheses in this research focus on the appraisal theme.

Negative Emotional States Construct

The third proposition from the Cohen, Kessler, and Gordon stress-health model posits that appraisal of a stress state result in negative emotional states for the individual. Negative emotional states involve the affective presentation of anger, anxiety, and depression.

Theoretical and empirical support for the negative emotional states construct. Emotional states (affect) have a long history of study in the social and behavioral sciences. Extremes in mood have always been part of the diagnostic process for major psychiatric conditions (Stone, 1995). However, few empirical studies examine the linkage between emotional responses and subsequent physiological effects (Cohen, Tyrell, & Smith, 1993).

Caregiver application of the negative emotional states construct. In three meta-analyses on caregiver stress, there is support for hypotheses that connect stress with negative emotional states like depression, anxiety, and/or negative affect (Yee & Schulz, 2000; Schulz, et. al., 1995; Schulz, et. al., 1990). Given, Given, Stommel, and Azzouz (1999) posit that data on caregivers show depression does not relate to the total number of stressors experienced, but rather to onset of new stressors. Though this study was not specific to dementia caregivers, it does have application given the progressive and therefore changing nature of memory impairment. After following 121 caregivers over two years, the most significant factor predicting mental health decline was found to be lower levels of mental health status at the start of the caregiving experience (Haug, Ford, Strange, Noelker, & Gains, 1999).

Negative emotional states construct summary. To reduce a caregiver's negative emotional states, intervention must occur at an earlier point in the stress process, namely during cognitive appraisal. Because of the importance of primary and secondary appraisal and the linkage to education interventions, the research in this study will not address the emotional states construct any further.

Behavioral and Physiological Responses Constructs

The fourth proposition from the Cohen, Kessler, and Gordon stress-health model states that negative emotions trigger behavioral and/or physiological responses.

Behavioral responses include changes in health or other practices employed by the individual. Physiological responses involve activation of the sympathetic-adrenocortical axis (increased secretion of epinephrine and norepinephrine) and the hypothalmic-pituitary-adrenocortical axis (increased secretion of adrenocorticotrophic hormone and corticosteroids).

Theoretical and empirical support for the responses construct. The early stress work by Cannon (1935) and Selye (1975; 1950) document general physiological changes as the result of stress. Recent works in the field of psychoneuroimmunology detail specific impacts. Healthy adults exposed to the cold virus were five times more likely to develop a cold if they were under work-related stress (Cohen, Frank, Doyle, Skoner, Rabin, & Gwaltney, 1998). Roberts, Anderson, and Lubaroff's study (as cited in Santrock, 2000) shows that the onset of acute stressors causes a decrease in T-cell function among relatively healthy HIV-infected individuals. Cancer patients with higher stress levels produce fewer natural killer (NK) cells (Levy, Herberman, Lee, Whiteside, Kirckwood, & McFreeley, 1990).

Caregiver application of the responses construct. There are no studies directly measuring a dementia caregiver's physiological responses/reactions to stress. Empirical research does provide some information that may be relevant to the construct of psychological responses and reactions. Responding to a mail survey, Alzheimer's Disease caregivers experience negative changes in health behaviors related to physical activity, meal schedule, proper nutrition, cigarette smoking, alcohol consumption, and body weight (older caregivers tended to lose weight, while younger ones gained) (Gallant & Connell, 1998, 1997). Though the authors assumed that social support would mediate health behavior changes, it did not. Irvin and Acton (1996) found self care resources to decline with caregiver stress, though their construct of self-care was not well defined.

Data from the National Alliance for Caregiving (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999) show that 55 percent of caregivers of dementia patients have given up their own activities, hobbies, and vacations, as compared with only 41 percent of non-dementia caregivers. Over half of dementia caregivers also felt they had less time for other family members, compared with only 38 percent of non-dementia caregivers. The preceding two items reflect strategies individuals might employ to combat personal stress. It is not surprising then that almost twice as many dementia caregivers (22 percent) experienced a mental or physical problem because of the caregiving experience. Though not specific to dementia caregivers, Brown and Mulley (1997) found that 67.4 percent of family caregivers experienced some type of injury during the course of the caregiving experience; many had to stop caregiving for a period.

Response construct summary. Attenuation of physiological and psychological responses requires intervention at an earlier point in the stress process model. Emphasis in this research study is on the cognitive appraisal concept. The response construct will not be addressed any further.

Disease Construct

The final proposition from the Cohen, Kessler, and Gordon stress-health process model states that the behavioral and/or physiological responses of the previous stage will place the person at risk for the development of physical and/or psychiatric disease.

Theoretical and empirical support for the disease construct. When stress reactions are frequent and intense, the immune system suffers. The cumulative effect damages the body at all levels (molecular, physiological, psychological, and social). Studies with vulnerable populations (men with human immunodeficiency virus) illustrate the critical connection with the immune system. Men who participated in a support group intervention experienced significant improvements in CD4 and total lymphocyte cell counts compared to a control group (Goodkin, Feaster, Asthana, Blaney, Kumar, Baldewicz, Tuttle, Maher, Baum, Shapshak, & Fletcher, 1998).

Caregiver application of the disease construct. Four years of longitudinal data from the Caregiver Health Effects Study have shown that stressed spousal caregivers are at increased risk for mortality (Schulz & Beach, 1999). Comparable data for non-spouse caregivers are not available. Ongoing analysis from the study has found, however, that after the death of the ill spouse, the level of distress does not continue to increase. In fact, the previously stressed caregivers reduce the number of risky health behaviors in which they engaged (Schulz, Beach, Lind, Martire, Zdaniuk, Hirsch, Jackson, & Burton, 2001). Kaplan and Boss (1999) did not find such benefits when the individual with dementia entered a nursing home. Ambiguity about the new caregiving role contributed to ongoing stress.

Several works study the connection between dementia caregiving stress and immune system function. A comparison of 27 caregiving wives (mean age of 67.2 years) finds higher sympathetic, neuroendocrine activation compared to 37 matched non-caregiving wives (Cacioppo, Burleson, Poehlmann, Marlarkey, Kiecolt-Glaser, Bernston, Uchino, & Glaser, 2000). Caregiving spouses have poorer antibody and virus specific T cell responses to an influenza virus vaccine, due to stress inhibition of the IgG antibody (Glaser, Sheridan, Marlarkey, MacCallum, and Kiecolt-Glaser, 2000). Nerve growth factor is also reduced (Hadjiconstantinou, McGuire, Duchemin, Laskowski, Kiecolt-Glaser, & Glaser, 2001). Among the impacts are poorer wound healing (Kiecolt-Glaser, & Glaser, 2001). It takes caregivers nine days longer to heal a small (3.5 millimeter) wound. The results merit cautious interpretation. Many factors contribute to an individual's risk for illness, including the stress of caregiving. Physical and mental health statuses before the onset of caregiving are important variables.

Disease construct summary. To monitor evidence for the disease construct in dementia caregiving research, a longitudinal study is required. Such effort is beyond the scope of this research project.

Application of the Cohen, Kessler, and Gordon Stress-Health Process Model to the Proposed Study of Distance Education for Dementia Caregivers

Research Question

The second proposition in the Cohen, Kessler, and Gordon Stress-Health Process Model serves as the basis for the research question. A fuller testing of all propositions is beyond the scope of this research.

The second proposition in the model states that stress perception results when environmental demands are appraised as threatening or taxing, and coping resources are viewed as inadequate. As established in the literature review, primary appraisal (perception of threat) and secondary appraisal (assessment of coping options) interact. Interventions designed to influence a caregiver's secondary appraisal process have the potential, in turn, to impact and change the caregiver's primary appraisal process. A focused education endeavor has the potential to enhance a caregiver's assessment of coping options, and the subsequent implementation of the options. If successfully implemented, the caregiver would reassess the care situation and find it less threatening. In the fuller view of the stress-health process model, caregivers would then experience a reduction in overall stress; physical and mental health status should then improve (proposition five).

Related to the second proposition in the model, the research question for this dissertation is: to what extent can self-directed, distance education alter a dementia caregiver's primary and secondary appraisal processes? To answer the question, three forms of self-directed, distance education will be compared: written brochure information distributed by postal mail to the caregiver; brochure information accessed by the caregiver through the Internet (content and layout identical to the written brochure); and identical information enhanced with multimedia, interactive techniques accessed by the caregiver through the Internet. While all three education formats use the principles of self-directed learning theory, the third format incorporates principles from cooperative (interactive) theory as well.

Research Hypotheses

Seven hypotheses will test the research question. The first two are main effect hypotheses. Chapter 3 will provide details on the measurement techniques and statistical analysis.

Hypothesis 1

All three education interventions will have a significant, positive association with reduced caregiver perceptions of threat caused by wandering behavior. Chapter 3 will provide details regarding the rationale for selection of wandering behavior. In context of the Cohen, Kessler, and Gordon stress model, wandering behavior does meet the definition of an environmental demand (an environmental experience that requires adjustment). It is a stressor that can be chronic (ongoing) or acute (episodic). Derivation of the hypothesis is the principal of primary cognitive appraisal. If education intervention can alter the individual's cognitive appraisal relative to the specific stressor, then the caregiver should begin to evaluate the environmental demand as benign or challenging. Either alternative alters the stress experience.

Hypothesis 2

All three education interventions will have a significant, positive association with the number of home modifications made for the management of wandering behaviors. Secondary evaluation involves review of eight coping options. Of the eight options, some are positive and action oriented; others involve emotional coping and escapism. If education presents dementia caregivers with new thoughts regarding ways to be action oriented in coping, the desired outcome would be implementation of the suggestions. Caregivers who make home modifications after the education intervention are engaging in positive secondary appraisal.

The next two hypotheses present assumptions regarding magnitude effects anticipated. Of the three education formats to be tested, only one incorporates principles from both the self-directed learning theory and the cooperative, interactive learning perspective (an interactive, multimedia Internet education program). From a theoretical perspective, this approach should be superior to the other education formats.

Hypothesis 3

There will be a significant, positive difference between mean threat reduction scores for participants in the interactive, multimedia education group compared with participants in the mail brochure and passive web site groups. If the dynamic format more fully engages the learner, comprehension and retention of information should be greater. Retained information has the potential to alter primary appraisal.

Hypothesis 4

There will be a significant, positive difference between the number of home modifications made by participants in the interactive, multimedia group compared with participants in the mail brochure and passive web site groups. As with the third hypothesis, when comprehension and retention of information increases, the potential exists for using the information to alter cognitive appraisal. As with the second hypothesis, positive secondary appraisal requires the caregiver to make home modifications. Operationalization of home modifications involves a numerical count of any changes identified by the participant. Thus, assessment of magnitude uses a ratio scale. To evaluate the quality of each modification would involve subjective judgments beyond the scope of this research.

The next two hypotheses continue the magnitude examination relative to both passive forms of education.

Hypothesis 5

There will be no significant difference in threat reduction scores for participants in the mail brochure and passive web site groups. This hypothesis addresses the primary appraisal construct. While both education formats incorporate principles of the self-directed learning theory, both formats are passive. The assumption is that the means of delivery (Internet compared with postal mail) will not have a differential impact on the caregiver's primary appraisal of the situation.

Hypothesis 6

There will be no significant difference in the number of home modifications made by caregivers in the mail brochure and passive web site groups. As with hypothesis 5, the passive nature of both formats should result in an equal number of changes identified by the participant. This hypothesis addresses the secondary appraisal construct, with the assumption that the means of delivery will not have a differential impact on secondary appraisal.

Hypothesis 7

There will be no significant difference in the number of home modifications made by caregivers within any groups as a function of the passage of time. The final hypothesis looks at the impact of time and maturation. If information is valuable to the caregiver and therefore has the potential to impact secondary appraisals, it is likely to be acted upon quickly (within one month). Reassessment at two months post-intervention will not change the reappraisal status.

Summary

This research question concerning dementia caregivers and the potential to alter stress appraisals using distance education is important for several reasons. Dementia caregiving is a physically, mentally, and financially stressful experience. The projected increase in the number of dementia victims in the future has both individual family and societal implications. Current systems of care and education are not reaching most families, as evidence by higher rates of morbidity and mortality among dementia caregivers. Internet education strategies offer the potential for a new, cost effective way to meet the education and information needs of the growing population of caregivers.

Using the Cohen, Kessler, and Gordon unified model of the stress-health process, the following proposition serves as the framework for this research involving dementia caregivers: stress perception results when appraisal of environmental demands finds them threatening or taxing, and coping resources are inadequate. Table 1 illustrates the relationship between propositions, constructs, and variables.

The first and second columns of Table 1 illustrate the relationship between propositions and constructs from the stress-health model and education theory. In brief, the experience of stress depends upon a perception that an environmental demand causes threat, and taxes coping abilities. Appraisal of coping abilities involves evaluation of potential methods for elimination of the threat. The progressive theory of adult education emphasizes problem solving, an important skill related to appraisal of coping abilities. Progressive education is consistent with principles of self-directed learning. The asynchronous nature of self-directed learning offers a medium that could be widely available to dementia caregivers. The dynamic nature of interactive,

Table 1

Summary of Research Study Propositions, Constructs, and Variables

Proposition	Constructs	Variables
Stress perception results when appraisal…finds them threatening or taxing and coping resources are inadequate.	Appraisal of threat (primary appraisal concept)	Dependent variable: perceived threat
	Appraisal of coping resources (secondary appraisal concept)	Dependent variable: home modifications made to enhance coping
Progressive (problem solving) adult education, based upon principles of self-directed learning, has the potential to influence secondary appraisal of coping resources.	Self-directed learning	Independent variable: three levels of distance education
Dynamic education formats enhance comprehension and retention of information.	Dynamic education format	Independent variable: interactive, multimedia education format

multimedia computer technology offers a way to enhance the effectiveness of self-directed learning.

The third and fourth columns introduce the variables for this study, along with measurement techniques. A fuller discussion of variables and measurements takes place in the next chapter. Chapter 3 will also describe the population of interest, sampling plans, study design, and statistical analysis.

CHAPTER 3

Methodology

Introduction

Many families engaged in dementia caregiving are not receiving as much information about the disease process and management strategies as they would like (Roper Starch Worldwide, Inc., 2001). The information deficit can exacerbate the level of stress experienced by the caregiver. As posited in the Cohen, et. al., (1995) stress-health process model, the experience of stress involves both a primary appraisal that a situation is threatening and a secondary appraisal regarding the potential methods or means the individual might use to reduce the effects of the perceived threat.

Educating dementia caregivers about disease management strategies has the potential to reduce caregiver stress by altering the individual's secondary appraisal of the situation. Because appraisal is an iterative process, altering secondary appraisal has the potential to change the primary threat appraisal as well. A number of studies document the positive impact of caregiver education programs (Opie, et. al., 1999; Biegel, et. al., 1991; Toseland & Rossiter, 1989). However, the resource intensity (intervention personnel and money) and narrow target populations (caregivers in larger cities with medical schools) makes broader implementation difficult (Montgomery, 1996). Education theories offer alternative approaches based upon the progressive (problem solving) philosophy in adult education and self directed learning concepts (Price, 1999; Donlevy & Donlevy, 1998; Knowles, 1988). Distance education using the Internet is a specific modality receiving increased attention.

The purpose of this chapter is to provide details on the organization of the distance education study involving dementia caregivers. Specific information allows for evaluation of the methods, as well as laying the groundwork for future replication studies. Key sections include participants (sampling, recruitment, inclusion and exclusion criteria, sample size, and informed consent), design (description, equipment, and independent and dependent variables and measurements), procedures (participant instructions and contacts), and analysis (descriptive and hypothesis testing).

Participants

Sampling and Recruitment Procedures

The population of interest is individuals who provide or assist with the home care of a person with dementia. Recruitment of the study population involves convenience sampling. Individuals calling the Sunflower Chapter of the Alzheimer's Association's 24-hour Helpline will receive information about the study and ways to contact the Principle Investigator. The association's Medical and Scientific Committee will provide information about the study to area physicians (family practitioners, internists, and neurologists) and encourage referrals. Cross-referrals are possible (participants referred by both the Helpline and/or more than one physician). Information obtained during the informed consent procedure ensures a participant enters the study only once.

Because convenience sampling is a nonprobability sampling technique, there are methodological concerns (Polit & Hungler, 1999). The more heterogeneous the population of interest, the greater the risk for bias. Subsequent sections on generalizability and threats to reliability and validity discuss the concerns in detail.

Setting. The Sunflower Chapter of the Alzheimer's Association serves 46 counties in central and western Kansas. The area is predominantly rural, with only one standard metropolitan area (Wichita). Kansas is a rural state. Only 56.8 percent of the population reside in urban areas, compared to 70.9 percent nationwide (Brangan, Griffin, & McDougall, 2000). The lack of support services in many rural areas contributes to a higher utilization of nursing care facilities in Kansas; 6.4 percent of Kansas 65 and older reside in nursing homes, compared to 4.3 percent nationwide (Nawrocki & Gregory, 2000). National studies also indicate that close to 60 percent of all nursing home residents have diagnoses of some form of dementia.

Many areas in Kansas are without dementia support groups to aid caregivers. Of the 46 counties in the Sunflower Chapter's service area, only 20 counties have support groups as of July 2001. Because of the limited service and support, distance education for dementia caregivers is a venue that merits closer attention in any rural setting. It is also of potential benefit to urban caregivers that may lack the time or transportation to attend education programs. Molinari, et. al., (1994) documented the significance of time, location, and transportation for determining support group attendance.

Inclusion Criteria

To participate in the study, a caregiver must provide or assist with home care for an individual who has dementia. Involvement in home care can include, but is not limited to, co-residence. Because co-residence has the potential to affect caregiver stress differentially, data collection includes co-residence for confounding analysis. The definition of dementia includes any medical condition that impairs memory and the ability to perform activities of daily living. Examples include, but are not limited to, Alzheimer's Disease, vascular dementia, multi-infarct dementia, dementia with Lewy Bodies, and Pick's Disease. Finally, the individual receiving care must be freely ambulatory (able to walk without the assistance of another person).

Exclusion Criteria

Any caregiver that does not have an email address and routine access to a computer with at least a 28 K Internet modem connection cannot participate in the study. The definition of routine access to a computer is either the presence of a computer in the home or ongoing ability to access a computer outside the home (such as a relative's home or a public access point like the library). Caregivers who routinely attend dementia-related support groups before the study cannot participate. Information from support groups could confound the effects of the education interventions.

Generalizability

The exclusion criteria cited presents concerns for generalizability of the research findings. While the population of interest is dementia caregivers, an unknown number are not able to participate in the study due to lack of computer with Internet access. As described in Chapter 1, 66 percent of American households will soon have Internet access (Library of Congress, 2000). Application of this finding to households caring for a person with dementia means approximately one-third of all caregivers in the service area are unable to participate. Though rates of female Internet use are increasing

(Rickert & Sacharow, 2000), as are users in lower income households (Thompson, 2000), these are the groups most likely to be denied participation in this study.

Number of Participants

Computation of sample size is a multi-part experience exercise (Polit & Hunger, 1999; Cone & Foster, 1993). The significance criterion (alpha) addresses the potential for Type I error (rejection of the null hypothesis when it is true); .05 is the accepted standard for psychological research. Power (1 – beta) addresses the potential for Type II error (acceptance of the null hypothesis when it is false); .80 is the accepted standard in psychological research. Support for both figures is in the seminal dementia work of Switzer, et. al., (2000). Population effect size (gamma) estimates the magnitude of relationship between research variables. The nature of the data determines the selection of the value of gamma. A pilot study is useful for estimation purposes, as are eta-squared values found in other published research on the same or similar problems. Cohen (1992) proposed general standards for the detection of small ($p < .01$), medium ($p < .05$), and large ($p < .10$) effects, a position generally supported in Schulz's seminal work on dementia caregiving.

Combining the advice of Cohen with the advice of Schulz and colleagues, the goal in this research is to be able to detect medium effect sizes, given an alpha of .05 and a power of .80. Standardized charts for three-group analysis using Analysis of Variance (ANOVA) techniques set the recommended sample size for this research at 62 participants per group (Jaccard & Becker, 1990).

Informed Consent

The informed consent document (Appendix A) follows the template adopted by Virginia Commonwealth University. In accordance with University rules, interested persons may contact the Principal Investigator to ask questions before signing the consent form. Such contacts may occur by telephone, email, postal mail, or in-person. Interested persons do not become study participants until the Principal Investigator receives the signed consent. All participants receive a copy of the signed form.

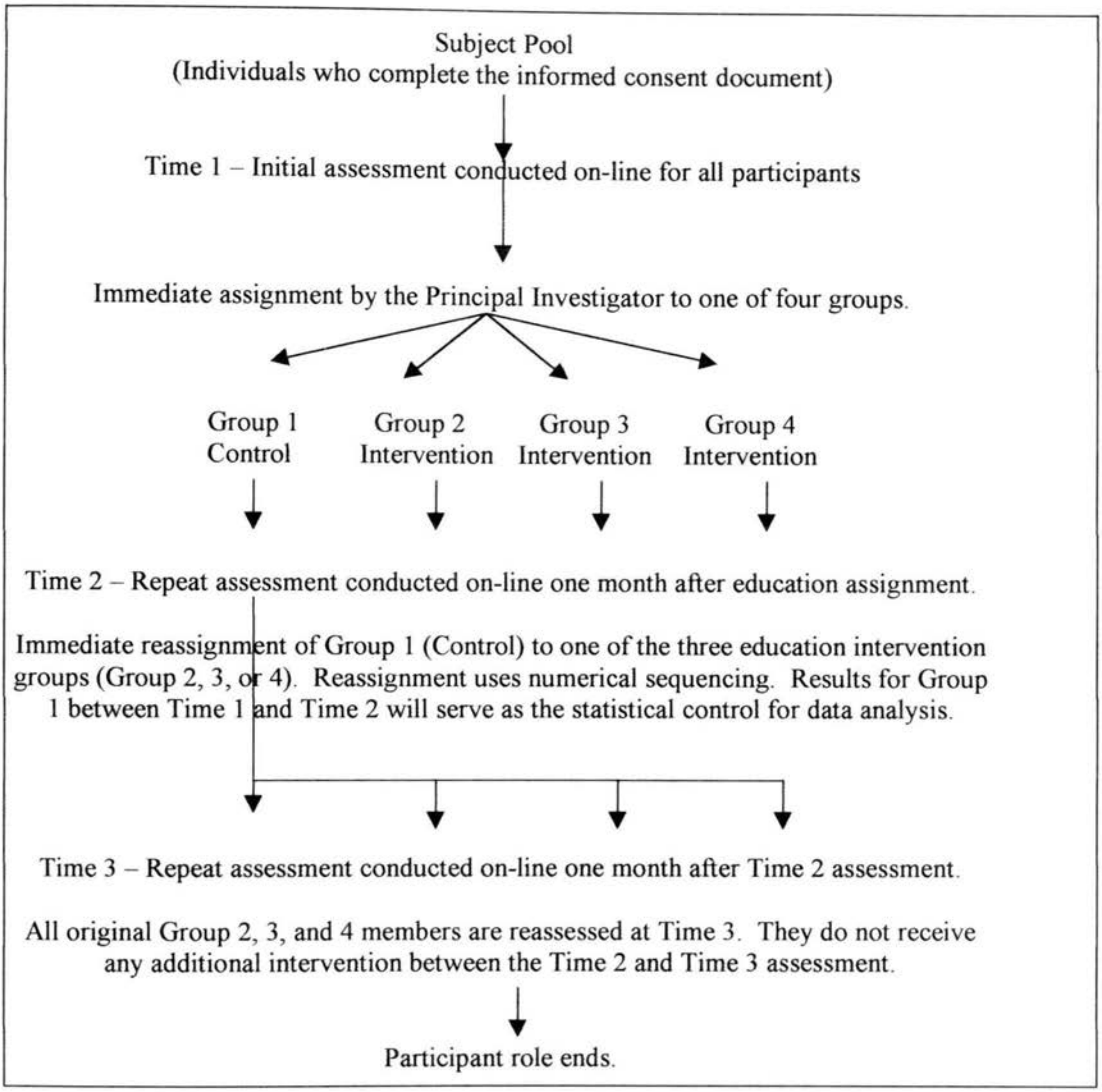
Design

Description

The study of distance education for dementia caregivers uses the Switching-Replications Design, a quasi-experimental design. This design is strong with respect to internal validity, as well as external validity and generalizability because it incorporates random assignment of participants, two independent intervention implementations, and three waves of measurement (Trochim, 2001). It is recommended in situations where program content is specific, can be mastered in a short time, and participant improvement is not expected to continue beyond the initial level. As will be discussed in subsequent paragraphs, the education content is specific (focused on wandering behaviors) and short (less than 10 minutes to review). The Switching-Replications Design is one of the most ethically feasible quasi-experiments because it ensures that all participants eventually receive intervention. This is important in dementia caregiving because of the physical and emotional stress experienced by family members. At the same time, a weakness of the design is the lack of a true control group. The basic pattern of the Switching-Replications Design is:

N	O	X	O		O
N	O		O	X	O

where N equals participants, O equals observation, and X equals intervention or treatment. Figure 3 illustrates implementation of the Switching-Replications Design.



Subject Pool
(Individuals who complete the informed consent document)

Time 1 – Initial assessment conducted on-line for all participants

Immediate assignment by the Principal Investigator to one of four groups.

Time 2 – Repeat assessment conducted on-line one month after education assignment.

Immediate reassignment of Group 1 (Control) to one of the three education intervention groups (Group 2, 3, or 4). Reassignment uses numerical sequencing. Results for Group 1 between Time 1 and Time 2 will serve as the statistical control for data analysis.

Time 3 – Repeat assessment conducted on-line one month after Time 2 assessment.

All original Group 2, 3, and 4 members are reassessed at Time 3. They do not receive any additional intervention between the Time 2 and Time 3 assessment.

Participant role ends.

Figure 3. Application of switching-replication design in dementia caregiver study

Equipment

The study does not require the purchase of new equipment. Virginia Commonwealth University provides the computer access, server space, and computer time for secure, password protected sites. Other computer equipment needed is the property of the Principal Investigator.

Independent Variable and Measurement

Table 2 illustrates the independent variable of interest, operationalization for measurement, and scaling.

Table 2

Independent Variable for the Study of Dementia Caregivers

Independent Variable	Operationalization for Measurement	Scale
Distance education	Brochure sent by postal mail	Nominal
	Brochure accessed from passive web site	Nominal
	Brochure enhanced with multimedia and computer interactive components	Nominal

The independent variable of interest is distance education for dementia caregivers. Chapter 2 defined distance education as a method of self-directed, asynchronous learning. Techniques for distance education include an array of media, ranging from mail, to facsimile, radio, television, satellite broadcasts, videotapes, teleconferencing, and the Internet (Matthews, 1999; Wolf & Johnstone, 1999).

Operationalization. This study involves three forms or levels of distance education. One form uses a written brochure sent by postal mail to the caregiver (henceforth referred to as Group 2 or the brochure group). A second form accesses identical content through an Internet site (Group 3 or the passive web group). The final form involves the same content enhanced with multimedia and computer interactive components, accessed through an Internet site (Group 4 or the active web group).

Group assignment procedure. Participants receive an education group assignment once the informed consent document is complete. Initial assignment follows the numerical sequencing of the groups: the first participant becomes a member of Group 1 (control group); the second participant, Group 2; the third participant, Group 3; the fourth participant, Group 4; the fifth participant, Group 1; the sixth participant, Group 2; and so forth. Reassignment of Group 1 members occurs after the Time 2 assessment. Reassignment continues to use the numerical sequencing technique.

Potential confounding factors. As noted previously, convenience sampling has the potential for bias, especially if the study sample is heterogeneous. Participants in the study of distance education and dementia caregivers include males and females of various ages. Some participants co-reside with the individual to whom they provide care, while others do not. Participants also vary in their relationship to the individual with dementia. These factors have the potential to exert a differential effect on the stress levels experienced by caregivers. Background information collected on all participants allows for statistical analysis of potential confounding factors.

Participant experience and comfort level with the Internet has the potential to influence outcomes. To minimize these concerns, participants complete all questionnaires and assessments on-line. This helps ensure a comparable level of Internet skill across groups. As well, data collection includes each participant's years of experience with the Internet and an overall rating of the comfort level with the Internet.

Potential threats to reliability and validity. Several factors have the potential to threaten study results. Maturation (changes over time) occurs with most forms of dementia. The short time span of the study (participant involvement over two months) should minimize changes in dementia symptoms or other disease states. In addition, recency concerns regarding pre and post-testing can affect reliability and validity if participants recall answers from the prior period. Given the one-month period between each assessment, this is a concern. However, empirical studies indicate readministration at two to four weeks post-intervention does occur (Switzer, et. al., 2000).

The instrumentation of assessment tools can be a threat. As discussed in the dependent variable section to follow, this research uses a previously tested and validated assessment instrument. However, for purposes of this study, the instrument is in an on-line format; original testing involved paper and pencil completion. To control for this difference, a sub-group of ten participants will complete the assessment instrument in both computer form, and paper and pencil form.

Attrition of participants in dementia research is a concern that requires ongoing monitoring (Gitlin, Corcoran, Martindale-Adams, Malone, Stevens, & Winter, 2000). Unfortunately, it has been unreported in many dementia studies (Nichols, Malone, Tarlow, & Loewenstein, 2000). In a meta-analysis of 43 studies, Opie, Rosewarne, & O'Connor (1999) identified ten studies that did not report demographic details for participants leaving the studies. The authors also identified five studies with attrition rates more than 20 percent.

Should participants leave the dissertation study, the Principal Investigator will follow-up to discern the reasons. It is possible that a caregiver could become ill or die, or the person to whom they provide care passes away. A caregiver might also experience financial difficulties and discontinue Internet access. Use of nursing home care during the study might discourage some caregivers, but they will continue and complete the study. Participant bias is possible as well. Because a convenience sample is used, those who do choose to participate may be unique from other caregivers in ways that cannot be precisely determined. The sample size for this study (62 participants per group) allows for attrition while still maintaining an adequate sample for statistical purposes.

Diffusion of information due to community events could be a threat. Any media stories about dementia could expose participants to similar content or to dementia education information outside the confines of the study. The short time span for participant involvement minimizes the potential. Seasonal issues represent a possible threat as well. With the study being conducted during winter months, caregivers may be more focused on the education content (management of wandering behaviors) due to cold Kansas winters. However, this factor would affect all intervention groups equally.

Diffusion and seasonal concerns are also an issue because of the staggered entry of study participants. Though each participant will only be involved for 60 days, it is highly unlikely recruitment can be completed within few weeks of study initiation.

Therefore, the Principal Investigator will monitor print media during the course of the study to collect articles on dementia-related themes.

Data collected from participants involves self-reports. A later section on variables and measurements reviews the accuracy of self-reports among dementia caregivers. While the literature finds self-reports generally accurate, dementia studies have not looked at social desirability as a source of bias. Study participants might misrepresent their responses in the direction of answers consistent with prevailing social norms that education should bring about change.

The focus and content of the educational message presented to participants could affect analysis of the education formats. As discussed in Chapter 2, taking care of a person with dementia is stressful and challenging in many ways. A broad educational message about dementia could be overwhelming, and it would be difficult to assess the impact and effectiveness of the education formats. Therefore, the education message used in this study involves only one challenging or threatening behavior, wandering. Relative to theme, specific suggestions present ideas for home management of the problem.

Justifications for education focus on wandering. Wandering is a tendency to move about in a seemingly aimless or disoriented fashion in pursuit of an indefinable or unobtainable goal (Coltharp, Richie, & Kaas, 1996). Estimates of wandering behavior range from a low of 19 percent in a British study (Burns, Jacoby, & Levy, 1990), to 56.9 percent (Devanand, et. al., 1997), and 65 percent (Logsdon, et. al., 1998). The behavior is most common during the middle stages of dementia (Morgan & Steward, 1997; Ryan, 1995; Burns, et. al., 1990; Henderson, Mack, & Williams, 1989). Additional details regarding wandering behavior are in Appendix B.

Wandering is a difficult behavior that increases caregiver stress (Logsdon, Teri, McCurry, Gibbons, Kukull, McCormick, Bowen, and Larson, 2000). Wandering is a major reason for institutional/nursing home placement (Logsdon, 1998); it doubles the risk of institutionalization (Kaspar & Shore, 1994).

There are many things caregivers can do to manage wandering behaviors in the home setting (Bakke, 1997; Holmberg, 1997; Maddox & Burns, 1997; Morgan & Steward, 1997; Begany, 1996; Glaser, 1996; Dickinson, McLain-Kark, & Marshall-Baker, 1995; Richter, Roberts, & Bottenberg, 1995; Edwards, 1994). A full review of the strategies is beyond the scope and purpose of this document. However, the breadth of options illustrates the concern regarding the potential impact of the educational content. It argues for a tailored message, focused on one area, with specific intervention suggestions. Accordingly, the decision is to focus the content of the education on home modifications that help to control wandering behaviors. A copy of the written content, which will serve for both the mailed brochure and the passive web intervention, is contained in Appendix C. The content in the active web intervention is available through the following Internet address: www.onlinecourse.net/dementia.

Integrity and checks. The three forms of distance education rely upon basic information available through national resources (Alzheimer's Association, 2001b; National Institute on Aging, 2001), and studies of dementia interventions cited in the preceding paragraph. As well, the Sunflower Chapter of the Alzheimer's Association and the dissertation committee at Virginia Commonwealth University review and approve all three forms of distance education.

The web site materials meet recommendations set forth by the Office of Communication at the National Institutes on Health (Koyani, 2001; National Cancer Institute, 2001). Appendix D contains a summary of the recommendations incorporated in the dissertation study.

Dependent Variables and Measurements

Table 3 illustrates the dependent variables of interest, along with operationalization for measurement, and scaling.

Table 3

Dependent Variables for Study of Dementia Caregivers

Dependent Variables	Operationalization for Measurement	Scale
Perceived threat from dementia behaviors	Agitated Behavior in Dementia Scale	Interval
Home modifications made by caregiver	Number of changes identified by caregiver	Ratio

There are two dependent variables of interest: the degree to which a caregiver perceives the dementia related behaviors to be of threat, and the home modifications made by the caregiver as a result of the distance education intervention.

Operationalization: Perceived threat and primary appraisal of stress. As described in Chapter 2, the amount of stress experienced relates to the degree of threat (primary appraisal) perceived by the caregiver. A caregiver that perceives wandering to be difficult and threatening should experience more stress. The threat variable in this study is operationalized using the Agitated Behavior in Dementia Scale (ABID) (Logsdon, Teri, Weiner, Gibbons, Raskind, Peskind, Grundman, Koss, Thomas, Thal, & members of the Alzheimer's Disease Cooperative Study, 1999). The ABID assesses 16 dementia-related behaviors that have the potential to challenge caregivers. Using a five-item interval response scale, caregivers rate the degree of "bother or upset" for each behavior. The response scale items are: not at all (0), a little (1), moderately (2), very much (3), extremely (4), and do not know or not applicable (9). A copy of the ABID is in Appendix E.

The ABID was developed and tested with 148 caregivers. Reliability testing evaluated internal consistency (coefficient alpha) and test-retest (intra-class) correlations. Coefficient alpha fell within an acceptable 0.70 range for both the frequency and reaction ratings. Evaluation of test-retest reliability involved a subgroup of 92 participants. Intra-class coefficients for frequency and reaction ratings were 0.73 and 0.60 respectively. Evaluations of validity examined correlation with other constructs, including demographic variables (caregiver education and age), cognitive status (measure by the Mini-Mental State Exam), and other behavioral disturbance scales (Behavior Rating Scale for Dementia, Revised Memory and Behavior Problems Checklist, and the Cohen-Mansfield Agitation Inventory). ABID scores did not significantly correlate with demographic variables of age and education. Scores were negatively related to the Mini-Mental State Exam ($r = -0.19$, $p < .02$) indicating that the more cognitively impaired subjects have higher ABID scores. ABID scores positively related to the Revised Memory and Behavior Problems Checklist ($r = 0.74$, $p < .0001$), the Behavior Rating Scale for Dementia ($r = 0.65$, $p < .0001$), and the Cohen-Mansfield Agitation Inventory ($r = 0.62$, $p < .0001$). Caregiver reaction ratings on the ABID were positively correlated with reaction ratings on the Revised Memory and Behavior Problems Checklist ($r = 0.69$, $p < .0001$).

Two primary resources review a number of geriatric assessment tools, including those that examine dementia and caregiving stress (Gallo, Fulmer, Paveza, & Reichel, 2000; Rubenstein, Wieland, & Bernabei, 1995). Assessment tools used in seven, federally funded Alzheimer's Disease research projects were reviewed by Smyth, Ferris, Fox, Heyman, Holmes, Morris, Phillips, Schulz, Teresi, and Whitehouse (1997). After a review of available tools, the ABID was selected for this study because it contained more content specific to wandering behaviors than the Revised Memory and Behavior Problems Checklist (Teri, Truax, Logsdon, Uomoto, Zarit, & Vitaliano, 1992), the Cohen-Mansfield Agitation Inventory (Cohen-Mansfield, 2000), the Behavior Rating Scale for Dementia (Tariot, Jack, Patterson, Edland, Weiner, Fillenbaum, Blazina, Teri, Rubin, Mortimer, and Stern, 1995), and the Caregiving Hassles Scale (Kinney & Stephens, 1989). The ABID also contains both objective and subjective measurement elements, while the Screen for Caregiver Burden (Vitaliano, Russo, Young, Becker, & Maiuro, 1991) and the Cost of Care Index (Kosberg, Cairl, & Keller, 1990; Kosberg & Cairl, 1986) are subjective in nature.

Operationalization: Home modifications and secondary appraisal of stress. The stress model presented in Chapter 2 indicated that secondary appraisals (the degree to which an individual feels there is something they can do to alleviate a stressor) influence the experience of stress. Education has the potential to alter the secondary appraisals made by an individual; this can then alter the primary appraisal. An individual who reviews an educational message about wandering behavior and subsequently makes home safety modifications has altered, and improved, their secondary appraisal.

To operationalize home modifications, participants specify the number of modifications made in the home at Time 2 and Time 3. The question format is open-ended. Any change identified by the participant counts. There will be no assessment of the qualitative nature of the changes; to do so would involve a level of subjective judgment beyond the scope of this study. A zero score is possible (caregiver made no changes), so data are ratio scale. There is no limit to the number of changes a participant can specify.

Other Variables and Measures

Descriptive analysis and comparison of group equality use the background variables listed in Table 4. Appendix F contains a copy of the tool used to collect the background information. All background variables selected have some differential effect on caregiver stress, as reported in Chapter 2.

Self Reported Data

All dependent variable data and participant characteristic information rely upon caregiver self reports. Five studies document the credibility of dementia caregiver, self-reported data. In a study involving 72 people with Alzheimer's Disease, family member reports of functional abilities were compared with clinical evaluations of performance (Lowenstein, Arguelles, Bravo, Freeman, Arguelles, Acevedo, &

Table 4

Descriptive Variables for the Study of Dementia Caregivers

Variable	Measurement	Ratio
Age	Calendar years as of last birthday	Ratio
Gender	Male = 1; Female = 2	Nominal
Relationship	Spouse = 1; Adult child = 2; Grandchild = 3; Other relative = 4; Friend or neighbor = 5	Nominal
Education	Highest grade level attained	Ratio
Caregiving Tenure	Years involved with home caregiving	Ratio
Racial/Ethnic Identification	African American = 1; Asian = 2; Hispanic = 3; Native American Indian = 4; Caucasian = 5; Other = 6	Nominal
Formal Assistance Received	Number of hours per week (if any) of outside/paid staff help	Ratio
Internet Experience	Years of Internet use	Ratio
Comfort Level with Internet	Very high = 5; high = 4; moderate = 3; low = 2; very low = 1	Interval
Frequency of Wandering Stressor	ABID scale of did not occur in the week = 0; occurred 1 to 2 times = 1; occurred 3 to 6 times = 2; occurred daily or more often = 3; do not know or not applicable = 9	Interval
Internet Access Problems	Open-ended opportunity to identify any access problems	Qualitative

Eisdorfer, 2001). Results indicated accuracy in the reports of caregivers with three exceptions: the ability of the patient to tell time, identify currency, make change, and utilize eating utensils. Depressive symptoms on the part of the caregiver did not relate to either over or underestimation of the patient's functional capacity.

Cavanaugh and Kinney (1998) studied 97 dementia caregivers for the accuracy of recall on five caregiving hassles (cognitive impairment, problem behaviors, basic and instrumental activity of daily living assistance, and social issues). Data collection occurred monthly for six months. Only 14 percent of respondents had incorrect recall. No characteristics distinguished caregivers with inaccurate recall.

As part of the Canadian Study of Health and Aging, Ostbye, Tyas, McDowell, and Koval (1997) collected information from 800 caregivers; approximately half were involved with dementia caregiving. Self and proxy reports by another person compared the care recipients' activity of daily living abilities. There was close agreement for reports on basic abilities (items such as bathing and dressing), but decreases occurred in comparisons of instrumental abilities (items such as cooking and cleaning). Level of agreement also decreased as severity of dementia increased. Nonetheless, the authors found few statistically significant differences.

Data from an Australian longitudinal study assessed 500 individuals with dementia and their caregivers over 3 ½ years (Jorm, Christensen, Henderson, Jacomb, Korten, & Mackinnon, 1996). Administration of five separate cognitive function tests took place at the start and end of the study. Compared with informant (primarily family) ratings, the authors found a close correlation between declines identified over time.

McLoughlin, Cooney, Holmes, and Levy (1996) examined the correlation between dementia caregiver reports of dysnomia (naming disorders) and professional clinical evaluations for 170 older adults. Results found that caregivers were aware of most cognitive impairments, but were not fully aware (underestimated) language difficulties.

Only one of the self-report studies discussed attrition. In the 3 ½ year study by Jorm, et. al. (1996), the original data pool included 1,135 subjects, but decreased to 500 by the end of the study. The authors identified death (283 subjects) as the leading cause of attrition, followed by lack of qualified informant (203), refusal for unspecified reasons (123), and inability to reach informant (26).

Procedures

Participant Instructions and Timing of Tasks

After the Principal Investigator obtains informed consent, participants receive the URL for the initial on-line assessment (Time 1). The assessment includes background demographics and administration of the ABID. Assignment to one of the three distance education groups or the control groups occurs within 12 hours of completing the on-line assessment. Participants in an education intervention group then receive the education URL or a postal mail brochure. Participant instructions request access of the education format within 24 hours.

The next contact with participants occurs 30 days after the initial assessment and assignment. An email from the Principal Investigator directs participants to the URL for the Time 2 assessment. This assessment repeats the ABID. Using an open-ended format, participants also identify all home modifications and any problems encountered in accessing the education URLs.

Reassignment of control group members (Group 1) occurs after completion of the Time 2 assessment. The numerical sequencing previously described guides reassignment to one of the three distance education interventions. The final contact with all participants occurs 30 days after the second assessment. The Principal Investigator contacts all participants by email and provides the URL for the final assessment (Time 3). As noted in a preceding section on threats to reliability and validity, it is important to note that not all participants will reach Time 3 during the same week or month of the study. This does raise concerns about diffusion of information as a source of bias, as well as changes in seasonal effect.

Because the computerized assessments are electronically sent direct to the computer of the Principal Investigator, it is possible to track participants over time. Individuals not completing assessments within 24 hours receive reminders by email. If problems persist, the Principal Investigator will call the participant by telephone to discern possible reasons for leaving the study and report the findings in differential analysis.

Participant Contacts

All participant contacts will be through the Internet or the US mail. There is no direct, in-person contact with participants once the individual signs the Informed Consent document, unless dropout occurs. Only the Principal Investigator has contact with the study participants. Appendix G contains the email messages sent to all participants over the course of the study.

Debriefing

All study participants may receive a copy of the final data summary and conclusions. No individual debriefings will take place. At the end of the study, participants have the opportunity to look at all three education formats.

Analysis

Descriptive Analysis

Descriptive statistics compare each group (control and three education interventions) on the basis of age, gender, relationship, education level, years of caregiving, racial/ethnic identification, hours of outside/paid assistance, years of internet experience, comfort level with the Internet, and frequency of wandering behaviors. This will establish comparability of the groups. In addition, the Principal Investigator plans follow- up with any participant leaving the study to discern the reasons.

Hypothesis Testing

Hypothesis testing uses the statistical technique of Analysis of Variance (ANOVA). ANOVA is a parametric procedure appropriate for analysis of data in designed experiments because it allows testing for the significance of differences between three or more group means (Polit & Hungler, 1999; Sharma, 1996; Cone & Foster, 1993; SAS Institute, Inc., 1990a, 1990b). This technique breaks the total variability in a data set into two components: variability resulting from the independent variable, and all other random error variability (including individual differences and measurement problems). By contrasting variation between treatment groups with variation occurring within treatment groups, ANOVA computes an F-ratio statistic. If the difference between groups is large relative to the fluctuation within a group, an estimated probability exists that the treatment relates to or associates with the group difference. The significance probability value (p-value) selected for this research project is 0.05.

Data must meet certain assumptions to be appropriate for ANOVA. There should be homogeneity of variance in the groups, as evidence by roughly equal standard deviations. Further, there should be normal distribution of the dependent variable. For this research project, frequency distributions will verify the validity of such assumptions. If violation of these assumptions occurs, procedures for data transformation (logarithms or square roots) will be considered, as well as procedures for adjusting degrees of freedom (Maxwell & Delaney, 1990). These procedures result in a more conservative statistical test of the hypotheses (decreasing the probability of Type I error, rejection of a null hypothesis when it is true).

ANOVA requires more than one level of independent variable; the independent variables must also be nonmetric (classification or nominal in nature). The independent variables in this research, different types of education for dementia caregivers, meet the nonmetric requirement. ANOVA techniques take into consideration different levels at which the independent variables exist. In this research, there are four group levels and three time levels (a 4 x 3 ANOVA).

- Group levels
  - "Control" group (subsequently referred to as Group 1)
  - Mailed, written brochure education group (Group 2)
  - Written brochure accessed through the Internet (Group 3)

    - Multimedia, interactive Internet education group (Group 4)
- Time levels
    - Pre-intervention assessment (subsequently referred to as Time 1)
    - One month assessment (Time 2)
    - Two month assessment (Time 3)

There is only one dependent variable in any given ANOVA calculation and it must be metric (continuous interval or ratio in scale). There are two dependent variables of interest in this research: degree of threat perceived by the dementia caregiver in response to wandering behavior (primary appraisal), and number of home modifications made by the caregiver after the education intervention (secondary appraisal). The ABID measures the degree of threat using a five-item, interval scale; this meets the metric requirement. Number of home modifications is a count of all changes identified by participants at Time 2 and Time 3 assessments. Because these data may include a zero reference (no changes made), the scale is ratio in nature, thus meeting the metric requirement for ANOVA.

A one-way ANOVA allows for statistical testing of the two main effect hypotheses in this study, which posit that any education intervention is better than no education. Table 5 displays the statistical hypotheses and analysis for hypotheses 1, which states that all three education interventions will have a significant, positive association with reduced caregiver perceptions of threat caused by wandering behavior. (Wandering is the theme of the educational message in the three study interventions.)

Table 5

Hypotheses 1

Statistical Hypothesis	Statistical Analysis
Ho: mu-group 1 = mu-group 2 = mu-group 3 = mu-group 4 Ha: mu-group 1 =/ mu-group 2 =/ mu-group 3 =/ mu-group 4	Mu = mean score on the ABID between Time 1 and Time 2

Table 6 presents the statistical hypotheses and analysis for hypothesis 2, which states that all three education interventions will have a significant, positive association with the number of home modifications made for the management of wandering behaviors.

Table 6

Hypothesis 2

Statistical Hypothesis	Statistical Analysis
Ho: mu-group 1 = mu-group 2 = mu-group 3 = mu-group 4 Ha: mu-group 1 =/ mu-group 2 =/ mu-group 3 =/ mu-group 4	Mu = mean number of home modifications made by the dementia caregiver between Time 1 and Time 2

The one-way ANOVA used for testing the main effect hypotheses does not allow determination of the association magnitude (whether one group differed significantly from all other groups). Education theory posits that active involvement of the learner enhances the retention of information (Gagne, 1985). Therefore, it might be assumed that Group 4 (multi-media, interactive Internet format) would have outcomes different from the groups exposed to a more passive education format. Multiple comparison procedures (also known as mean separation tests) are required for these determinations (Polit & Hunger, 1999; SAS Institute, Inc., 1990a, 1990b). There are several ANOVA enhancements available for multiple comparison procedures. These include the Multiple-Stage Test (MSTs) and the Bayesian Approach (SAS Institute, Inc., 1990b). This level of ANOVA is required for testing two hypotheses related to magnitude of effect. Table 7 presents the statistical hypotheses and analysis for hypothesis 3, which states that there will be a significant, positive difference between mean threat reduction scores for participants in Group 4 compared with participants in Groups 3 and 2.

Table 7

Hypothesis 3

Statistical Hypothesis	Statistical Analysis
Ho: mu-group 4 = mu-group 3 = mu-group 2 Ha: mu-group 4 > mu-group 3 or mu-group 2	Mu = mean score on the ABID between Time 1 and Time 2

Table 8 presents the statistical hypotheses and analysis for hypothesis 4: there will be a significant, positive difference between the number of home modifications made by participants in Group 4 compared with participants in Groups 3 and 2.

Multiple comparison procedures can result in Type II error (failure to reject a null hypothesis when it is false). Nontransitive results occur when, given three sample means, the largest and smallest may be significantly different from each other, but neither is significantly different from the middle one. Computation of confidence

Table 8

Hypothesis 4

Statistical Hypothesis	Statistical Analysis
Ho: mu-group 4 = mu-group 3 = mu-group 2 Ha: mu-group 4 > mu-group 2 or mu-group 2	Mu = mean number of home modifications made by the dementia caregiver between Time 1 and Time 2

intervals (CI) address the concern. CIs document the degree of uncertainty in each comparison, and make it easier to assess both the practical and statistical significance of any differences (SAS Institute, Inc., 1990a, 1990b). The MST Tukey-Kramer method meets this need for subsequent analysis (SAS Institute, Inc., 1990a, 1990b; Dunnett, 1955).

ANOVA reduces to a simple t-test when the number of nonmetric, independent variables, as measured by dummy variables, is one (Sharma, 1996). This is the case for testing the remaining hypotheses. The hypotheses 5 and 6 recognize that Group 2 and Group 3 interventions are identical in layout; the only difference is mode of delivery (either postal mail or through the Internet). Both formats are passive and require reading only. The lack of more active involvement by the learner would suggest that the results for the two formats would be similar. The final hypothesis suggests that people assimilate and act upon education information quickly or there will be no changes over time. This is consistent with the premise of the Switching Replications design discussed previously. Table 9 presents the statistical hypotheses and analysis for hypothesis 5, which states there will be no significant difference in threat reduction between caregivers in Group 2 and Group 3.

Table 9

Hypothesis 5

Statistical Hypothesis	Statistical Analysis
Ho: mu-group 2 = mu-group 3 Ha: mu-group 2 =/ mu-group 3	Mu = mean score on the ABID between Time 1 and Time 2

Table 10 presents the statistical hypotheses and analysis for hypothesis 6, which states there will be no significant difference in the number of home modifications made by caregivers in Group 2 and Group 3.

Table 10

Hypothesis 6

Statistical Hypothesis	Statistical Analysis
Ho: mu-group 2 = mu-group 3 Ha: mu-group 2 =/ mu-group 3	Mu = mean number of home modifications made by the dementia caregiver between Time 1 and Time 2

Table 11 presents the statistical hypotheses and analysis for hypothesis 7, which states there will be no significant difference in the number of home modifications made by caregivers within any group as a function of the passage of time.

Summary

The research question for this dissertation (as presented in Chapter 2) is: to what extent can self-directed, distance education alter a dementia caregiver's primary and secondary stress appraisal processes? Answers to the question have both individual and social implications. At a personal level, the stress of dementia caregiving results in higher rates of physical and psychological morbidity; it also increases the risk of

Table 11

Hypothesis 7

Statistical Hypothesis	Statistical Analysis
Ho: mu-Time 2 for all groups = mu-Time 3 for all groups Ha: mu-Time 2 =/ mu-Time 3	Mu = mean score on the mean number of home modifications made for each individual groups (2, 3, and 4).

premature mortality. At a societal level, dementia caregiving is costly. By some estimates, it is the third most expensive American health problem after heart disease and cancer (Ernst & Hay, 1994).

The methodology used to answer the research question involves data from a convenience sample of dementia caregivers. To participate in the study caregivers must provide or assist with home care for an ambulatory individual who has dementia. The caregiver must also have routine access to a computer with at least a 28K Internet modem connection. The quasi-experimental design of Switching-Replications guides participant group assignments across three waves of measurement.

The independent variable of interest is distance education. Distance education is a means for implementing progressive (problem solving) adult education philosophies using self-directed, asynchronous learning. The study examines three forms of distance education: a written brochure sent by postal mail to the caregiver, written brochure content accessed through an Internet site, and brochure content enhanced of interactive, multimedia content accessed through an Internet site. The Switching-Replications design allows comparison with a control group that does not experience education intervention until after the second wave of assessment.

Justification for the two dependent variables of interest (primary and secondary appraisals of stress) comes from the unified model of the stress-health process developed by Cohen, et. al., (1995). As discussed in Chapter 2, there is an iterative relationship between primary and secondary appraisal. Although initial assessment of a situation may result in a threat perception, subsequent identification (secondary appraisal) and implementation of coping strategies should reduce threat perceptions (primary appraisal). Seven study hypotheses test this premise using ANOVA to compare the different forms of distance education. In the context of the stress-health process model, changing both primary and secondary appraisals should affect the physical and psychological health of the caregiver. This dissertation will not be testing the fuller context of the model.

Operationalization of primary appraisal involves use of a standardized assessment tool, the ABID. Operationalization of secondary appraisal occurs in an open-ended format in which participant's list the home modifications made. Each modification listed has equal weight; evaluation of the quality of each modification is beyond the scope of this research.

Chapter 4 presents results from the statistical analysis. Descriptive data establish the comparability of the intervention and control groups. Results from hypothesis testing follow. Chapter 5 concludes the research presentation with a discussion of limitations and implications for the future.

CHAPTER 4

Results

Introduction

This chapter presents results for the study of distance education with dementia caregivers. The Introduction reviews the purpose of the study, the research question, and important constructs, definitions, and study variables. The second section, Descriptive and Baseline Statistics, profiles the study sample of 189 participants, and the equivalency of the intervention groups. Results from hypothesis testing appear in the third section, Statistical Analyses. Discussion of the results appears in Chapter 5, along with limitations of the study and directions for future research.

Dementia Caregiving Experience

The purpose of the dissertation study is to examine the experience of dementia caregivers and design an education intervention to help family members in the caregiving role. Literature documents the physical and mental stress of dementia caregiving (Yee & Schulz, 2000; Schulz, et. al., 1995; Schulz, et. al., 1990). Intervention study results illustrate that didactic education programs help some caregivers learn new coping skills, thus altering the stress experience (Opie, et. al., 1999; Biegel, et. al., 1991; Toseland & Rossiter, 1989). Unfortunately, most dementia caregivers do not have access to didactic programs (Montgomery, 1996).

Research Question, Constructs, and Variables

The study blends principles from the stress-health process model (Cohen, et. al., 1995) and the progressive (problem solving) education method of self directed learning (Knowles, 1988). The resulting dissertation research question is: to what extent does self-directed, distance education alter a dementia caregiver's primary and secondary appraisal processes? Operationalization of the independent variable (the progressive, self-directed education construct) involves three distance education formats: a postal mail brochure, a passive web site brochure, and a multimedia, interactive web site.

The dependent variables relate to the constructs of primary and secondary stress appraisals. The first dependent variable involves a perception that harm has or is likely to occur because of some environmental demand. Operationalization of the dependent variable, threat perception, uses the Agitated Behaviors in Dementia scale (ABID) (Logsdon, et. al., 1999). The ABID asks caregivers to rate 16 dementia behaviors on a six-item scale. Scores range from zero to 64. Zero reflects no degree of "bother or upset" and 64 reflects extreme "bother or upset" for all 16 behaviors. In validation testing by Logsdon and colleagues, the mean threat perception score is 15.19 for the 148 caregivers in the original study.

Secondary appraisal involves evaluation of potential methods for eliminating or reducing the effects of a perceived threat. Positive evaluations result in use of coping strategies to alter the situation (Lazarus & Folkman, 1984). For dissertation study purposes, operationalization involves asking caregivers to identify the number of home modifications made after exposure to one of the education interventions.

Descriptive and Baseline Statistics

Participant Recruitment

The Sunflower Chapter of the Alzheimer's Association referred potential participants to the study. This results in a nonrandom, self-selected sample. Inclusion criteria required that all caregivers be assisting with the home care of an ambulatory person diagnosed with dementia. The inclusion criteria also required that the caregivers have an email address and routine access to a computer with Internet connection. Computer access could occur at home, a family member's home, a public site (such as a library), or a work site. The principal investigator reviewed informed consent materials with each potential participant. A total of 189 individuals signed consent forms. Of the participants, 22 expressed prior knowledge of the Principal Investigator. Discussion of the potential confounding effect occurs in Chapter 5.

Demographic and Background Variable Profile of the Sample

Participant demographics. Mean age of the 189 participants in the sample is 54.90 (range 28 to 77; SD = 8.97). The sample is predominantly female (61.9 percent). The largest percentage of caregivers are adult children (61.4 percent), followed by spouses (27.5 percent), grandchildren (10.1 percent), and other relatives (1.1 percent). Most participants are Caucasian (82.5 percent), followed by African American (15.3 percent), and Hispanic American (2.1 percent). The mean years of education are 12.92 (range 9 to 16 years, SD = 1.49). The mean number of caregiving years is 2.95 (range 1 to 10; SD = 2.02). The majority of participants did not use any paid assistance (62.4 percent). For those that used paid assistance, the mean number of hours per week is

2.33 hours (range 0 to 10; SD = 3.63). Table 12 displays the mean, standard deviation, and range for the demographic variables.

Table 12

Participant Demographics

	Age	Education	Caregiving Years	Paid Assistance
Mean	54.90	12.92	2.95	2.33
Standard Deviation	8.97	1.59	2.02	3.63
Range	28-77	9-6	1-10	0 to 10

Several significant correlations exist between caregiver age and other demographic variables. As age increases, so does the tenure of the caregiving experience (r = .518, p = .000). Male participants are older (56.78) than female participants (53.94) (r = .164, p = .024). Spouses are considerably older (63.40) than all other caregivers (r = .543, p = .000). Cross tabulation shows the mean age of adult children caregivers is 53.38; for grandchildren, the mean age is 42.84, and for all other relative caregivers, the mean age is 57.00. Spouse/non-spouse relationship also correlates with the mean tenure of caregiving (r = -.551, p = .000). Spouses have the longest tenure (4.75 years compared to 2.27 for non-spouses). Cross tabulation finds a mean tenure for adult children of 2.44 years, 1.16 years for grandchildren, and 3.00 for all other relatives.

Gender and hours of paid assistance per week correlate (r = .144, p = .048). Male caregivers are more likely to use paid services (3.00 mean hours per week) compared to female caregivers (1.92 mean hours per week). Paid assistance also correlates with the tenure of caregiving. As the number of caregiving years increases, so to do the hours of paid assistance (r = .226, p = .002). The only significant ethnic correlation is with spouse/non-spouse relationship (r = -.357, p = .170). Caucasian caregivers are more likely to be spouses. Table 13 displays correlations for the demographic variables.

Table 13

Correlations Among Study Variables

	Age	Gender	Spouse /Non-spouse	Education Years	Caregiving Years	Caucasian/ Other	Hours Paid Help	Web Years	Web Comfort	Time 1 Threat Score
Age	1.000 .									
Gender	.164* .024	1.000 .								
Spouse /Non-spouse	.543** .000	-.078 .287	1.000 .							
Education Years	-.080 .273	-.058 .429	-.043 .557	1.000 .						
Caregiving Years	.518** .000	.132 .069	-.551** .000	.041 .575	1.000 .					
Caucasian/ Other	.153 .087	.031 .729	-.357** .170	.003 .972	.011 .904	1.000 .				
Hours Paid Help	.107 .144	.144* .048	-.055 .488	-.094 .199	.226** .002	.026 .729	1.000 .			
Web Years	-.564** .000	-.141 .053	.440** .000	-.030 .681	-.344** .000	-.155 .083	-.028 .704	1.000 .		
Web Comfort	.353** .000	.067 .362	-.328** .000	.006 .933	.175* .016	.060 .718	.031 .676	-.662** .000	1.000 .	
Time 1 Threat Score	-.209** .004	-.244** .001	.172* .018	-.073 .321	-.196** .007	-.073 .419	-.028 .704	.168* .021	-.113 .122	1.000 .

* Correlation is significant at the .05 level.

** Correlation is significant at the .01 level.

Participant Internet exposure. Participants responded to questions regarding years of Internet experience, comfort level (1 equal very high and 5 equal very low), and problems (if any) with access. The mean number of years using the Internet is 4.12 (range 1 to 10; SD = 3.08). Most participants rate the comfort level with Internet use as very high (36.0 percent) or high (30.2 percent), followed by moderate comfort level (23.8 percent), low comfort level (6.3 percent), or very low comfort level (3.7 percent).

In an open-ended question, participants identified problems with access or completion of the computerized baseline assessment. Only five participants reported problems. Four participants needed additional directions for entering security information (password and user identification numbers). The fifth participant experienced difficulties related to a web TV Internet connection, and had to switch to a telephone Internet connection.

There are several significant correlations between Internet related variables and sample demographics. Internet years and comfort level with the Internet correlate (r = -.662, p = .000). As years of experience increase, participants are more likely to rate the comfort level as very high (score of one on a five point scale). As age increases, the number of years of experience with the Internet decreases (r = -.564, p = .000) and the comfort level score reflects less comfort with the Internet (r = .353, p = .000).

Relationship correlates with years of Internet use (r = .440, p = .000) and comfort level with the Internet (r = -.328, p = .000). The mean years of Internet use are longest for grandchildren, 8.42 years, and shortest for spouses, 1.88 years; mean years for adult children are 4.42, and for other relative caregivers, it is 3.00. Mean comfort level for grandchildren is highest, 1.00 (very high), and mean comfort level for spouses is lowest, 2.72 (approaching a moderate level); mean comfort level for adult children is 2.04, and for other relative caregivers, it is 2.12. There is a significant correlation between Internet years and caregiving years (r = -.344, p = .000). As the tenure of caregiving increases, years of experience with the Internet decrease. Comfort level with the Internet correlates with caregiving years (r = .175, p = .016). Table 13 displays the correlations.

Baseline for dependent variable. Baseline threat perception, measured using the 16 item ABID scale, is 16.85 (range 3 to 42; SD = 6.76). This reflects "some" to a "moderate" amount of bother from dementia behaviors. The dissertation sample mean is slightly higher than the mean for the original ABID testing by Logsdon and colleagues, 15.19 (range 1 to 39; SD = 8.0). Higher scores reflect a greater perception of threat.

The ABID also measures the frequency with which agitated behaviors occur; scores range from zero indicating no behavioral problems, to 96, indicating all 16 behavioral problems occur on a daily basis. At baseline, the dissertation sample mean is 25.46 (range 5 to 47; SD = 7.34), indicating that most dementia behaviors occur several times per week. In the reliability and validity testing by Logsdon and colleagues, the 148 caregivers in the original study report a mean of 29.12 (range 3 to 70; SD = 14).

Correlations between several demographic variables and the baseline dependent variable are significant. As caregiver age increases, perceptions of threat decrease (r = -.209, p = .004). Closely related is the finding that as years of caregiving increase (older participants have more years), threat perceptions decrease (r = -.196, p = .007). As years of Internet experience increase (common for the younger participants), perceptions of threat also increase (r = .168, p = .021). Gender influences threat perceptions (r = -.244, p = .001). Females report higher levels of threat (18.02) than males do (14.75). Finally, threat perceptions are higher for non-spouses (17.56) compared with non-spouses (14.56) (r = .172, p = .018). The mean score for adult children is 17.95, compared with 16.53 for grandchildren. Table 13 displays the correlations.

Of the 189 participants in the sample, 22 indicate prior awareness of the Principal Investigator (defined as attendance at education programs involving the Principal Investigator). To determine possible influence and bias, a One-Way ANOVA is used to compare mean scores on the baseline threat perception variable. There is no significant difference between scores, with F (1, 187) = .099, p = .754.

Sample attrition. There is no attrition in the sample. The short time frame for the study (two months) is the likely contributing factor. One member of the passive web group placed the family member in a nursing home one week before the time 3 (final) assessment. This participant's data is in the database because the change occurred so close to the end of the participant's involvement in the study.

Study Design and Intervention Assignments

The study design is the quasi-experimental Switching-Replications, which includes two phases and three waves of measurement. The waves of measurement guide the statistical analyses. The basic Switching Replications pattern is:

		- Phase I -		- Phase II -	
N (group a)	O (time 1)	X	O (time 2)		O (time 3)
N (group b)	O (time 1)		O (time 2)	X	O (time 3),

where N equals participants, O equals observations or measurement, and X equals intervention (Garson, 2002; Trochim, 2001).

Statistical analysis occurs in two phases. Phase I compares the time 1 (baseline) observations and the time 2 observations for the group receiving intervention (group a) with group not receiving intervention (group b). After time 2, the groups "switch" roles. Group b receives the intervention while group a does not receive any additional intervention. Phase II analysis compares the time 2 and time 3 observations for the groups. By switching roles, "the original control group becomes the treatment group in phase II, while the original treatment group acts as the control" (Trochim, 2001). When the intervention content is specific (as it is in this study) and mastery is expected in a short time (proposed in this study), the expected outcome is a "convergence" at the time 1 observation or assessment, "divergence" at the time 2 assessment, and "reconvergence" at the time 3 assessment (Trochim, 2001). The overall design helps control for carryover effects if the content is specific and mastery is quick.

As applied to the dissertation study, there are three applications of the Switching Replications design because there are three educational interventions. The interventions involve postal mail information, passive web information, and active web information. Sample size computations in Chapter 3 require 62 participants in each intervention group (postal mail, passive web, and active web) to obtain medium effects, given an alpha of .05 and a power of .80. The final number of participants in each intervention is 63, one over the number required.

At entry into the study, the Principal Investigator assigns a participant to one of the three interventions, or to a pooled "control" group who receive no intervention between time 1 and time 2. At the time 1 (baseline), the number of participants in the postal mail group is 42; the number in the passive web group is 42; the number in the active web group is 42; the number in a pooled "control" group is 63. After the time 2 assessment, the Principal Investigator reassigns "control" group members to one of the interventions. Thus between time 2 and time 3, 21 members of the pooled "control" group experience the postal mail intervention, 21 experience the passive web intervention, and 21 experience the active web intervention. Table 14 displays the assignments.

Table 14

Number of Participants by Group Assignment and Time

	Observation Time 1	Intervention	Observation Time 2	Switch	Observation Time 3
"Control" Group	63		63		
Postal Mail	42	X	42		42
Passive Web	42	X	42		42
Active Web	42	X	42		42
Switched "Control"					
Postal Mail	21		21	X	21
Passive Web	21		21	X	21
Active Web	21		21	X	21
Total Observation					
Postal Mail	63		63		63
Passive Web	63		63		63
Active Web	63		63		63

Demographic Comparisons by Intervention Assignment

It is important to discern if any significant differences exist between the demographic profiles of the participants based upon the intervention assignment. One-Way ANOVA is used to examine time 1 (baseline) interval and ratio scale variables of threat perceptions, caregiver age, caregiver education level, length of tenure as a caregiver, hours of paid assistance, years of Internet experience, and comfort level with Internet use. Only one significant difference exists: threat perception score (F [3, 182] = 2.726, p = .046). Post hoc testing with Tukey HSD identifies the significant difference between the passive web intervention (threat perception score of 18.63) and the "control" participants (threat perception score of 15.08). The mean difference, 3.55, is significant, p = .04. This difference is not a problem for hypothesis testing because Repeated Measures ANOVA analyses the change over time, not the total score per se.

The Kruskal Wallis test is used to compare the nominal variables of caregiver's gender, relationship with the person diagnosed with dementia, and ethnicity. There is no significant difference between the groups on these measures.

Data Distribution

ANOVA requires data with a normal distribution for the dependent variable. Since hypothesis testing requires One-Way and Repeated Measures ANOVA, distribution of the baseline dependent variable measure is important. Diagnostics indicate the data slightly skew to the right (skew equals .674). This reflects the higher scores previously noted for non-spouse relatives who comprise a large percentage of the sample. The kurtosis value (.930) indicates some clustering around the mid-point.

Neither statistic is at a level to threaten the validity of ANOVA outcomes from the data set.

Data Collection Technique

The ABID design of Logsdon, et. al., (1999) involves paper and pencil administration. All data collection for this research is through the Internet. Because of the difference in administration format, ten randomly selected participants agreed to complete the original paper and pencil version of the ABID, as well as the computer version of the assessment. Participants first completed the baseline computer assessment and then completed the paper and pencil version. The time between the two assessments (including postal mail time) was 6 days. This is important because few, if any, changes in dementia behaviors should occur during the short cycling time.

A paired t-test is used to analyze the computer questionnaire responses with the paper and pencil responses. The mean threat perception score for computer administration is 13.80 (SD = 4.84), compared with a mean threat perception score of 13.60 (SD = 4.71) for paper and pencil administration (r = .992, p = .000). The t statistic is 1.00, with a significance of .343. This indicates the two administration formats do not differ significantly.

Statistical Analysis

Chapter 3 introduced seven study hypotheses. The discussion in this section begins with the presentation of each study hypothesis. Discussion of the analytical tools for hypothesis testing follows the presentation. Results of the testing complete each section. Discussion of the results takes place in Chapter 5.

Hypothesis 1

The study hypothesis states that all three education interventions (postal mail, passive web, and active web) will have a significant, positive association with reduced caregiver perceptions of threat caused by wandering behavior. Perception of threat relates to the stress-health process model construct of primary appraisal. As stated in Chapter 3, the statistical hypothesis is that the threat perception mean at time 1 (baseline) and time 2 will differ for participants experiencing an education intervention compared with participants initially assigned to the Switching Replications pooled "control" group. Threat perception measurement uses ratings from the complete, 16 item ABID. Scores can range from zero (no perception of threat) to 64 (extreme perceptions of threat). Because the comparison involves changes over time, the statistical analysis involves Repeated Measures ANOVA.

Primary hypothesis testing. Table 15 illustrates that mean threat perception scores for the "control" group and the postal mail group increase over time (indicating increasing levels of threat), while mean threat perceptions for the passive and active web groups decrease. However, the Repeated Measures ANOVA test for between-subject effects is not significant, with F (3,185) = 1.265, p = .288. Therefore, data do not support the study hypothesis. The different education interventions do not effect a caregiver's perception of threat.

Related threat perception analyses for hypothesis 1. Three items on the ABID specifically address wandering behaviors. A second analysis used only those items to test hypothesis 1. Scores for these three items range from zero, indicating no threat

Table 15

Time 1 and Time 2 Threat Perceptions by Intervention Group Assignment

	Time 1 Mean (SD)	Time 2 Mean (SD)
"Control" Group (N=63)	15.08 (6.00)	15.71 (5.60)
Postal Mail Group (N=42)	16.64 (6.59)	17.71 (6.74)
Passive Web Group (N=42)	18.67 (7.49)	16.31 (6.27)
Active Web Group (N=42)	17.88 (6.79)	15.57 (5.81)

perceptions related to wandering behaviors, to 12, indicating extreme threat perceptions related to wandering behaviors. In the original ABID testing by Logsdon and colleagues, the mean score for the three wandering items is 4.60, indicating a moderate amount of threat perception related to wandering. Mean scores for the pooled "control" and postal mail groups increase over time, as displayed in Table 16. Mean scores for the passive web and active web groups decrease. However, the Repeated Measures ANOVA test for between-subject effects is not significant, with F (3,185) = .937, p = .424. Therefore, the more specific data on wandering still do not support the study hypothesis that education will reduce perceptions of threat.

The timeframe for the study may be an influencing factor. Because of the nature of the Switching Replications design, 126 participants experienced an intervention immediately after the baseline assessment, while 63 were in the pooled "control" group. For the 126 participants, data are available at time 3 (two months after the intervention). Repeated Measures ANOVA using time 1 and time 3 observations shows a similar

Table 16

Time 1 and Time 2 Wandering Threat Perceptions by Intervention Group Assignment

	Time 1 Mean (SD)	Time 2 Mean (SD)
"Control" Group (N=63)	2.92 (2.26)	3.27 (2.13)
Postal Mail Group (N=42)	3.36 (2.33)	3.76 (2.26)
Passive Web Group (N=42)	3.02 (2.43)	2.60 (1.82)
Active Web Group (N=42)	3.43 (2.18)	2.67 (2.14)

pattern. Table 17 illustrates that scores for participants in the postal mail intervention increase over time, while scores for passive and active web intervention decrease. However, the Repeated Measures ANOVA test for between-subject effects is not significant, with F (2,123) = .118, p = .889. Even with the extended time, education does not alter threat perceptions. Chapter 5 discusses the issue of the timeframe.

Table 17

Time 1 and Time 3 Threat Perceptions by Intervention Group Assignment

	Time 1 Mean (SD)	Time 3 Mean (SD)
Postal Mail Group (N=42)	16.64 (6.59)	17.48 (6.44)
Passive Web Group (N=42)	18.67 (7.49)	15.86 (5.99)
Active Web Group (N=42)	17.88 (6.79)	15.38 (5.70)

Demographic variables and related analysis for hypothesis 1. The next factor to explore for significance related to hypothesis 1 is the influence of demographic variables. Although data in the Descriptive Statistics section document no significant differences between the participants in the intervention groups and the "control" group, several demographic variables in the study sample differ from the national caregiving experience. The study sample is predominantly adult children, 61.9 percent, while national studies identify spouses as the predominant caregiver category (National Alliance for Caregiving and the American Association of Retired Persons, 1997). Spouses usually live with the person who has dementia (coresidence), while adult children and other relatives are less likely to live with the person who has dementia. Coresidence could affect perceptions of threat and accuracy of reporting, thus contributing to the lack of significant findings for study hypothesis 1. Coresidence is not one of the demographic variables in the dissertation study, but using relationship as a proxy measure for coresidence, significant differences in threat perception emerge.

Table 18 displays differences between threat perceptions based on relationship. Using One-Way ANOVA at time 1, there is a significant difference between spouse caregivers and non-spouse caregivers, with F (1,187) = 5.723, p = .018. Repeated Measures ANOVA show that the difference persists over time, with F (1, 187) = 8.824, p = .003. Chapter 5 elaborates on how relationship could contribute to the results.

Table 18

Time 1 and Time 2 Threat Perceptions by Relationship

	Time 1 Mean (SD)	Time 2 Mean (SD)
Spouses (N=52)	14.96 (6.76)	13.98 (6.55)
Non-Spouses (N=137)	17.56 (6.64)	17.12 (5.67)

Gender is another demographic variable that differs between the study sample and national caregiving population. As noted in the Descriptive Statistics, 63.5 percent of the sample is female; national studies place the figure at 72.5 percent (National Alliance for Caregiving and the American Association of Retired Persons, 1997). Table 19 displays the differences in threat perception means based on gender. One-Way ANOVA finds the difference significant at time 1, with F (1,187) = 11.842, p = .001. Analysis using Repeated Measures ANOVA documents ongoing, significant differences between the genders, with F (1,187) = 11.931, p = .001. Chapter 5 will elaborate on the ways gender may contribute to non-significant results.

Table 19

Time 1 and Time 2 Threat Perceptions by Gender

	Time 1 Mean (SD)	Time 2 Mean (SD)
Male (N=72)	14.75 (6.24)	14.58 (5.80)
Female (N=117)	18.14 (6.76)	17.29 (6.03)

One additional background variable influences caregiver stress: ethnic identification. A meta-analysis documents higher levels of stress among Caucasian populations (Janevic & Connell, 2001), and the study sample is predominantly Caucasian (82.5 percent). One-Way ANOVA finds the difference approaching significance at time 1, with F (2,186) = 2.798, p = .064. Analysis using Repeated Measures ANOVA documents a significant difference between the ethnic groups over time, with F (2,186) = 4.840, p = .009. Differences in threat perceptions based on ethnic identification appear in Table 20. Chapter 5 elaborates on the way ethnic identification may contribute to non-significant results.

Table 20

Time 1 and Time 2 Threat Perceptions by Ethnic Identification

	Time 1 Mean (SD)	Time 2 Mean (SD)
Caucasian (N=156)	17.18 (6.58)	16.62 (6.00)
African American (N=29)	16.07 (6.81)	15.72 (5.69)
Hispanic (N=4)	9.50 (10.38)	6.00 (1.15)

Controlling for the significant correlations does not affect the results. Analysis of covariance (ANCOVA) does not support the study hypothesis that education affects threat perceptions. Therefore, ANOVA remains the primary tool for statistical analysis.

Hypothesis 2

The study hypothesis is: all three education interventions (postal mail, passive web, and active web) will have a significant, positive association with the number of home modifications made for the management of wandering behaviors. Home modifications relate to the stress-health process model construct of secondary appraisal. As stated in Chapter 3, the statistical hypothesis is that the mean number of home modifications made between time 1 (baseline) and time 2 will differ for participants experiencing an education intervention compared with participants initially assigned to the Switching Replications pooled "control" group. Measurement of home modifications is a count of changes identified by participants at the time 2 assessment.

Primary hypothesis testing. Table 21 displays the total number of home modifications made at time 2, as well as the mean number of modifications by intervention group assignment. One-Way ANOVA identifies a significant difference between groups, with F (3, 185) = 3.329, p = .021. This finding supports study hypothesis 2. Subsequent post hoc analysis with Tukey's HSD defines the significant mean difference (.21) between the active web intervention and the pooled "control" group (p = .019).

Table 21

Time 2 Home Modifications by Intervention Assignment

	Total Number of Modifications	Mean Number of Modifications
"Control" Group (N=63)	3	.03
Postal Mail Group (N=42)	6	.14
Passive Web Group (N=42)	9	.21
Active Web Group (N=42)	11	.26

Demographic variables and related analysis for hypothesis 2. As discussed with hypothesis 1, significant differences in threat perception associated with the demographic variables of relationship, gender, and ethnic identification. Under the stress-health process model, primary appraisal of threat influences the secondary appraisal process. In turn, secondary appraisal influences coping strategies (changes) employed. Therefore, it is important to examine the possible influence of relationship, gender, and ethnic identification on the number of home modifications made by caregivers. Table 22 displays the total and mean number of modifications made at time 2 by relationship, gender, and ethnic identification. One-Way ANOVA for the relationship variable is not significant, with F (3, 185) = .720, p = .541. One-Way ANOVA for the gender variable is not significant, with F (1, 187) = .143, p = .705. One-Way ANOVA for the ethnic variable is not significant, with F (2, 186) = .644, p = .526. Therefore, although the demographic variables influence threat perceptions, they do not appear to influence secondary stress appraisal, as measured by home modifications.

Table 22

Time 2 Home Modifications by Relationship, Gender, and Ethnic Identification

	Total Number of Modifications	Mean Number of Modifications
Spouses (N=52)	5	.09
Adult Children (N=116)	21	.18
Grandchildren (N=19)	3	.16
Other Relatives (N=2)	0	.00
Males (N=72)	12	.17
Females (N=117)	17	.15
Caucasian (N=156)	23	.15
African American (N=29)	6	.21
Hispanic American (N=4)	0	.00

Hypothesis 3

Hypothesis 3 posits there is a significant, positive difference between mean threat reduction scores for participants in the active web group compared with participants in the postal mail group and the passive web group. Perception of threat relates to the stress-health process model construct of primary appraisal; measurement involves participant ratings on the ABID scale. As stated in Chapter 3, the statistical hypothesis is that over time, the mean threat perception scores for participants receiving active web intervention will differ from the mean scores for participants receiving information through the postal mail or passive web interventions.

Primary hypothesis testing. Table 23 illustrates how mean scores for the postal mail intervention increase between time 1 and 2, and then decline. Scores for the passive and active web interventions decline over time. However, the Repeated Measures ANOVA for between-subject effects is not significant between time 1 and 2 (F [2,186] = .149, p = .862), nor is it significant between time 2 and 3 (F [2, 186] = .526, p = .592). Therefore, results do not support the study hypothesis. The groups appear to be equal and education does not influence threat perceptions.

Table 23

Threat Perceptions Over Time by Intervention Assignment

	Time 1 Mean (SD)	Time 2 Mean (SD)	Time 3 Mean (SD)
Postal Mail Group (N=63)	15.87 (6.51)	16.84 (6.42)	16.62 (6.03)
Passive Web Group (N=63)	17.56 (7.15)	16.22 (6.01)	15.94 (5.75)
Active Web Group (N=63)	17.08 (6.58)	15.73 (5.70)	15.59 (5.61)

Related threat perception analyses for hypothesis 3. Three items on the ABID specifically address wandering behaviors. A secondary analysis with only those items explores the data for associations. Table 24 illustrates variability in wandering threat perception scores over the three observations. Repeated Measures ANOVA for between-subject effects is not significant between time 1 and 2 (F [2,186] = .321, p = .726). However, between time 2 and 3 the situation changes and the difference is significant (F [2, 186] = .4.318, p = .015). Subsequent post hoc testing using Tukey HSD identifies the significant mean difference (1.04) between the postal mail intervention and the active web intervention (p = .015). This finding merits cautious interpretation, however. Validity and reliability testing of the ABID involves the full, 16-item tool. Literature does not address the validity and reliability of sub-scale items. Further, carryover effects of the time series design may be an influence.

Table 24

Specific Wandering Threat Perceptions Over Time by Intervention Assignment

	Time 1 Mean (SD)	Time 2 Mean (SD)	Time 3 Mean (SD)
Postal Mail Group (N=63)	3.14 (2.29)	3.57 (2.22)	4.68 (2.28)
Passive Web Group (N=63)	3.14 (2.44)	2.97 (1.98)	3.65 (2.28)
Active Web Group (N=63)	3.41 (2.27)	3.05 (2.17)	3.13 (2.06)

Hypothesis 4

Hypothesis 4 posits there will be a significant, positive difference between the number of home modifications made by participants in the active web group compared with participants in the postal mail group and the passive web group. Home modifications relate to the stress-health process model construct of secondary appraisal.

As stated in Chapter 3, the statistical hypothesis is that over time, the mean number of home modifications will differ for participants receiving active web intervention compared to mean scores for participants receiving information through the postal mail or passive web interventions. Statistical analysis uses Repeated Measures ANOVA involving all three observation times. Analysis now enters data for participants originally in the "control" pool to their subsequent intervention group assignment.

Primary hypothesis testing. Table 25 identifies the total number of changes made by intervention group at each measurement, as well as the mean number of home modifications for each group. Regardless of intervention format, all groups show a trend toward improvement (more modifications) over time. Repeated Measures ANOVA for between-subject effects is significant between time 2 and 3 (F [2,186] = 4.360, p = .014). Subsequent post hoc testing using Tukey HSD identifies the significant mean difference (.17) between the postal mail intervention and the active web intervention (p = .010). This finding supports the study hypothesis that active web intervention leads to more home modifications.

Table 25

Home Modifications Over Time by Intervention Assignment

	Time 2 Home Modifications		Time 3 Home Modifications	
	Total	Mean	Total	Mean
Postal Mail Group (N=63)	7	.11	9	.14
Passive Web Group (N=63)	10	.16	14	.22
Active Web Group (N=63)	14	.22	23	.37

Related home modification analysis for hypothesis 4. At assessment time 2 and 3, participants respond to a question about outside contacts (if any) made during the course of the study. Outside contacts include individuals and/or education resources. Table 26 details the total and mean number of contacts by intervention group assignment. Only participants in the active web intervention increased the number of contacts over time. Repeated Measures ANOVA for between-subject effects is not significant between time 2 and 3 (F [2,186] = 1.244, p = .291). An open-ended question allows participants to identify the specific sources contacted. The most common response is the web (35.7 percent), followed by family members (28.5 percent), the Alzheimer's Association (21.5 percent), and the doctor (14.3 percent). Participants were not specific as to web sites visited.

Table 26

Outside Contacts Over Time by Intervention Assignment

	Time 2 Outside Contacts		Time 3 Outside Contacts	
	Total	Mean	Total	Mean
Postal Mail Group (N=63)	8	.12	8	.12
Passive Web Group (N=63)	9	.14	7	.11
Active Web Group (N=63)	11	.17	15	.23

Hypothesis 5

Hypothesis 5 states there will be no significant difference in threat reduction between caregivers in the postal mail group and the passive web group. It is important to note that wording of the hypothesis favors the null hypothesis: threat perception scores will not differ between the postal mail and passive web interventions. Statistical analysis uses Repeated Measures ANOVA involving all three observation times. Analysis now enters data for participants originally in the "control" pool to their subsequent intervention group assignment.

Primary hypothesis testing. Table 27 illustrates that mean scores for the postal mail intervention increase between time 1 and 2, and then decline slightly, while scores for the passive web intervention decline over time. Repeated Measures ANOVA for between-subject effects is not significant between time 1 and 2 (F [1,124] = .229, p = .633), nor is it significant between time 2 and 3 (F [1, 124] = .367, p = .546). Results support the study hypothesis, which posits that the two groups will not differ in their impact over time. Neither education format influences threat perceptions.

Table 27

Threat Perceptions Over Time by Intervention Assignment

	Time 1 Mean (SD)	Time 2 Mean (SD)	Time 3 Mean (SD)
Postal Mail Group (N=63)	15.87 (6.51)	16.84 (6.42)	16.62 (6.03)
Passive Web Group (N=63)	17.56 (7.15)	16.22 (6.01)	15.94 (5.75)

Related threat perception analyses for hypothesis 5. Three items on the ABID specifically address wandering behaviors. A secondary analysis with only those items explores the data for associations. Repeated Measures ANOVA for between-subject effects is not significant between time 1 and 2 (F [1,124] = .627, p = .430). However, between time 2 and 3 the situation changes and the difference is significant, with F(1, 124) = 4.832, and p = .030. This finding merits cautious interpretation, however. Validity and reliability testing of the ABID involves the complete, 16-item tool. Literature does not address the validity and reliability of using only select sub-scale items. Table 28 displays the mean scores and standard deviations.

Table 28

Specific Wandering Threat Perceptions Over Time by Intervention Assignment

	Time 1 Mean (SD)	Time 2 Mean (SD)	Time 3 Mean (SD)
Postal Mail Group (N=63)	3.14 (2.29)	3.57 (2.22)	4.68 (2.28)
Passive Web Group (N=63)	3.14 (2.44)	2.97 (1.98)	3.65 (2.28)

Hypothesis 6

Hypothesis 6 posits there will be no significant difference in the number of home modifications made by caregivers in the postal mail group and the passive web group. It is important to note that wording of the study hypothesis favors the statistical null hypothesis: the postal mail and passive web interventions will not differ significantly in their impact on home modifications. Home modifications relate to the stress-health process model construct of secondary appraisal. Given the nature of the hypothesis and the data, a two independent sample t-test is the statistic for analysis. Statistical analysis uses Repeated Measures ANOVA involving all three observation times. Analysis now enters data for participants originally in the "control" pool to their subsequent intervention group assignment.

Primary hypothesis testing. Results in Table 29 identify the total and mean number of changes for postal mail intervention, compared with passive web intervention. Both interventions show a slight trend toward improvement (more modifications) over time. Repeated Measures ANOVA for between-subject effects is not significant between time 2 and 3 (F [1,124] = 1.544, p = .216). This finding supports the study hypothesis that postal mail and passive web interventions are similar.

Table 29

Home Modifications Over Time by Intervention Assignment

	Time 2 Home Modifications		Time 3 Home Modifications	
	Total	Mean	Total	Mean
Postal Mail Group (N=63)	7	.11	9	.14
Passive Web Group (N=63)	10	.16	14	.22

Related home modification analysis for hypothesis 6. At assessment time 2 and 3, participants respond to a question about outside contacts (if any) made during the course of the study. Outside contacts include individuals and/or education resources. Table 30 details the total and mean number of contacts by intervention group assignment. Contacts are stable for the postal mail group, but decline for the passive web intervention. Repeated Measures ANOVA for between-subject effects is not significant between time 2 and 3 (F [1,124] = 1.190, p = .278).

Hypothesis 7

Hypothesis 7 states there will be no significant difference in the number of home

Table 30

Outside Contacts Over Time by Intervention Assignment

	Time 2 Outside Contacts		Time 3 Outside Contacts	
	Total	Mean	Total	Mean
Postal Mail Group (N=63)	8	.12	8	.12
Passive Web Group (N=63)	9	.14	7	.11

modifications made by caregivers within any education group as a function of the passage of time. The study hypothesis favors the statistical null hypothesis. This analysis compares the changes at time 2 for all interventions, with the changes at time 3 for all interventions. A one-sample t-test is used for the analysis.

Primary hypothesis testing. As displayed in Table 31, the total number of home modifications increases over time, as do the mean number of changes. The change is statistically significant, with t (188) = 7.012, p = .000. The finding rejects the null hypothesis; participants continue to make changes over time. This contradicts a premise of the Switching Replications design, which posits that mastery of content will occur in a short time. The impact of education is lasts longer than anticipated. Discussion in Chapter 5 elaborates on this finding, and implications for the construct of secondary stress appraisals.

Related home modification analysis for hypothesis 7. A One-Way ANOVA separating participants based on home modifications (yes or no) examines the data for correlations beyond intervention assignment that might help explain modifications

Table 31

Home Modifications Over Time for all Participants

	Total Number of Modifications	Mean Number of Modifications
Time 2 (N=189)	34	.18
Time 3 (N=189)	46	.24

made. Only one variable met the significance test of .05; the variable is threat perception at time 3 (p = .031). Specifically, participants perceiving higher levels of threat at time 3 made more modifications at time 3.

As discussed in the hypothesis 1 and 2 sections, caregiver relationship, gender, and ethnic identification associate with statistically significant higher threat perceptions for non-spouse caregivers, females, and Caucasians. The same variables do not associate with differences in the number of home modifications. Because time may be a factor influencing home modifications, the variables of relationship, gender, and ethnic identification merit further analysis to see if differences emerge over time.

Differences in the number of home modifications between spouse and non-spouse caregivers approach, but do not reach statistical significance at the p = .05 level. At time 3, the mean number of changes made by spouse caregivers is 0.149, while the mean for non-spouse caregivers is 0.269. Females and males both made more changes at time 3, than at time 2. The mean number of changes for females at time 3 is .223; for males, the figure is .262. The difference between the genders over time is not statistically significant at the p = .05 level. Caucasians and all other ethnic groups made more changes at time 3, than at time 2. The mean number of changes for Caucasian caregivers at time 3 is .228; for all other ethnic groups, the mean number of changes is .281. The difference between the ethnic groups over time is not statistically significant at the $p = .05$ level.

Summary

Table 32 summarizes the results of the statistical analysis. Overall, statistically significant findings support four of the seven study hypotheses.

Hypotheses 1, 3, and 5 address the dependent variable, perception of threat related to coping with dementia behaviors. This variable reflects the stress-health process model construct of primary appraisal. When a situation has the potential to cause harm, a caregiver may perceive the situation as threatening. Over time, the stress perception can impair the caregiver's physical and mental health. Hypotheses 2, 4, 6, and 7 address the dependent variable of home modifications. This variable reflects the stress-health process model construct of secondary appraisal. If the caregiver evaluates potential coping strategies and views the situation as amenable to change (a positive secondary appraisal), then primary appraisal of threat may change.

The study posits that education will significantly influence the secondary appraisal processes, and that the format of the educational presentation will have a differential impact on appraisal. Education that actively involves the learner should be more effective than passive forms for education. Statistical results indicate that multimedia, interactive web education is more effective than no education (hypothesis 2) and is more effective than a postal mail brochure (hypothesis 4) in prompting

Table 32

Summary of Statistical Results by Hypothesis

	Premise of Hypothesis	Statistical Result
Hypothesis 1	Any education (postal mail, passive web, or active web) will associate with reduced caregiver perceptions of threat.	Not supported.
Hypothesis 2	Any education (postal mail, passive web, or active web) will associate with home modifications by caregivers.	Supported.
Hypothesis 3	Active web education will differ significantly from postal mail and passive web education in reducing perceptions of threat.	Not supported, but qualified findings using sub-scale items from the ABID.
Hypothesis 4	Active web education will differ significantly from postal mail or passive web education in the home modifications made.	Supported.
Hypothesis 5	Postal mail and passive web education will not differ significantly in their impact on threat perceptions.	Supported.
Hypothesis 6	Postal mail and passive web education will not differ significantly in their impact on home modifications.	Supported.
Hypothesis 7	Home modifications made will not differ as a function of time.	Not supported.

positive secondary appraisals, as measured by the number of home modifications. However, only qualified results support the impact of active education on threat perception reduction (hypothesis 1 and 3). Passive forms of education (postal mail and passive web) appear equal in effect (hypotheses 5 and 6). Of interest is the finding that secondary appraisal may continue longer than anticipated (hypothesis 7).

Chapter 5 contains the detailed discussion of study results. The discussion emphasizes factors that may contribute to non-significant findings, and relates the results of the dissertation study to the body of knowledge from previous dementia caregiver studies. Sections will also address limitations of the study. The chapter concludes with implications and suggestions for future research.

CHAPTER 5

Discussion and Limitations

Introduction

The purpose of the dissertation study is to examine the family experience of dementia caregiving, and to design an education intervention to assist family members in the caregiving role. The research question is to determine the extent to which self-directed, distance education can alter a caregiver's primary and secondary appraisal of stress. In Chapter 4, the statistical analyses for the seven study hypotheses were presented.

Chapter 5 discusses the results and relates the findings to the body of knowledge from previous studies of dementia caregivers. The chapter has four primary sections. The Introduction provides a brief review of basic concepts and constructs. The Discussion section describes major findings for the dependent variables of threat perception and the home modifications. Literature from research with dementia caregivers provides possible explanatory factors for the study results. The Limitations section reviews weaknesses of the study, including threats to internal, statistical, construct, and external validity. Policy and Practice Implications examine educational themes and measurement concerns. The chapter concludes with the presentation of future directions for research.

Study Concepts and Constructs

The seven study hypotheses relate to the stress-health process model concepts of primary and secondary stress appraisal. Primary appraisal focuses on the potential for an environmental situation to affect personal well being (Lazarus, 1977, 1981; Lazarus & Folkman, 1984). A situation must be cognitively evaluated to determine if it is irrelevant to well being, benign (non-threatening), or potentially stressful. Stress appraisal occurs if the situation involves: harm (some damage or loss has occurred); threat (anticipation of future damage or loss); or challenge (possibility for growth or gain). In the dissertation study, measurement of stress appraisal involves use of the validated tool, the Agitated Behaviors in Dementia (ABID) scale (Logsdon, et. al., 1999). Threat perception scores on the ABID range from zero (dementia behaviors are not upsetting) to sixty-four (dementia behaviors are extremely upsetting). Primary appraisal is the focus of hypotheses 1, 3, and 5.

Secondary appraisal involves evaluation of eight coping strategies and the likelihood that a particular strategy will be effective (Folkman, et. al., 1986; Lazarus, 1977, 1981; Lazarus & Folkman, 1984). The coping strategies include: confrontive coping, distancing, self-control, accepting responsibility, escape-avoidance, seeking support and information, planful problem solving, and positive reappraisal. Positive strategies reduce stress. The positive strategies are: seeking support and information, confrontive coping, planful problem solving, and positive reappraisal. The number of home modifications made by caregivers at time 2 and time 3 assessment operationalizes the construct. Secondary appraisal is the focus of hypotheses 2, 4, 6, and 7.

There is an iterative relationship between primary and secondary appraisal. A positive secondary appraisal can influence the primary appraisal process. If the subsequent primary re-appraisal finds the situation to be less threatening, stress levels decline. In the long term, the risk for physical and mental health problems declines. Education is a way to influence positive secondary appraisals. Progressive adult education theory emphasizes problem-solving skills and self-directed learning which actively engages the learner. The educator takes on the role of facilitator in self-directed learning. The dissertation study tests three forms of self-directed education: multimedia, interactive Internet education, passive Internet education, and postal mail education.

Discussion

Major Findings and Results

Table 33 states the seven study hypotheses and the statistical results from Chapter 4. Hypotheses 1, 3, and 5 address the construct of primary appraisal and the dependent variable of threat perception. Hypotheses 2, 4, and 6 address the construct of secondary appraisal and the dependent variable of home modifications.

Dependent Variable: Perceptions of Threat (Primary Appraisal Construct)

Complexities in the stress-health process model help explain rejection of hypothesis 1 and qualified acceptance of hypothesis 3. Multiple factors contribute to primary appraisal of stress. As discussed in Chapter 2, before a perception of threat develops, the individual faces an environmental demand that requires evaluation of the potential for harm and evaluation of adaptive capacities for coping (Cohen, et. al., 1995). Because of the progressive nature of dementia and the behavioral implications,

Table 33

Summary of Statistical Results by Hypothesis

	Premise of Hypothesis	Statistical Result
Hypothesis 1	Any education (postal mail, passive web, or active web) will associate with reduced caregiver perceptions of threat.	Not supported.
Hypothesis 2	Any education (postal mail, passive web, or active web) will associate with home modifications by caregivers.	Supported.
Hypothesis 3	Active web education will differ significantly from postal mail and passive web education in reducing perceptions of threat.	Not supported, but qualified findings using sub-scale items from the ABID.
Hypothesis 4	Active web education will differ significantly from postal mail or passive web education in the home modifications made.	Supported.
Hypothesis 5	Postal mail and passive web education will not differ significantly in their impact on threat perceptions.	Supported.
Hypothesis 6	Postal mail and passive web education will not differ significantly in their impact on home modifications.	Supported.
Hypothesis 7	Home modifications made will not differ as a function of time.	Not supported.

caregivers face a variety of demanding situations (McCarty, et. al., 2000; Devanand, et. al., 1997; Whitlatch, et. al., 1997; Vitaliano, et. al., 1991).

Environmental demands and threat perceptions. One possible explanation for the lack of unqualified significance for hypothesis 1 and 2 relates to the concept of environmental demands. If caregivers in the dissertation study did not perceive situations to have meaning for personal well being, the processes of primary and secondary appraisal would not occur. Therefore, scores on threat perception measures would not change. A speculation that caregivers in the dissertation study do not perceive environmental demands does not fit the data available, however. In original work on the ABID, the mean threat perception score is 15.19 (Logsdon, et. al., 1999). The group mean for the dissertation study is higher, 16.40, indicating the sample in this research experiences slightly more stress than the original ABID population. As noted in Chapter 4, the sample participants include a large percentage of non-spouse caregivers, and threat perceptions for this group are higher.

A second possible explanation is that caregivers in the study did not specifically perceive wandering to be an environmental demand. This issue is important because the content in the educational interventions addresses home modifications to manage wandering behaviors. Wandering behaviors do stress caregivers and correlate with increased likelihood of nursing home placement (Logsdon, et. al., 2000; Logsdon, et. al., 1998; Kaspar & Shore, 1994).

In the original ABID testing by Logsdon, et. al., (1999), the mean threat perception score for the three sub-scale items that focus on wandering is 3.60. All participants in the dissertation study report threat perceptions due to wandering behaviors, but the dissertation study mean is slightly lower, 3.15. The lower score indicates a slightly reduced perception of threat related to wandering behaviors. In the original ABID work by Logsdon and colleagues, participants report a mean occurrence score for wandering of 7.3; this indicates wandering behaviors occur two or more times per week. While all participants in the dissertation sample report scores for wandering behaviors, the mean frequency is 5.5; this indicates wandering occurs approximately one to two times per week.

Threat appraisals may differ because the sample is not experiencing the same intensity of wandering. As well, the adult children who comprise a significant proportion of the sample may not be aware of the occurrence of wandering since the children are less likely to live with the patient. Together, these factors may attenuate the process of primary appraisal and contribute to the non-significant finding for hypothesis 1. The qualified support for hypothesis 3 (active web education is different from postal mail education) is the result of statistical analysis using only the three sub-scale items that address wandering. However, literature does not document the reliability and validity of using sub-scale items. The section on Limitations will address measurement issues.

Subjectivity and measurement sensitivity. The process of threat evaluation (primary appraisal construct) is subjective. This presents unique measurement challenges. Several caregiver studies address the issue with varying degrees of success (Braithwaite, 2000; Pot, et. al., 2000; Pot, et. al., 1998; Braithwaite, 1996; Lawton, et. al., 1991; Lawton, 1989). The earliest works by Lawton and colleagues established multifactoral models addressing domains from satisfaction, to mastery, caregiver ideology, religious principles, and role models. Work on the model did not resume until Braithwaite (1996) reexamined the Lawton model, attempting to redefine dimensions.

In 2000, Braithwaite pilot tested a new assessment with 144 Australian caregivers. While finding the tool generally valid, Braithwaite cautions against implementation in the United States until cross validation testing. This has not taken place. Pot and colleagues created an appraisal tool for use in a Netherlands study involving 175 caregivers. Results find the tool promising and analysis is ongoing. Cultural validation of the tool has not taken place.

Influence of demographic variables. Differences in caregiving tenure may contribute to the dissertation results. The mean tenure of caregiving in the study sample is 2.8 years. Data from the National Alliance for Caregiving and the American Association of Retired Persons (1997) find a mean tenure of 5.1 years. The original ABID work did not collect tenure of caregiving information. The difference in the length of caregiving is important because wandering behaviors generally occur during the middle stages of dementia (Morgan & Steward, 1997; Ryan, 1995; Burns, et. al., 1990; Henderson, et. al., 1989). Educational interventions focused on information about home management of wandering behaviors. The shorter caregiving tenure in the dissertation sample may indicate that some caregivers are not facing major challenges related to wandering behaviors. Frequency of wandering data in a previous section supports this position. If the intensity of the behavior is missing, the caregiver may not engage in primary and secondary stress appraisals.

Tenure of caregiving has implications for the "journey" taken by caregivers. In a model developed by Bar-David (1999), dementia caregiving involves a three stage "journey." In the first stage, caregivers begin to develop the capacity to care for the person diagnosed with dementia. Developing the capacity to care involves resolution of four elements: an accurate perception of the problem, genuine motivation to help, a personal sense of competency to help, and willingness to take action to help. The first stage of the journey takes more than three years. Given the dissertation sample's mean tenure of caregiving, 2.8 years (range 1 to 10; SD = 2.02), some participants are in the very early stages, while others are in the second stage where self-care is the focus. For participants in the first stage, inaccurate perceptions and issues of personal motivation and competency could influence participant perceptions, thus contributing to non-significant results. Simply put, caregivers in the study may not have been mentally "ready" for an educational intervention.

Relationship. The dissertation sample is predominantly adult children (61.9 percent), with a smaller proportion of spouses (26.2 percent); the remaining participants are grandchildren and other relatives. Caregiving spouses report lower levels of threat perceptions compared to adult children, grandchildren, and other relatives. This supports findings by Motenko (1989). In contrast, spouses comprise 70 percent of the sample in the original ABID validity testing (Logsdon, et. al., 1999).

Relationship associates with differences in participant age. Mean age for the dissertation sample is 55.2, while mean age in the original ABID test sample is 65.6. A telephone survey by the National Alliance for Caregiving and the American Association of Retired Persons (1997) finds the mean age of caregivers to be 46.2 years. The national study also finds that 61.6 percent of caregivers work outside the home, and 43.5 percent still have children who reside in the family home. Managing multiple priorities contributes to stress. As well, most adult children do not live with parent who has dementia. The inclusion criteria for the dissertation study (caregiver email address and access to a computer with Internet connection) favor a younger sample and participation by adult children.

Knowing relationship by category (spouse, adult child, grandchild, or other relative) provides only basic information about family dynamics. Several studies suggest that the quality of interactions is more important than relationship (Gaugler, et. al., 2000; Fisher & Lieberman, 1999; Lieberman & Fisher, 1999). The dissertation study did not collect family information beyond the categorical variable of relationship.

Coresidence. Coresidence (living together) is not one of the background variables collected for the study. Relationship could be a proxy measure for coresidence, although coresidence would not ensure a familial relationship. Additional analyses for hypothesis 1 and 2 explore the impact of a relationship/coresidence proxy measure. Threat perceptions differ significantly between spouse (proxy for coresidence) and non-spouse caregivers; non-spouse caregivers report higher levels of threat. However, differences in threat perception do not correlate with statistical differences in the number of home modifications made by caregivers. Related to the theme of coresidence is the issue of self-report data. Caregivers not living with the person diagnosed with dementia might have inaccurate perceptions of the dementia problems. However, information in Chapter 3 documents the validity of self-reports even when coresidence does not occur (Lowenstein, et. al., 2001; Cavanaugh & Kinney, 1998; Ostbye, et. al., 1997; Jorm, et. al., 1996; McLoughlin, et. al., 1996).

Relationship and coresidence. Ultimately, the influence of relationship and coresidence on caregiver stress is complex. Some researchers argue that specific relationships do not influence stress and well being (Nunley, et. al., 2000). Other researchers find family dynamics more predictive of stress levels. Important family dynamics include emotional closeness, family efficacy, and level of assistance (Atienza, et. al., 2001; Gaugler, et. al., 2000; Fisher & Lieberman, 1999; Lieberman & Fisher, 1999; Yates, et. al., 1999; Williamson & Schulz, 1990; Haley, et. al., 1987; Zarit, et. al., 1980). The dissertation study did not examine family dynamics beyond the simple identification of relationship.

Use of paid assistance. In a national telephone survey, only 28 percent of caregivers report using outside (paid) assistance (National Alliance for Caregiving and the American Association of Retire Persons (1997). In the dissertation sample, 36.5 percent of participants report using outside, paid assistance. This difference might imply a differential effect on threat perceptions, but data from the multi-year Medicare Alzheimer's Disease Demonstration Project finds that paid services do not significantly affect caregiver burden or depression (Newcomer, et. al., 1999). The Medicare study also finds that outside assistance does not alter the number of hours of care provided by family (Newcomer, et. al., 1999). Nonetheless, with one out of three participants in the study sample using outside services, this could modify the secondary appraisal of stress (evaluation of coping strategies). Participant caregivers might believe it is the responsibility of paid assistants to evaluate the home for safety modifications, and it is the responsibility of the paid assistants to initiate the modifications. With this rationale, participant caregivers may avoid engaging in either primary or secondary stress evaluations.

Ethnic identification. Ethnic identification correlates with perceptions of stress. As reported in Chapter 1, African American caregivers report lower levels of stress and burden, and are less likely to place family members in nursing homes (Janevic & Connell, 2001). In the dissertation sample, 18 percent of participants selected a category other than Caucasian. The original ABID work does not report ethnic identification of the participants, so there is no base for comparison. Additional analyses for hypothesis 1 and 2 find that while Caucasians in the sample have higher threat perception scores, Caucasian caregivers do not make more home modifications.

Gender. Gender influences perceptions of threat. In the dissertation sample, 63.5 percent of caregivers are female; threat perception scores for these participants are higher than the male counterparts. In the original ABID work, 68 percent are females. In the national telephone survey of caregivers, 72.5 percent are females. The literature review in Chapter 2 documents the differential impact of the caregiver's gender (Gallicchio & Siddiqi, 2002; Robinson, et. al., 2001; Hooker, et. al., 2000; Miller & Guo, 2000; Rose-Rego, et. al., 1998; Kramer, 1997a; Rose, et. al., 1997). Males use fewer emotion-focused coping strategies and more outside, formal (paid) assistance. Their overall sense of caregiver burden is lower. Additional analyses for hypothesis 1 and 2 find the same significant results for the dissertation sample. However, females in the study sample do not make more home modifications. Gender stereotypes may influence perceptions. If a man perceives all aspects home maintenance as the masculine domain, any changes made during the study may seem "routine" and unrelated to the caregiving role.

Other potential confounds. Literature documents various motivations for caregiving (Nunley, et. al., 2000; Dellasega, 1998; Magai & Cohen, 1998; McCarty, 1996; Motenko, 1989), but does not address motivations for participating in research studies. No background variables in the study address this issue. During the Informed Consent process, 22 of the 189 participants indicate prior awareness of the principal investigator. In all cases, participants attended some education program involving the principal investigator; in no case did the awareness involve individual attention or counseling. The most recent public education program presented by the principal investigator was November 1998. Prior education contact with some participants could bias responses, including the halo effect, the self-fulfilling prophecy, or the social desirability bias. Didactic education studies face similar problems (Switzer, et. al., 2000; Montgomery, 1996). As presented in Chapter 4, Descriptive Statistics, there is no significant difference between the baseline threat perception scores for participants with prior awareness and those without prior awareness of the principal investigator. Therefore, responses for these caregivers are in the sample database.

Timeframe for study. A final influencing factor is the timeframe for the study. Two months may not be long enough to discern appreciable changes in primary appraisal (threat perceptions) due to the iterative effect with secondary appraisal. Results for hypothesis 7 support this position; caregivers continue to make home modifications over time though this counters the original study hypothesis. To engage in the positive secondary appraisal strategies of seeking information and planful problems solving may take time; once changes do occur, it may still take additional time before threat perceptions change.

Extending the timeframe could result in other problems that attenuate the education effect. Most dementing illnesses are progressive in nature (Teel, et. al., 2001; Vetter, et. al., 1999; Vitaliano, et. al., 1991). Only one study in the literature review addresses the issue of time. Gignac and Gottlieb (1996) find changes in appraisal do take place over a two to five month span. The progressive nature of dementia and ongoing changes in the person-environment transactions are the reasons why short time spans are valid. Person environment transactions take a system view of interactions. When one element changes (such as disease progression), everyone involved in the system undergoes change.

Dependent Variable: Home Modifications (Secondary Appraisal)

Hypotheses 2, 4, 6, and 7 address the dependent variable of home modifications made after the educational intervention. Home modifications operationalize the construct of secondary appraisal. Positive secondary appraisal views a situation as amenable to change. There is statistically support for hypothesis 2; active web education differs significantly from Switching Replications pooled "control" group. For hypotheses 4, a significant difference exists between the active web intervention and the postal mail intervention. Results for hypothesis 6 find no significant differences between the postal mail and passive web interventions. The hypothesis 7 finding that education effects continued over time was encouraging, although it contradicted the study hypothesis.

Positive appraisal and education influences. Several factors help explain the results. From the theoretical perspective, secondary appraisal involves evaluation of eight coping strategies (confrontive coping, distancing, self-controlling, seeking support and information, accepting responsibility, escape-avoidance, planful problem solving, and positive reappraisal). Education appears to promote positive secondary appraisal strategies (confrontive coping, seeking support and information, planful problem solving, and positive reappraisal). Though the dissertation study did not find a subsequent relationship between primary appraisal and secondary appraisal, literature documents the iterative relationship in non-caregiving studies (Shaw, 1999; Park, 1998; Webb, 1996; Aldwin & Revenson, 1987; Billings & Moos, 1981).

The dissertation study integrates the stress appraisal concepts with theories from the field of education. Combining principles from the self directed learning model (Knowles, 1988) with active participant involvement (Gagne, 1977), hypothesis testing finds the computer interactive educational format significantly different from the postal mail format and significantly better than no educational intervention. The formats of postal mail and passive web education did not differ significantly.

Timeframe for study. Despite a belief that participants would make modifications quickly or not at all, this is not the result. Modifications increase overtime, contradicting hypothesis 7. At the same time, participants have fewer outside contacts at time 3. Outside contacts include any discussions with other person about the educational messages and/or the seeking of additional information from other sources. The trend of more modifications over time, but fewer outside contacts may reflect the need to think and plan before acting. This describes the secondary appraisal process of planful problem solving. The trend may also reflect a carryover effect in the study design. The Limitations section addresses the carryover effect. The section also discusses seasonal factors that could influence the study.

Influence of demographic variables. As noted in discussion for the threat perception variable, the study sample is unique in several ways. Mean tenure of caregiving in the sample is shorter than national populations. More participants are male and the caregiving relationship is most likely to be adult child, grandchild, or other relative. A greater percentage of participants use paid assistants, compared to national populations. Although these factors contribute to significant differences in threat perceptions, no differences exist regarding the number of home modifications. The iterative relationship between primary and secondary appraisal may explain the results. If the first primary appraisal is not noteworthy, then secondary appraisal does not occur. In the case of this study, if participants did not engage in secondary appraisal, they would not make home modifications.

Measurement considerations. The dissertation study uses the number of home modifications made by caregivers as a measure of the secondary appraisal process. Shyu (2000) uses a similar method to measure active coping. However, this may be too simplistic to measure the richness of the secondary appraisal concept. The section on Limitations explores measurement issues in detail.

Limitations

Limitations address weaknesses in the design of the study and problems that occur during the study. Emphasis in this section is on validity. The following sections highlight four categories of validity concerns.

Internal Validity

Several factors bias the ability to interpret the impact of education on the primary and secondary stress appraisal process. The quality of sampling is one of the concerns. The principal investigator resides in the same area as the study sample. At Informed Consent, 22 of the 189 participants in the sample indicate prior awareness of the principal investigator (defined as attendance at education programs involving the principal investigator). Although the most recent education program involving the principal investigator took place in November 1998, prior contact introduces a potential for response bias. Participant responses could reflect an apprehension to identify perceptions and activities taking place during the study, or responses might skew in the direction of social desirability (in essence, "education should help, so I better say it did"). For future studies, exclusion criteria should eliminate these potential participants during the Informed Consent process.

Control group issues threaten internal validity in two ways. First, the Informed Consent document required by Virginia Commonwealth University clearly indicates that some participants receive education immediately, while others do not. Participant awareness introduces the potential for demoralization or resentment among members in the original control group. It is important to stress that participants in the study do not interact, and resentment (if any) is individual and not fostered by group interaction. At the same time, participants immediately assigned to an educational intervention may feel "special." The Hawthorne effect of attention may result in behaviors the caregiver would not normally initiate. No participants contacted the Principal Investigator during the study to express resentment or to ask additional questions.

The study design, Switching Replications, raises additional control group concerns. The quasi-experimental design forms a non-equivalent pooled "control" group who receive no intervention between the first two assessments. After the second assessment, controls "switch." The pooled "control" participants receive the intervention; participants initially assigned to an intervention do not receive any further treatment. All participants complete a final, time 3 assessment. Analysis blends comparison of participants by intervention assignment, and by time. In a true experimental design, the control group receives no treatment. This reduces threats to internal validity. However, the true experimental design is an ethical concern in caregiver research because it denies intervention to caregivers needing assistance (Zarit & Leitsch, 2001; Nichols, et. al., 2000). The Switching Replications model represents a compromise position. The two independent implementations of the intervention help address validity concerns (Trochim, 2000).

All time series designs, including Switching Replications, introduce validity threats. Carryover effects can occur when participants undergo pre and post testing. To minimize carryover, Switching Replications is valid when the intervention is immediate, and not delivered in graduated steps. This describes the process for the dissertation study. Switching Replications is also valid when the intervention effect decays with time. Though the decay assumption guided the dissertation study, results for hypothesis 7 indicate that educational effects may not decay. This finding adds to validity concerns about use of the Switching Replications model in future caregiver studies. However, the essence of the Switching Replications design and the with-in subject repeated measurements is that each person serves as his or her own control. This helps counterbalance the effect of carryover. The counterbalance effect does not remove all possible carryover effects of bias (such as the test practice effect), but within the frame, the bias effects should be equal.

History and intervening effects can influence time series designs and are threats to internal validity. Normally, a short timeframe helps control seasonal effects. Between the first participant enrollment (December 2001) and the final time 3 assessment (March 2002), the geographic area in which participants reside experienced weather extremes. Unseasonably warm weather (over 70 degrees) at the start of the study might attenuate concerns about wandering. If the person with dementia did leave the home, threats to personal safety would not include hypothermia. Within weeks, two major snow and ice storms swept the area. There was significant property damage from the first storm; 35 counties in the state are federal disaster areas (State of Kansas, 2002). While cold weather increases caregiver concerns about wandering behaviors, some participants had to deal with property damage and storm repairs. The time to focus on suggestions from the educational intervention may have been limited.

The short timeframe for participant involvement (two months) prevented participant attrition. All participants completed the study. The short timeframe creates other problems, however. Due to the complex nature of the stress-health process, two months appears too short to discern appreciable changes in perceptions and behaviors. Caregivers may need more time to seek and analyze information before making modifications. The findings for hypothesis 7 (increased home modifications at time 3) support this conclusion. Caregiver literature does not posit particular timeframes for caregiver intervention studies (Schulz, 2000). Meta-analyses find timeframes range from two months to longitudinal analysis over several years (Opie, et. al., 1999; Biegel, et. al., 1991; Toseland & Rossiter, 1989).

Information diffusion is a concern with time series designs. The principal investigator monitored media stories about dementia during the data collection period (December 2001 to March 2002). The only items in the media are notices of support group meetings and publication of the local Alzheimer's Associations Helpline number.

Both items (support group notices and Helpline number) are ongoing themes in the area media. The potential for information diffusion based on media information is minimal.

Statistical Validity

Reliability of the assessment measure affects statistical validity. Literature documents the reliability and validity of the 16-item ABID instrument used in this research (Logsdon, et. al., 1999). Literature does not document reliability and validity of sub-scale items in the ABID. The dissertation study examined some sub-scale items. The section on Construct Validity discusses some of the measurement concerns.

Sample size is a major factor influencing power and the potential for type II error. For medium effects, the dissertation sample size established in Chapter 3 required 62 participants per group for a power or .80 and an alpha of .05. Some results in Chapter 4 approach but do not reach statistical significance. Future studies need a larger sample size for more power.

Construct Validity

Primary appraisal of stress. To study the stress construct of primary appraisal, measurement must assess the domain of caregiver burden and threat evaluations. Chapter 3 reviews the reliability and validity of tools in previous caregiver studies (Gallo, et. al., 2000; Rubenstein, et. al., 1995). Despite the past efforts, caregiver literature documents ongoing concerns with the measurement sensitivity of assessment tools (Braithwaite, 2000; Caro, 2000; Montgomery & Kosloski, 2000; Switzer, et. al., 2000). Further discussion of the need for more sensitive tools appears in the Policy and Practice Implications section.

The dissertation study uses the established ABID measurement instrument. Of all assessment tools available, the ABID includes the largest number of items specific to wandering behaviors and caregiver perceptions of threat related to wandering behaviors (three out of 16 items). This is important because the educational intervention addresses wandering behavior. The inclusion of non-wandering behaviors limits the assessment and interpretation of the study results. Future studies should examine the reliability and validity of sub-scale items of the ABID.

Multiple measurements of the dependent variable enhance construct validity. A multi-method, multi-trait comparison documents the reliability and validity of the ABID (Logsdon, et. al., 1999). The dissertation study uses only one measure of threat perception, the ABID. This introduces bias, and limits the validity of the results. Despite the established reliability and validity of the ABID, future studies should use two measures of threat perception.

A final theme is the dissertation study's use of wandering behaviors for the specific intervention content. With the construct of interest being primary appraisal of stress, focused information on wandering may be too narrow to influence the caregiver's appraisal process. Experts do caution that education efforts should not be "shot gun" or broadly based (Montgomery & Kosloski, 1998). Wandering is a behavior that affects 65 percent of caregivers (Logsdon, et. al., 1998). As well, wandering is an educational content area for which there are numerous inexpensive suggestions for home modifications (Bakke, 1997; Holmberg, 1997: Maddox & Burns, 1997; Morgan & Steward, 1997; Begany, 1996; Glaser, 1996; Dickinson, et. al., 1995; Richter, et. al., 1995; Edwards, 1994). The latter issue is important for measurement of the next construct, secondary appraisal of stress.

Secondary appraisal of stress. The secondary appraisal of stress involves evaluation of options for coping with a situation. When positive evaluation takes place, changes occur. To assess this domain, the dependent variable is a self-report measure of home modifications at time 2 and time 3 assessments. Shyu (2000) uses a similar method to measure active coping. Since the start of the dissertation study, literature documents a new approach to this type of coping assessment (Gitlin, Winter, Dennis, Corcoran, Schinfeld, & Hauck, 2002). A 19 item Task Management Strategy Index (TMSI) is reliable and valid in identifying actions taken by caregivers to simplify home care. Future studies should consider this tool as a way to enhance validity through multi-method, multi-trait methodology.

Another data collection issue concerns queries of participants at time 2 and time 3 regarding other sources of information used during the study. If the participant indicated contact with other sources, an open-ended question asked the participant to specify the nature of the sources. At time 3, some participants indicate contacts occurred but did respond to the open-ended question. Though a follow-up email contact from the principal investigator requested clarification, the participants did not respond with details. The format of the open-ended question was not pilot tested before the study. This should take place before future studies. It is possible that the question should be more precise, perhaps offering check box options for sources contacted.

Progressive (problem solving) adult education using self-directed learning. Principles from adult education theory guided design of the educational materials for the interventions in this study. The format of the intervention materials is unique to the dissertation study. This includes: presentation style (font sizes and color); organization (items identified first, middle, or last); and amount of content (overall number of suggestions). Pilot testing of presentation style, organization, and amount of content did not occur before presentation to study participants. Future studies should pilot test the format.

External Validity

Several factors threaten the external validity of the study. The sample is not random. The Sunflower Chapter of the Alzheimer's Association referred potential participants to the study. Further, the Sunflower Chapter serves approximately half of the State of Kansas, but includes only one major metropolitan area. The inability to separate participants by rural and urban residence limits generalizability. In addition, the rural areas of Kansas focus on farming (primarily wheat) and ranching. This unique combination could impair the ability to generalize results to other rural areas.

Demographics of the sample also affect generalizability. Participants in the sample are primarily adult children, with a limited number of years in the caregiving role. There are more males than normally found in caregiver research. Caregivers in the sample also use more paid assistance than normally found in caregiver studies. Therefore, results of the study may only be applicable to a select sub-population of dementia caregivers.

The dissertation study did not collect information on the length of time since the dementia diagnosis, hours of caregiving per week, and coresidence. Future studies should add these variables. While the new variables may correlate with tenure of caregiving, it is important to verify the participant's stage in the caregiving journey. Given the short tenure of caregiving in the sample, participants may not be at a stage in the process where wandering is a major concern. This would influence responses to questions about threat perceptions and home modifications. Therefore, it may be the education content, not the distance education formats, that affects the findings. Collection of additional information to clarify the stage of caregiving for each participant would address this concern. In future studies, stage might also become a control variable for further analysis.

Policy and Practice Implications

Review of the dissertation results offer insights for the future policy and practice with dementia caregivers. The following paragraphs highlight implications regarding methods of education and measurement issues for caregiver research. Also presented are suggestions for future research directions.

Implications Regarding Methods of Caregiver Education in the Future

Chapter 1 identified the three primary theoretical perspectives that guide progressive (problem solving) adult education (Price, 1999; Donlevy & Donlevy, 1998). The Kolb (1984) perspective on experiential learning is not optimal for dementia caregivers. To "learn by doing" means dementia caregiving proceeds by trial and error. Most caregivers do not receive any type of formal or semi-formal education (Connell & Kole, 1999; Molinari, et. al., 1994). One correlation is high rates of physical and psychological abuse and neglect experienced by people with dementia (National Center on Elder Abuse, 2001; Dyer, et. al., 2000).

The cooperative learning approach of Johnson and Johnson (1989) focuses on small group interactions. The earliest intervention programs, caregiver support groups, rely on this model (Collins, et. al., 1991). Literature documents varying degrees of success for support groups in terms of reducing caregiver stress; as well, the literature documents barriers to support group attendance (Connell & Kole, 1999; Peak, et. al., 1995; Farran & Keane-Hagerty, 1994; Toseland, et. al., 1990; Gonyea, 1989; Toseland, et. al., 1989).

Emphasis in the dissertation study is on the third form of adult education: self-directed learning (Knowles, 1988). This perspective stresses the role of the educator as a facilitator, helping the adult learner take an active role in the education process. Self-directed learning involves asynchronous experiences (separation of the educator and the adult learner). Distance education is self-directed learning. In health care, numerous studies document the distance education effectiveness of different forms of distance education: print brochure materials (Kreuter, et. al., 2000; Meischke, et. al., 2000; Husted, et. al., 1999; Rybarczyk, et. al., 1999; Mant, et. al., 1998; Frederikson & Bull, 1995; Higgins & Ambrose, 1995); videos (Mahler, et. al., 1999; Renton-Harper, et. al., 1999; Yamada, et. al., 1999; Mahler & Kulik, 1998; Phillips, 1992; Gagliano, 1988); teleconferencing and telephone networking (Paul, et. al., 2000; Chang, 1999; Novotny, et. al., 1995; Goodman & Pynoos, 1990); and a meta-analysis of 21 Internet education studies (Lewis, 1999).

As the age of Internet users and the number of households with connections increases (Library of Congress, 2000; Rickert & Sacharow, 2000), self-directed learning programs offered over the World Wide Web have the potential to reach dementia caregivers. Through March 2002, only four published studies examine Internet interventions with dementia caregivers (Coulson, 2000; White & Dorman, 2000; Bass, et. al., 1998; Mahoney, et. al., 1998). Therefore, the dissertation study adds to this body of information in several important ways.

The theoretical base for the dissertation study is a respected stress-health process model (Cohen, et. al., 1995). A major criticism of past caregiver intervention studies is the lack of a strong theoretical perspective (Braithwaite, 2000; Montgomery & Kosloski, 2000; Switzer, et. al., 2000). None of the four published studies on the Internet and caregiver education uses a stress model. In his seminal work on dementia caregiving, Schulz (2000) argues that interventions use a stress theory base.

The dissertation study blends education theory principles with the stress-health process model. The Lazarus and Folkman (1984) concept of secondary stress appraisal, one of the major elements in the stress model, is an opportunity for education interventions. Positive secondary appraisal of a situation involves techniques of information seeking, planful problem solving, confrontive coping, and/or social support. If a positive secondary appraisal occurs (view the situation as amenable to change), the potential exists to alter the primary appraisal that the situation is harmful or threatening. Reducing perceptions of harm or threat improve the long term physical and mental health of the caregiver.

The self-directed learning principles of Knowles (1988) provide guidance on ways to impact secondary appraisal through education. Knowles posts that educators need to design "packages" of useful information that actively involve the adult learner. The educator then facilitates asynchronous access to the packages. In essence, the dissertation study designed and delivered one information "package." The delivery component compared different methods for involving the learning, from passive receipt of postal mail information to multimedia, interactive (active web) content. From a delivery perspective, the project flowed smoothly with minimal problems experienced by participants.

Although results indicate that distance education does not influence perceptions of threat (primary appraisal construct), it appears to have some effect in prompting caregivers to take recommended actions to modify the home environment (secondary appraisal construct). Statistical results indicate active web intervention is more effective than no intervention and more effective than postal mail intervention. Results do not find a significant difference between passive web information and active web information. If verified in replication studies, the policy and practice implications for organizations are important. There may be too much emphasis on the new "bells and whistles" of computer technology at the expense of the education message. Many organizations and companies are hiring webmasters to create dynamic, interactive Internet sites. In fact, what the organization may need are education personnel with basic Internet programming skills.

Implications Regarding Measurements in Future Caregiver Studies

Caregiver literature documents concerns about the measurement sensitivity of caregiver assessment tools (Burgio, Corcoran, Lichstein, Nichols, Czaja, Gallagher-Thompson, Bourgeois, Stevens, Ory, & Schulz, 2001; Braithwaite, 2000; Caro, 2001; Martin-Cook, et. al., 2000; Montgomery & Kosloski, 2000; Switzer, et. al., 2000; Kramer, 1997b). Despite the acknowledged need for better measures of outcome, the issue is complex. Multiple factors influence an individual's perception of stress. Successful intervention at even one point in the stress-health process does not guarantee overall success, measured as a reduction in overall stress.

Caro (2001) defines a "quality of circumstances" framework for the design of methodologically improved measurements. Emphasis is on identification of objective measures to determine the adequacy of proposed solutions to the problems of everyday caregiving. Instead of broad measures, such as reduction of overall stress or prevention of premature nursing home placement, the measurable objective is to ease or simplify one aspect of caregiving. The dissertation study attempts this with the simplistic measure for the dependent variable, home modifications. Two hypotheses that use this measure show statistical significance.

The on-line data collection method in this study is unique. As of March 2002, literature reports no caregiver studies using this method. As noted in Chapter 4, the method is effective for most participants; only five of the 189 participants report any difficulty. A sub-sample test established reliability of the computer administration of the ABID. Because caregiver recruitment and research can be expensive (Tarlow & Mahoney, 2000), use of the Internet for future data collection has policy and practice implications, including cost savings and ease of administration.

Future Directions for Distance Education Research with Dementia Caregivers

To enhance the discussion of future directions, suggestions focus on two broad categories. Research Content addresses issues of educational message content and definitions of educational formats. Research Methodology addresses issues of future study designs, sampling procedures, and measurement.

Research Content

Future studies should design and test new education "packages." The dissertation study focus on the specific behavior of wandering limits the results. In home care, the information needs of dementia caregivers are multifaceted due to the progressive nature of most dementing illnesses. To determine the effectiveness of distance education for dementia caregivers, testing must address a wider array of issues. Suggestions include content areas on verbally aggressive behavior, physically aggressive behavior, socially inappropriate behavior (such as disrobing), sexual behavior, refusal of needed help (such as with bathing and dressing), self abusive behavior, hallucinations, and inaccurate perceptions (such as expressing a desire to go home when the patient is at home).

There are ways that Internet education can be interactive beyond the multimedia method used in this study. At a basic level, interactivity could involve follow-up email contact after a caregiver accesses information over the Internet. A follow-up contact offers a more personal level of interaction. The personal connection may be important for dementia caregivers, who often feel isolated by their experiences. It would also allow caregivers to ask additional questions and play a more active role in directing the learning process, an important principle in the self-directed learning theory. At the most sophisticated level, interactivity could involve an on-line "diagnostic" program. Caregivers could enter a query about a specific behavioral problem and receive "real time" feedback on possible actions to address the behavior.

Replication studies need to compare any interactive, multimedia web format with passive (brochure-style) web content and postal mail content. It is important to determine if the more dynamic format does make a difference. Over reliance on computer technology may be at the expense of useful educational content. The Internet "digital divide" that once separated the population by age and income is disappearing (SPRY Foundation, 2001; Thompson, 2000). As a broader cross section of people access information from the Internet, organizations are turning to this dissemination mechanism. Some organizational decisions may be financially motivated. For example, in fiscal year 1999, the national Alzheimer's Association spent $5.0 million printing and publishing education materials; postage and shipping of education materials added $2.7 million (Alzheimer's Association, 2000). Using the Internet to disseminate information has cost saving implications, but the effectiveness of the medium is equally important.

Research Methods

Based on the results of the dissertation research, replication studies need to continue for at least three months. Because home modifications (secondary appraisal) continue to increase at the time 3 assessment, it appears that caregivers need more time to evaluate information before they act. Perceptions of threat (primary appraisal) will not change until the secondary appraisal process is complete. Literature does not document a timeframe for the iterative relationship between primary and secondary appraisal. Therefore, the suggestion that studies continue for at least three months is a minimum recommendation.

It is desirable to increase the number of participants in future studies. Some results presented in Chapter 4 approach significance at the .05 level. A larger sample size could clarify the findings by increasing statistical power. As well, a larger sample should draw from a broader geographic area. A larger geographic base enhances external validity and generalizability of the results.

Caregiver intervention studies must be sensitive to study design. To obtain an experimental control group, some subjects cannot participate in the educational interventions. To move forward with research on distance education, future studies of distance education should use designs different from the Switching Replications model. The common design for didactic caregiver education involves a quasi-experimental design with a wait-list control group (Nichols, et. al., 2000).

Summary

Families are the backbone of the long-term care system in America (Noelker, 2001). Dementia is one of the leading reasons a patient might need help and assistance on a long-term basis. Dementing illnesses impair memory and higher cortical functions (such as abstract thinking and judgment), as well as the ability to complete activities of daily living on an independent basis. When a family member provides care to a person diagnosed with dementia, physical and emotional stress results (Yee & Schulz, 2000; Schulz & Beach, 1999; Schulz, et. al., 1995; Schulz, et. al., 1990). Over time, the stress and burden of caregiving tend to increase (Teel, et. al., 2001; Vetter, et. al., 1999; Vitaliano, et. al., 1991).

Despite the stress of caregiving, 70 percent of the people diagnosed with dementia receive care in the home setting (Alzheimer's Association, 2001a). Families provide most of the care, 72 percent, with no outside assistance (National Academy on an Aging Society, 2000b). Family members want to provide effective dementia care (Schumacher, et. al., 1998), but a study conducted for the Alzheimer's Association finds that information deficits make the job difficult (Roper Starch Worldwide, Inc., 2001). If a caregivers sees a situation as amenable to change (the process of secondary stress appraisal), the potential exists to reduce overall levels of stress (the process of primary appraisal).

Although education programs for dementia caregivers are helpful, most programs involve didactic experiences in resource intense environments (larger cities with medical schools) (Opie, et. al., 1999; Montgomery, 1996; Biegel, et. al., 1991; Toseland & Rossiter, 1989). The majority of caregivers do not attend such programs due to distance, transportation, or lack of time (Connell & Kole, 1999; Molinari, et. al., 1994). Distance education is a form of self-directed learning that has the potential to overcome some of the didactic program barriers.

The dissertation study compares three forms of distance education. Two forms involve the learner in a passive way (receipt of written material by postal mail or web site), while the third form uses multimedia, interactive Internet technology to provide the information. Results indicate these forms of education do not affect the primary stress appraisal process, but do affect secondary appraisal (as measured by home modifications). Active, multimedia presentation of the information is significantly different from postal mail, but not significantly different from passive web information. While several factors affect the validity of the dissertation results, the findings do point in important directions for future research.

Assuming no cure or effective treatment, projections indicate the number of people diagnosed with dementia will increase from the 2.3 million, to 8.6 million by 2040 (General Accounting Office, 1998). As the third most expensive illness in the United States, dementia costs more than $1.75 trillion (Moore, et. al., 2001; Ernst & Hay, 1994). Families are, and will likely remain, the primary caregivers for people who have dementia, despite the physical and emotional stress experienced. Given the magnitude of dementing illnesses, both in terms of people affected and cost, research on effective ways to help family caregivers in their role is important. It appears that distance education offers hope for the future.

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APPENDICES

APPENDIX A

Research Subject Information and Consent Form

TITLE: Distance Education for Dementia Caregivers: A Comparison of Three Methods

VCU IRB PROTOCOL NUMBER: 2268

SPONSOR: Iris Parham, Ph.D., and Mary Corrigan, M.A.

INVESTIGATORS: Iris Parham, Ph.D., and Mary Corrigan, M.A.

This consent form may contain words that you do not understand. Please ask the study investigator to explain any words or information that you do not clearly understand. You may be given or sent an unassigned copy of this consent form to think about or discuss with family or friends before making your decision.

PURPOSE OF THE STUDY:

The purpose of this research study is to test the effectiveness of three distance education methods for dementia caregivers. You are being asked to participate in this study because you are an individual who provides home-based care to an ambulatory (can walk) person with some type of dementia (memory impairing illness), and you have access to a computer with Internet capability.

DESCRIPTION OF THE STUDY:

The study will involve a comparison of three methods of distance education: a brochure delivered by postal mail, and two forms of computer based education. The specific education content is designed to help caregivers manage the home-based care of individuals with dementia. Your participation in this study will last 3 months. Approximately 186 individuals will participate in this study.

PROCEDURES:

If you decide to be in this research study, you will be asked to sign this consent form after you have had all your questions answered. Your first study contact involves completion of an on-line (Internet) based assessment that will ask questions about the type of dementia-related behaviors you must address as a caregiver, and your reaction to those behaviors. You will also be asked a few background questions, such as your email address, date of birth, gender, and relationship with the person to whom you provide care. It is estimated that completion of the initial assessment will take 30 to 60 minutes.

Following the initial assessment, you will either be assigned to one of three education formats, or to a wait list control group. If you are in one of the three education groups, you will be asked to access and read the information content within 48 hours of assignment. The educational content will take approximately 15 to 30 minutes of your time. If you are in the wait list control group, your assignment to an education group will be delayed by 30 days.

Thirty days later you will be contacted by email and asked to complete a second on-line (Internet) assessment. It will ask questions similar to the first assessment. It is estimated that completion will take 30 to 60 minutes of your time. After the second assessment, the wait list control group will be assigned to one of the education formats, and asked to access the educational content within 48 hours.

The last study contact will occur after another 30-day time period has passed. It will also involve completion of an on-line (Internet) assessment that will take 30 to 60 minutes. Completion of the third on-line assessment marks the end of your participation in the study.

STUDY RISKS:

Participation in this study would have nominal risks for you. It is possible that following the education content, you will modify some aspect of your home-based care. The modification might not help address the dementia-related behaviors you deal with on a regular basis. This could increase your level of caregiver frustration.

Participants who are assigned to one of the computer education interventions may need to download a program called Real Media Player. The download is free and instructions will guide you through the process. There is a remote chance that participants could have trouble with the downloading procedure, resulting in frustration.

BENEFITS:

Participants will be exposed to educational information that may help with the home-based care of an individual with dementia. However, there is no guarantee that you will receive any benefit from participating in this study.

COSTS:

There are no costs or charges for participation in the study

CONFIDENTIALITY:

The study investigators will confidentially hold information you provide. Information you provide will never be released on an individual basis. Information from all study participants will be pooled and summarized for statistical research purposes. It will not be possible to identify any individual participant because of the statistical analysis.

Aggregate results from the study may be presented in written articles or at professional meetings. Again, your identity will not be disclosed in any way.

COMPENSATION FOR INJURY:

Virginia Commonwealth University and the VCU Health System have no plan for providing long-term care of compensation in the event you suffer injury because of your participation in this study. As noted previously, the risk of any harm is minimal.

VOLUNTARY PARTICIPATION AND WITHDRAWAL:

Your participation in this study is voluntary. You may decide not to participate in this study. If you do participate you may freely withdraw from the study at any time.

QUESTIONS:

In the future, you may have questions about your study participation. If you have any questions, you may contact:

Mary Corrigan
Gerontology Program
Wichita State University
University
Phone: [redacted]

Iris Parham, Ph.D.
Gerontology Department
Virginia Commonwealth
Phone: [redacted]

If you have questions about your rights as a research subject, you may contact:

Office for Research Subjects Protection
Virginia Commonwealth University
[redacted]
Telephone: [redacted]

Do not sign this consent form unless you have had a chance to ask questions and received satisfactory answers to all your questions.

CONSENT:

I have read this consent form. I understand the information about his study. All my questions about the study and my participation in it have been answered. I freely consent to participate in this research study.

I understand that I will receive a signed and dated copy of this consent form for my records.

By signing the consent form I have not waived any of the legal rights which I otherwise would have as a participant in a research study.

____
Participant Name – please print

Participant Signature Date

Signature of Person Conducting Informed Consent Discussion Date

Investigator Signature (if different from above) Date

APPENDIX B

Justifications for Education Focus on Wandering

Wandering is a tendency to move about in a seemingly aimless or disoriented fashion in pursuit of an indefinable or unobtainable goal (Coltharp, et. al., 1996). It can involve inefficient travel (lapping or walking in a repetitive path), pacing (repetitive back and forth walking), random travel (haphazard walking to several points without repetition), and modeling (following other individuals) (Algase, Kupperschmid, Beel-Bates, & Beattie, 1997; Coltharp, et. al., 1996). Estimates of wandering behavior range from a low of 19 percent in a British study (Burns, et. al., 1990), to 56.9 percent of Alzheimer's Disease victims over a two year period (Devanand, et. al., 1997), to 65 percent (Logsdon, et. al., 1998).

The behavior is most common during the middle stages of dementia when three different parts of the brain are affected (Morgan & Steward, 1997; Ryan, 1995; Burns, et. al., 1990; Henderson, et. al., 1989). The hippocampus, located in the limbic system, is involved with short-term memory. The frontal lobe of the brain is involved with executive control, decision making, and judgement. The parietal lobe helps individuals make sense of the things seen around them (spatial orientation). The individual with dementia cannot control damage occurring in these areas. Therefore, they are not able to control the urge to wander. For these reasons, wandering meets the Elliot and Eisdorfer (1982) definition of an activator, and the Cohen, et. al., (1995) definition of an environmental demand. It is a difficult behavior, shown to increase caregiver stress (Logsdon, et. al., 2000).

Individuals who wander are at risk for becoming lost in the community and injured. Though not specific to the problem of wandering, Oleske, Wilson, Bernard, Evans, and Terman (1995) identified a high rate of injury, 58.4 injuries per 100, among people with Alzheimer's Disease over the course of one year. Bowen, Malter, Sheppard, Kukull, McCormick, Teri, & Larson (1996) found wandering to be one of eight factors that increased mortality rates among Alzheimer's Disease victims. The other factors included increased age, male gender, impaired status on Mini-Mental Status Exam (MMSE), rate of decline in MMSE, agitation, vascular disease, and sensory impairment. Ryan (1995) found wanderers three times more likely to sustain a hip injury, compared to non-demented elders. Although participants in the Logsdon, et. al., (1998) study were not found to have an increased likelihood of falls and hip fractures, wandering was a major reason families decided to terminate home care and seek institutional/nursing home services. Wandering behaviors and getting lost increased the risk of institutionalization by a factor of two (Kaspar & Shore, 1994).

There are many things caregivers can do to manage wandering behaviors in the home setting. The actions include communication strategies, daily routine modifications, and home safety modifications (Bakke, 1997; Holmberg, 1997; Maddox & Burns, 1997; Morgan & Steward, 1997; Begany, 1996; Glaser, 1996; Dickinson, et. al., 1995; Richter, et. al., 1995; Edwards, 1994). A full review of the strategies in each classification is beyond the scope and purpose of this document. However, the breadth of suggestions available illustrates the concern regarding the potential impact of the educational message on the assessment of the effectiveness of the three forms of distance education. It argues for the need to tailor the educational message to one area and present very specific suggestions to the study participants. Accordingly, a decision was made to focus the content of the education on home safety enhancements that could be implemented to reduce unsafe wandering behaviors. A copy of the written content, which will serve for both the mailed brochure and the passive web intervention, is contained in Appendix C. The content in the active web intervention is available through the following Internet address: http://128.172.185.61/Dementia.

APPENDIX C

Content and Layout of Postal Brochure and the Passive Web Site

Wandering and Dementia: What's a Family to Do?

"Where did he go? I only left for a moment. Now the door is open and he is gone."

"I don't understand. Why can't your mother just sit still and watch television with me? She's going to wear a hole in the carpet with all her pacing."

"Yes, officer. I know she was trying to 'go home.' But we've lived in this house for 35 years."

Sound familiar?

People with dementia often wander. For families providing home care, wandering is a "difficult" or "problem" behavior. It increases the stress of caregiving.

Why Does Wandering Occur?

There are two answers.

It sounds strange, but wandering serves a purpose. A person who is afraid wanders to "get away." Scary stories on television may seem real to a person with dementia. Inactivity and restlessness cause wandering. Even "aimless" walking is self-stimulating. Wandering can be a way to achieve some "goal." Following family members around prevents loneliness. Trying to "go home" is a search for comfort and security.

Wandering occurs when dementia damages three sections of the brain:

- a center area where short-term memories are made,
- the front part used when we make decisions, and
- a side portion that helps us make sense of things we see around us.

Damage in these areas is common during the middle stages of dementia.

What's A Family To Do About Wandering?

The individual with dementia cannot stop the damage in the brain. Therefore, they can't stop the urge to wander. "Just say don't" strategies are not effective. Family members need proactive ways to manage wandering.

It is important to remember that not all wandering is bad. It does serve a purpose. It is exercise that increases blood flow, breathing, and muscle tone. Wandering is "bad" when the individual leaves the home and gets lost in the community. They may fall and get hurt, or come in contact with criminals.

There are many things a family can do to improve safety of the home and prevent "bad" wandering.

Taking action to make doors more secure is vital.

- Place locks very high or low on the door; avoid eye level.
- Don't leave keys in locks or near doors.
- "Hide" doorknobs. Put two Velcro strips above the doorknob and on a bit of fabric. Attach the material to the door and the knob disappears.
- Make a stop sign out of red construction paper. Tape it to the door.
- String bells on a ribbon and hang at the top of a door. The jingling lets you know if the door is opened.
- Make doorknobs harder to twist and open using knob covers. They can be found at most hardware stores.
- Divert attention from unsafe areas. Create a "wall" using a portable safety gate covered with fabric.
- Use the Yellow Pages to find security companies and price more sophisticated door alarm systems.

Simple modifications inside the home reduce the risk for harm when wandering occurs.

- Keep rooms well lit and free of clutter to minimize falls.
- Arrange furniture so there is room to safely wander through the house.
- Avoid throw rugs. They increase the risk for falls.
- Tape labels and pictures to doors. "Aimless" wandering may really be a search for a specific place like the bathroom.
- If nighttime wandering is a problem, keep rooms and hallways lit with nightlights and reflective strips.
- Install locks on windows. Some people with dementia do leave the home by climbing out.
- Safety latches on cabinets help prevent contact with unsafe household cleaners.

Carefully check out the backyard and any outdoor storage areas.

- Gates must be locked.
- Fences should be high and in good repair.
- Remove clutter and fill in holes to prevent falls.

No single strategy can manage all wandering problems. Families need to make as many safety changes as possible. Even in the safest home, there is still a potential for "bad" wandering. A final suggestion is to enroll the person in the Safe Return program. Sponsored the Alzheimer's Association, Safe Return maintains information about the individual. It provides identification bracelets and tags for clothing. This is useful to police in the event a search is need. To enroll a family member, cal [redacted] There is a one-time $40 fee.

Summary

Wandering is a difficult behavior for many caregivers. It sometimes leads to nursing home placement. Home safety plans do help cope better.

APPENDIX D

Web Site Design Recommendations

The web site materials meet recommendations set forth by the Office of Communication at the National Institutes on Health (Koyani, 2001; National Cancer Institute, 2001).

- Design considerations: Automate sites to the greatest extent possible. Do not use split frames as they can cause confusion.
- Content and organization: Sentences and paragraphs are short. The national recommendation is for sentences to contain 20 or fewer words, and paragraphs, fewer than 5 sentences. Use lists to break up long sentences.
- Titles and headings: Each web page should have a descriptive and different title that relates to the information.
- Page length: Home and navigation pages are short (defined as those containing one or two screens of text). For "destination" content that the user might want to print, use longer pages. There is an 80-20 rule, with 80 percent of the users time spent on the first full screen and the remaining 20 percent on the remainder of the page.
- Page layout: Align information vertically and horizontally. Logos, recurring text, buttons, and graphics are in consistent positions on all pages. Minimize unused space; "density" pages (filled screen) allow faster scanning without affecting accuracy, according to national studies. Use white space to separate paragraphs and ideas.
- Font and text size: Font size is at least 12 point; this is important for any sites accessed by people age 65 and older. Serif or sans serif font are used, but are not mixed. Times Roman is an acceptable style, along with Georgia, Helvetica, and Verdana.
- Links: Use blue color and underlining for unused links; the link should change color after use. "Click here" markers have been found to be useful, and are incorporated in the site. Make all links using text, not images or graphics. This is especially important as some users deactivate graphical browsers.
- Graphics: Graphics are minimal and small; this reduces download time.
- Navigation: Use the same navigation scheme on all pages. The site's main index is on the right margin; users click more efficiently on the right side.
- Software and hardware: Design is for a 56 kilobyte per second (kbps) or slower connection speed. This means it will take at least 8 seconds to download 30,000 bytes, 13 seconds to download 40,000 bytes, and 16 seconds for 50,000 bytes. Timing is important as users lose interest if it takes longer than 15 seconds for a

page to download. Design is for a 17-inch monitor with screen resolutions of 800 by 600 pixels.

- Accessibility: Text and graphics are understandable when viewed without color. The background is light (off-white) and text is dark (black).

APPENDIX E

Agitated Behavior in Dementia (ABID) Scale

NOTE: On-line format uses drop boxes.

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

Behavior Frequency Rating:	**Caregiver Reaction Rating:**
0 = did not occur in the week	0 = not at all
1 = occurred 1 to 2 times in the week	1 = a little
2 = occurred 3 to 6 times in the week	2 = moderately
3 = occurred daily or more often	3 = very much
9 = don't know/not applicable	4 = extremely
	9 = don't know/not applicable

Please answer all questions below. Check on box from 0-9 for both **Behavior Frequency** and **Caregiver Reaction**.

Week 1 refers to the past week; Week 2 refers to the week before last

Frequency	Caregiver Reaction	
Week 1 ☐ ☐ ☐ ☐ ☐ 0 1 2 3 9 Week 2 ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐ 0 1 2 3 4 9	1. Verbally threatening or aggressive toward others
Week 1 ☐ ☐ ☐ ☐ ☐ 0 1 2 3 9 Week 2 ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐ 0 1 2 3 4 9	2. Physically threatening or aggressive toward others
Week 1 ☐ ☐ ☐ ☐ ☐ 0 1 2 3 9 Week 2 ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐ 0 1 2 3 4 9	3. Harmful to self (e.g., biting, pinching self)

Week 1 ☐ ☐ ☐ ☐ ☐ 0 1 2 3 9 Week 2 ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐ 0 1 2 3 4 9	4. Inappropriate screaming or crying out
Week 1 ☐ ☐ ☐ ☐ ☐ 0 1 2 3 9 Week 2 ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐ 0 1 2 3 4 9	5. Destroying property
Week 1 ☐ ☐ ☐ ☐ ☐ 0 1 2 3 9 Week 2 ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐ 0 1 2 3 4 9	6. Refusing to accept appropriate help (e.g., with personal care)
Week 1 ☐ ☐ ☐ ☐ ☐ 0 1 2 3 9 Week 2 ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐ 0 1 2 3 4 9	7. Trying to leave (or leaving) home inappropriately
Week 1 ☐ ☐ ☐ ☐ ☐ 0 1 2 3 9 Week 2 ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐ 0 1 2 3 4 9	8. Arguing, irritability, or complaining
Week 1 ☐ ☐ ☐ ☐ ☐ 0 1 2 3 9 Week 2 ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐ 0 1 2 3 4 9	9. Socially inappropriate behavior (e.g., loud, offensive remarks)
Week 1 ☐ ☐ ☐ ☐ ☐ 0 1 2 3 9 Week 2 ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐ 0 1 2 3 4 9	10. Inappropriate sexual behavior (e.g., unwanted advances)
Week 1 ☐ ☐ ☐ ☐ ☐ 0 1 2 3 9 Week 2 ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐ 0 1 2 3 4 9	11. Restlessness, fidgetiness, inability to sit still
Week 1 ☐ ☐ ☐ ☐ ☐ 0 1 2 3 9 Week 2 ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐ 0 1 2 3 4 9	12. Worrying, anxiety, and/or fearfulness
Week 1 ☐ ☐ ☐ ☐ ☐ 0 1 2 3 9 Week 2 ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐ 0 1 2 3 4 9	13. Easily agitated or upset
Week 1 ☐ ☐ ☐ ☐ ☐ 0 1 2 3 9 Week 2 ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐ 0 1 2 3 4 9	14. Waking and getting up at night (other than trip to bathroom)

Week 1 ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐	15. Incorrect, distressing belief (e.g., being threatened or harmed by others – delusions
0 1 2 3 9	0 1 2 3 4 9	
Week 2 ☐ ☐ ☐ ☐ ☐		
Week 1 ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐	16. See, hear or sense distressing people/things that are not really present
0 1 2 3 9	0 1 2 3 4 9	
Week 2 ☐ ☐ ☐ ☐ ☐		

APPENDIX F

Participant Background Questions

Instructions: Please answer each of the following questions by typing your answer in the box provided or checking the appropriate options box.

1. Age (years as of last birthday)
2. Gender ☐ Male ☐ Female
3. Relationship
   ☐ Spouse ☐ Adult Child ☐ Grandchild ☐ Other relative ☐ Friend
4. Education (highest grade level)
5. Length of Caregiving (number of years total)
6. Ethnic Identification
   ☐ African American ☐ Asian ☐ Hispanic ☐ Native American Indian
   ☐ Caucasian
7. Paid Assistance (number of hours per week, if any, of outside/paid help)
8. Internet Experience (number of years of experience using the Internet)
9. Comfort Level with Internet
   ☐ Very high ☐ High ☐ Moderate ☐ Low ☐ Very low
10. Access Problems: If you encountered any problems using the Internet during the course of this study, please describe in the box below.

APPENDIX G

Email Communications with Study Participants

Step 1

After completion of the Informed Consent document, participants received the following message by email.

Dear ___,

I have received your signed Informed Consent document and I thank you for your interest in and willingness to participate in my dissertation study on distance education and dementia caregivers. I would again assure you that any information you share during the course of this study is confidential. Further, I would remind you that you always have the right to refuse to answer any questions and the right to withdraw from the study at any time.

To begin the study, I would ask that you go to the following web site:http://128.172.185.61/Dementia/

At this site, click on Item #1. A security box will appear. Where the box asks for "user name," input the following information: abid1. (The last item is the number 1, not the letter L). Where the box asks for "password," input the following information: 6732. Then click on the continue button. Having done this will take you to an online questionnaire that provides me with baseline information for the study.

If you are familiar with the computer technology of "drop down boxes," completion of the questionnaire may take as little as 10 to 15 minutes. Instructions in the questionnaire will tell you how to use the "drop down boxes" if you are not familiar with them. After you have completed the online survey (results of which are automatically sent to my email address), I will send you information on how to access an educational piece via the Internet.

Again, thank you for your interest and willingness to participate in my study. If you have questions, please do email me at any time [redacted].

Sincerely,
Mary Corrigan

Step 2

Within 12 hours of completing the baseline assessment, participants received one of the following email messages.

Dear ____,

Thank you for taking the first step in my dissertation study by completing the initial baseline assessment. The next step is to access the following education information. Go to the following URL: http://128.172.185.61/Dementia/

Click on item #4. When the security box appears type in the following information: User name = passive and Password = 5345. Directions inside the item #4 site will guide you the rest of the way.

If you have any questions or encounter any problems, please contact me at [redacted] In 30 days, I will be in contact again for the second caregiver assessment.

Again, thank you for participating in this study
Sincerely,
Mary Corrigan

Dear ____,

Thank you for taking the first step in my dissertation study by completing the initial baseline assessment. The next step is to access the following education information. Go to the following URL: http://128.172.185.61/Dementia/

Click on item #5. When the security box appears type in the following information: User name = active and Password = 6543. Directions inside the item #4 site will guide you the rest of the way.

If you have any questions or encounter any problems, please contact me at [redacted] In 30 days, I will be in contact again for the second caregiver assessment.

Again, thank you for participating in this study
Sincerely,
Mary Corrigan

Dear ____,

Thank you for taking the first step in my dissertation study by completing the initial baseline assessment. The next step is to review some information that you will receive by postal mail. Assuming normal mail delivery, you should receive the material in 2 to 3 days.

If you have any questions or encounter any problems, please contact me at [redacted] In 30 days, I will be in contact again for the second caregiver assessment.

Again, thank you for participating in this study
Sincerely,
Mary Corrigan

Step 3

After 30 days had passed, participants received the following email message, directing them to the site for collection of the time 2 data.

Dear _____,

It has been one month since you answered the first questionnaire for my study of distance education and dementia caregiving. I now need to ask you to complete a second, on-line assessment. Go to the following web site: http://128.172.185.61/Dementia/

At this site, click on Item #2. A security box will appear. Where the box asks for "user name," input the following information: abid2. Where the box asks for "password," input the following information: 8456. Then click on the okay button. Having done this will take you to the second online questionnaire.

Again, thank you for your interest and willingness to participate in my study. If you have questions, please do email me at any time

[redacted]

Sincerely,
Mary Corrigan

Step 4

After 30 more days, participants received the final email message of the study directing them to the site for collection of the time 3 data.

Dear _____,

It has been one month since you answered the second questionnaire for my study of distance education and dementia caregiving. I now need to ask you to complete the final on-line assessment. Go to the following web site: http://128.172.185.61/Dementia/

At this site, click on Item #3. A security box will appear. Where the box asks for "user name," input the following information: abid3. Where the box asks for "password," input the following information: 3245. Then click on the okay button. Having done this will take you to the final online questionnaire.

Again, thank you for your interest and willingness to participate in my study. If you have questions, please do email me at any time

[redacted]

Sincerely,
Mary Corrigan

Vita

[redacted]