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# Increasing Self-care Activities for Caregivers of Persons with Alzheimer's Disease and Other Dementias to Reduce Burden and Depression

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Capstone Paper

Increasing self-care activities for caregivers of persons with Alzheimer's disease  
and other dementias to reduce burden and depression

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### **Abstract**

Caregivers in the United States are a rapidly growing segment of the system of care for those with Alzheimer's disease and other dementias. Lack of training and support puts them at risk of depression, anxiety and failure to take care of their own healthcare needs. Different interventions with caregivers have been studied in both randomized controlled and non-randomized studies and many tools are available to assess burden of care and the effectiveness of interventions to reduce the negative consequence of the experience. Results are inconclusive and numerous studies have found that minimal evidence exists to support any one model of intervention. There is however consensus that the needs of caregivers are not currently being met. The purpose of this capstone project was to address those needs by developing a structured support group focused on psycho education, self-care and an introduction to complementary medicine. The goal was to reduce burden and depression and increase self-care by providing participants with information and tools to assist in their role as caregivers. The results indicate that support group provides emotional support, information and problem solving skills for caregivers but does not necessarily reduce burden or depression or increase self-care. The meaningful significance of this intervention is reflected in the satisfaction survey completed by participants.

Selected validated tools did not yield results that were reliable due to: partially completed forms; resistance to completing forms; confusion on the part of participants as to how to complete forms leading to errors; some only completing the pre or post test but not both. Future efforts should consider qualitative methods like storytelling and pre and post interviews. Although the tools did not provided useful data the intervention was well attended and satisfaction surveys revealed that for almost all of the attendees the group provided them with

important information, tools and support both from the leaders and from each other. Further research is needed to clearly understand the needs and determine effective interventions for our rapidly aging population and diminishing number of caregivers. Nurses are in a pivotal position to implement and evaluate evidence-based interventions for Alzheimer's disease and other dementias.

### **Introduction**

Caregivers in the United States are a rapidly growing segment of the system of care with close to 11 million providing care for those with Alzheimer's disease and other dementias (Levine, Helper, Peist, & Gould, 2010). Lack of training and support puts them at risk of depression, anxiety, and failure to take care of their own healthcare needs (Wallis, 2011). Caregivers in the U. S. are predominantly women. They provide 75%-80% of long-term care and face many challenges that create both physical and psychological stress as they are increasingly expected to provide more demanding and complex care including medication management (Levine, Helper, Peist, & Gould, 2010). The cost of unpaid care for AD represents 42% of the total costs of the disease (World Alzheimer Report, 2010).

The global prevalence of AD is expected to double in the next 20 years increasing the need for caregivers (Ferri, Prince, Brayne, Broday, Fratiglioni, Ganguli, --- Scazufca, 2005). Alzheimer's disease currently receives a lot of attention but little funding in comparison to spending for Heart research and Cancer research at 15 times and 30 times respectively of that for AD research (The World Alzheimer's Report, 2010). Recently President Obama signed the National Alzheimer's Project Act (NAPA) into law creating a national plan to coordinate efforts to address the crisis of Alzheimer's disease epidemic through research and support with over 150 million devoted to the effort.

We can no longer ignore the growing incidence and prevalence, the enormous burden on caregivers and the financial burden of Alzheimer's disease on families and society. Addressing the needs of caregivers is an increasingly important public health agenda that requires attention to address the complexity of issues that negatively affect caregivers and their loved ones (<http://www.healthypeople2020>).

### **Problem statement**

Risk of physical and psychological disorders among caregivers of those with Alzheimer's disease (AD) or other dementias, indicated by depression, anxiety, and reported burden is caused by lack of time for self-care, inadequate supportive services, burden of providing care and lack of respite services to relieve caregivers of their duties (Chu, Yang, Liao, Chang, Lin and Chou et. al., 2011; Gaugler, Roth, Haley, & Mittelman, 2008; Koerner & Kenyon, 2007; Lavretsky, Siddarth & Irwin, 2010; Martin-Carrasco, Martin, Valero, Millan, Garcia, Montalban & Vilano, 2009). This is mediated by individual resilience and access to services including: respite-care to allow for self-care; support group; psychotherapy; psychopharmacology; yoga; and other complementary care services (Pinquart & Sorensen, 2006; Sorensen, Pinquart & Duberstein, 2002; Thompson, Spilsbury, Hall, Birks, Barnes & Adamson, 2007). Knowledge about the progression of the disease, healthy life styles, social engagement, diet, exercise, and keeping active moderate the causes of the stress of providing twenty-four hour care for a loved one diagnosed with AD or other dementia (Carbonneau, Chantel, & Desrosiers, 2011; Chu et al., 2011; Elliot, Burgio & DeCoster, 2010; Lu & Wykle, 2007; Martin-Carrasco et al., 2009; Raingruber & Robinson, 2007).



### **Needs assessment**

Martha's Vineyard's year round census is 15,974 of which 16.6 percent or 2,652 are 65 or older (<http://www.quickfacts.com>). The prevalence of Alzheimer's disease is estimated to be 13% of those over 65 and 40% of those over 85 (Alzheimer's Association Annual Report, 2011). The 2010 census reports that close to 17 % of the island residents are over 65 and 34% are over 55 (U. S. Census, 2010). The population is projected to increase for the six towns on Martha's Vineyard between just under 75% to just over 225% from 2000-2020 as compared to Massachusetts projection of just over 35 percent.

Martha's Vineyard is designated as a rural health area and suffers from inadequate primary care, specialty care and supportive services. The Islands four Councils on Aging have identified supporting caregivers as a priority component of their mission. Elder services are also a priority of the Island's County Health Care Council and elder issues were designated as a priority project for the University of Massachusetts Rural Scholars program hosted on Martha's Vineyard in the fall of 2011. The Island departments of public health have also identified hoarding among elders, often associated with dementia, as a priority problem and a task force was formed to address this issue. All of the programs on Island supporting elders, Island Elderly Housing, Supportive Day Program, Counseling and Outreach Services to name a few, are reporting being at capacity with waiting lists for services.

### **Goals, Objectives and Outcome measures**

The goal of this project was to reduce burden and depression and improve self-care of caregivers. This intervention provided support and education for those caring for a loved one with AD, introducing them to complementary medicine and encouraging them to improve self-care by increasing self-care activities (Elliott, Burgio, & DeCoster, 2010; Sorenson, Pinquart, &

Duberstein, 2002). Although not a direct goal of this intervention it is reported that interventions with caregivers may also benefit the care receivers who dependent on them for care (Elliott, Burgio, & DeCoster, 2010; Sorenson, Pinquart, & Duberstein, 2002). Specifically addressing self care included; increasing caregiver's self-care activities through education; identifying opportunities for self-care; encouraging time out from care giving to improve mental health; introducing complementary services (Yoga and Reiki); and offering relaxation and stress reduction. Further objectives included increasing positive aspects and reducing negative aspects of care giving through education on strategies to manage care receiver behaviors; decrease depression and isolation through psycho educational support group services and identification of other community supports for care givers.

The target group for this intervention was the members of the four Councils on Aging (COA) of Martha's Vineyard who are identified as spousal or partner caregivers of someone with Alzheimer's disease or other dementias and those identified by primary care physicians, visiting nurses, nurse practitioners and other community providers.

### **Literature Review**

There are many definitions of dementia but the essence of this primary disease is the loss of multiple components of cognitive functioning, thinking, remembering, and reasoning and the resultant interference in the lives of the person's with dementia and the lives of those who care for them (Alzheimer's organization <http://www.alz.org>; World Health organization <http://www.seao.who.int>). Caring for a loved one with Alzheimer's disease affects caregivers in negative ways. This literature review will explore multiple aspects of the impact of the caring giving role in the following order; depression, sleep deprivation and feelings of burden; how the negative aspects of their role impact their own health status; strategies and tools to assist in

managing leisure activities; complementary medicine resources; dealing with behavior problems of care receivers; lessening stress; improving functional abilities; anticipating future needs for support or institutionalization; assessment tools to measure burden, depression and self-care; and change models that look at readiness to make changes.

Identifying interventions that effectively increase positive aspects of caregiving (feeling good and finding meaning in providing care) and reduce negative aspects of caregiving (burden, depression, anxiety and burnout) has been the goal of many research studies (Carbonneau, Chantel, & Desrosiers, 2001; Chu et al., 2011; Gaugler, Roth, Haley, & Mittelman, 2008, Lavretsky, Siddarth, & Irwin, 2010; Martin-Carrasco et al., 2009; Puymbroeck, Payne, & Hsieh, 2007; Raingruber & Robinson, 2007; Rowe, Kairalla, & McCrae, 2010; Sherwood et al., 2007; Willette-Murphy, Toderro, & Yeaworth, 2006. These and others will be discussed. Giovannetti and Wolff (2010) address important policy issues in an attempt to determine the number of family caregivers by reviewing population-based surveys over the course of 25 years. They advocate for greater consistency in defining caregivers as future estimates show an increasing number of care receivers with a decreasing number of those available to provide the care. The authors emphasize the need to understand the impact of population-based survey design methods and how they affect estimates for this specific population. The authors challenge policy makers to prioritize developing a comprehensive and consistent approach to monitoring and supporting older disabled adults and their families.

The Centers for Disease Control and Prevention developed a caregiver module to be added to the Behavioral Risk Factor Surveillance System so that for the first time caregiver data will be collected on a statewide basis (Talley & Crews, 2007). States can now determine the number

and the needs of caregivers in their jurisdiction. This is a good first step but more is needed going forward.

### **Caregiving and depression**

Depression is a common caregiver complaint and research specific to the incidence among caregivers is inconsistent and effectiveness of interventions has mixed results. While much is known in the field of psychiatry about depression and effective treatment for this common disorder, less is known when it applies to caregivers. Experts in the field report that little is known about the effectiveness of caregiver interventions or their mediating process when it comes to symptoms of depression (Roth, Mittelman, Clay, Madan, Haley, 2005). MetLife reports that 20% of working female caregivers over the age of 50 experience depression as compared to 8% of peers who are not caregivers (National Alliance for caregiving, MetLife Mature Market Institute, 2010). Depression among caregivers is well documented with one author reporting clinically significant depression in 40%-70% of caregivers with somewhere between 25%-50% of those meeting DSM IV-TR criteria for major depression (Zarit, 2006). Marriott, Donaldson, Tarrier & Burns (2000) designed a prospective, single-blind randomized controlled trial with a three month follow-up to determine the effect of a family intervention for those with a family member with Alzheimer's disease. The intervention consisted of education, stress management and coping skills training. Based on a pre-test and post-test model they applied two self report measures; the General Health Questionnaire (Goldberg & Williams, 1989); and the Beck Depression Inventory (Beck, 1988). Their results showed a significant reduction in distress and depression for those in the intervention group based on a cognitive-behavioral family intervention model as well as a positive impact on modifying patient's

behaviors. Unfortunately the intervention was lengthy and requires special training for the interventionist.

A Support group was found to reduce caregiver's depression but did not have an effect on burden of care (Chu et al., 2011). In one study spouses of persons with AD (n= 406) were randomly assigned to support and counseling comprised of six counseling sessions followed by support group or a control group who received routine care (Mittelman, Roth, Coon and Haley, 2004). Applying the Beck depression scale pre and post for all participants their results show significantly fewer symptoms of depression in the intervention group that were evident for 3.1 years post intervention. Thompson et al., (2007) concurred with this finding: support groups provide emotional support, information and problem-solving skills to caregivers but do not reduce caregiver burden. In a later publication using results from their earlier randomized trial Mittelman, Roth, Clay & Haley, (2007) conclude that additional studies of psychosocial interventions for caregivers are warranted and should incorporate biological measures of physical health outcomes.

In an effort to address depression among caregivers of family members with dementia, the majority of whom are women and elderly, Lavretsky, Siddarth & Irwin, (2010) developed the first randomized placebo-controlled double-blind trial of the use of an antidepressant to reduce depression and improve resilience and quality of life. The researchers report a positive effect of the antidepressant over the placebo with 86% of caregivers in the intervention group reporting remission as compared to 44% in the control group. These findings are limited due to the small sample size (N= 40). The authors report reduced anxiety, improved resilience, and decreased burden and stress among caregivers and that the level of depression and burden correlate to the severity of the care receiver's dementia, related disability and behavioral problems (Lavretsky et

al., 2010). Eliot et al., (2010) found that depression serves a mediating function between the health of care givers and their experience of burden. They further noted that those most at risk for depressive symptoms when in the caregiver role are young adult caregivers and females.

A study that focused on caregiver mastery and its influence on depressive symptoms using a telephone interview tool to examine the physical and emotional well being of caregivers (n=95) sought to answer the question: Does caregiver mastery moderate or mediate caregiver's level of depression (Sherwood et al., 2007)? Applying multiple regression analysis they found care recipients problem behaviors ( $p < .01$ ) and caregiver mastery ( $p < .01$ ) were predictive of caregiver depressive symptoms, however on the second stepwise regression the prediction held but the interaction was not significant (Sherwood et al., 2007). They report no evidence of a moderating role of caregiver mastery. Further statistical analysis to test for mediation found partial mediation that indicated care recipients problem behaviors affected caregiver's symptoms of depression and lowered caregiver's mastery. Age and gender of the caregiver along with behavior problems of the care receiver predicted caregiver depression but relationship between caregiver's depressive symptoms and care recipients problem behaviors were not affected by caregiver mastery (Sherwood et al., 2007).

Others cite that caregiver depression is known to mediate the relationship between caregiver health and caregiver burden (Elliott et al., 2010). Care receivers problem behaviors were identified as the strongest and most consistent predictors of distress for caregivers (Pinquart & Sorensen, 2004). The report from The National Institute of Health REACH II study showed that although caregivers do not usually meet criteria for clinical depression they nonetheless experience depressive symptoms (Schultz et al., 2003).

Depression was the most widely studied outcome of the known health consequences of being a caregiver for someone with Alzheimer's disease (Gottlieb, Thompson and Bourgeois, 2000). A later study on caregiver burden and depression explored the impact of providing a 12-week structured support group to Taiwanese caregivers of those with dementia (n=85) and determined that depression reported in the experimental group was decreased after the intervention and remained decreased at a one month follow-up (Chu et al., 2011). Similar to findings of their American Colleagues who report that support groups have a significant impact on depression but no affect on caregiver burden (Chu et al., 2011; Elliott, Burgio, & DeCoster, 2010; Sorensen, Pinquart, & Duberstein, 2002). In an analysis of 44 studies, only group interventions based on psycho educational theory had a positive effect on depression of caregivers (Thompson et al., 2007). This warrants further study.

In addition to depression, sleep disturbances among caregivers have been studied. The interrelationship between sleep and depression requires further attention as we seek to improve caregiver's lives on a day to day basis.

### **Caregiving and sleep disturbances**

Sleep deprivation is known to contribute to caregiver burden and its health-related sequelae. Two recent studies explore issues of sleep deprivation, one focused on the impact on the mental health of caregivers (Willette-Murphy et al., 2006) and the other addressed the intervention of a night time monitoring system to improve sleep of caregivers who are worried about night time wandering or restlessness of their loved ones (Rowe, Kairalla, & McCrae, 2010).

A descriptive study to measure patient behavioral problems, burden of care and sleep problems used a convenience sample of wife caregivers of spouses with dementia (n=37) and a

matched control, applying standardized scales to measure memory, behavior problems, burden, sleep and mental health. Caregiver's scores indicated that they experienced more anxiety and depression, and less feelings of belonging with the authors reporting that caregivers have mental health issues and poorer sleep. They further conclude that the mental health of caregiver wives can be predicted from both their appraisal of burden of caregiving and perception of sleep, with sleep disturbances a commonly known symptom of depression (Willette-Murphy et al., 2006).

The findings of a controlled clinical study that followed dementia caregivers (n=49) for up to one year measuring the effect of care recipient monitoring systems on the sleep of caregivers indicated no difference between the groups leading them to conclude that sleep problems were being caused by other issues than the one being studied (Rowe et al. 2010).

### **Caregiver Burden**

The concept of caregiver burden is the focus of many studies (Chu et al., 2011; Lai & Thompson, 2011; Martin-Carrasco et al., 2009; Wimo, Von Strauss, Nordberg, Sassi, Johansson, 2002). In a multicenter, prospective, randomized study conducted in 11 hospital and non-hospital psychiatric outpatient clinics in Southern Europe (N=115) the treatment group participated in eight sessions over four months that focused on learning strategies for managing AD patient care with data collected for caregiver's stress, quality of life and perceived health to determine their impact on caregiver burden. This intervention was found to minimize caregiver burden as measured on the Zarit scale (Zarit, Reever, & Bach-Peterson, 1980) and assist with developing problem solving skills (Martin-Carrasco et al., 2009).

A study using a random sample of family caregivers (n=340) concluded that perceived adequacy of support services predicts family burden (Lai & Thompson, 2011). Their findings include the concept of first providing tangible services and resources to caregivers of elders with



emotional support showing marginal benefits. Others concurred with this finding, support groups provide emotional support, information and problem-solving skills to caregivers but do not reduce caregiver burden (Thompson et al., 2007). For caregivers of those with dementia the strongest predictor of distress is care recipients problem behaviors (Pinquart and Sorensen 2004). This supports the concept of providing respite care and encouraging self-care for caregivers.

Another study focused on caregiver mastery and its' influence on depressive symptoms. Using a telephone interview tool to examine the physical and emotional well being of caregivers (n=95), the researchers sought to answer the question: does caregiver mastery moderate or mediate caregiver's level of depression (Sherwood et al., 2007)? They report a moderating role of caregiver mastery. Others cite that caregiver depression is known to mediate the relationship between caregiver health and caregiver burden (Elliot, Burgio & DeCoster, 2010).

Three areas that cause burden for caregivers are: Activities of daily living (ADL's) that includes eating, bathing and toileting; Instrumental Activities of Daily living (IADL's) encompassing shopping, food preparation and managing finances; and the third area is managing behavior and safety addressing falls, fires and driving (Wimo et al., 2002). Caregivers experience physical symptoms, depression and feelings of burden when faced with more tasks, more problematic behaviors and/or more family disagreements (Koerner and Kenyon, 2007).

Using a 42- item Caregiving Hassles scale Kinney and Stephens (1989a) examined the mediating function of the relationship between care giving stress and self-care behavior in response to symptoms and found caregiver stress to correlate to self-rated health at a statistically significant level ( $r=.30$ ,  $p=.003$ ). The investigators also found that the more negative symptoms family members reported (depression, poor health) the more self-care behaviors they used and further determined that depressed mood was a strong mediator between caregiver stress and

response to the symptoms with self-care behaviors. They suggest that hotlines and coaches available to speak with caregivers and assist them with planning may increase coping style. They advocate for the availability of respite care, use of journaling techniques and family programs early in the caregiving process.

Examining the relationship of burden and depression among caregivers of Alzheimer's (n=421) using the data from the Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE)-AD study, the authors examined 421 outpatients who were identified with a diagnosis of dementia of Alzheimer's or probable Alzheimer's with agitation or psychosis. They screened participants using tools to measure burden and depression and found that higher levels of burden and depression at baseline were associated with more severe psychiatric and behavioral problems (Mohamed, Rosenheck, Lyketsos & Schneider, 2010). At six month follow-up they found that decreased burden resulted in decreased symptoms (Mohamed et al., 2010). The intervention group that received psychosocial and pharmacological interventions experienced a statistically significant ( $p= 0.0083$ ) change while the control group worsened (Mohamed et al.2010). The authors conclude that the severity of psychiatric and behavioral issues were associated with caregivers experiencing greater burden and that the essence of caregiver burden is significantly related to these issues suggesting the psychosocial and pharmacological interventions are likely to improve both caregivers and care receivers quality of life. Burden and depression appear to be closely linked for AD caregivers. A correlational cross-functional design along with a survey mailed to caregivers (n=99) found that those caregivers who reported poorer self-health also reported higher levels of caregiving stress (Lu & Wykle, 2007).

While the literature is mixed in its findings of the effectiveness of interventions for reducing burden of care and depression for caregivers and improving self-care, there is some

evidence that psycho education and psychotherapeutic interventions have a positive effect on caregiver burden and depression (Pusey & Richards, 2001; Sorensen, Pinquart & Duberstein, 2002). Others determined that minimal evidence exists to suggest that providing information or support to caregivers is consistently effective (Thompson et al. 2007). Still others speculate that caregivers may experience less burden and depression when there is a focus on improving their health (Elliot et al., 2010). Positive effects of support group intervention were reported by Chu et al. 2010; Martin-Carrasco et al., 2009. It is clear that we must continue to pursue interventions to reduce burden and stress for the growing numbers of caregivers.

The Zarit Burden Scale is widely used and scores are reported to be significantly correlated in two areas, behavior problems in older adults ( $p < .001$ ) and depression of caregivers ( $R^2 = .57$ ) and to have good internal consistency reliability (Chronbach's alpha coefficient = .92) (Hebert, Bravo & Preville, 2000). Given that the Zarit scale is a widely used validated measure these findings are promising and the authors conclude that psycho educational interventions are effective to reduce burden, improve quality of life and lower rates of psychiatric morbidity for caregivers (Martin-Carrasco et al., 2009).

In 1995 the National Institutes of Health implemented six randomized control studies across the country to evaluate several multi component interventions for Alzheimer's caregivers known as the Resources for Enhancing Alzheimer's Caregivers Health (REACH). Each study shared common goals, designed theory-driven interventions and developed standardized outcome protocols (Wisniewski et al., 2003). REACH researchers concluded that interventions that focused on active interventions of the caregiver (face to face, workshop vs. telephonic, computerized, and information and referral) were most effective in reducing burden. They also report that reduction of burden resulting from active interventions was more evident for women

and those with high school or less education and depression scores were lower for Hispanics, non spouses, and those with less than a high school education (<http://www.ncbi.nlm.nih.gov>). One might speculate that those with more education were already using effective coping skills and had knowledge of resources to assist in reducing the burden of their caregiving role. Other findings related to the REACH Alabama project reported that African Americans showed greater benefits from interventions than their white comparison group (Mahoney, Tarlow, & Jones, 2003). Their colleagues in Palo Alto, California found that female caregivers showed improved coping after participation in a skills enhancing intervention (Gallager-Thompson et al. 2003). The conclusion from the REACH studies was that the multiple challenges of caregiving are not easily addressed and they were unable to identify a consistently effective method to address caregiver needs (Schultz et al., 2003). When considering the key findings it is important to take into account that the caregivers in this study were over the age of 21 and provided a minimum of 4 hours of care per day (Koerner, Kenyon & Shirai, 2009), as compared to spousal partners of those with AD who themselves are usually elderly and providing 24-hour care in many cases.

REACH II was designed to test a single intervention to reduce burden and stress in caregivers of those with AD at multiple sites with a diverse population (N=1222). The authors report being disappointed with the caregiving research literature due to the lack of significant success in improving indicators of burden, depression and psychological well-being. Their intervention included use of a risk appraisal approach, the results of which were used to target interventions in the area of safety, self-care, social support, emotional well-being, and problem behaviors. Results include that active interventions were more effective than control and depression was effected positively by active engagement of caregivers (Schultz et al., 2003).

Caregiver's isolation in their roles may suggest that decreasing isolation will lessen anxiety and depression and improve their feelings of belonging. Lu & Wykle, (2007) found caregiver stress to correlate to self-rated health at a statistically significant level.

### **Caregiving and health status**

Caregiver's believe that caregiving causes the deterioration of their physical health (Center on Aging Society, 2005). According to a 2004 survey sponsored by the National Alliance for Caregiving and the American Association of Retired Persons (AARP), seventy two percent of family caregivers acknowledge not going to the doctor as often as they should and frequently skipping scheduled appointments. Most report their health to be fair or poor and of those reporting poor health 35% report that caregiving has worsened their health (National Alliance for caring and Evercare, 2006).

Based on a meta analysis of 78 caregiver intervention studies, aimed at family caregivers taking care of older adults, the authors found that combined interventions (respite care, improving competence of care, psycho educational interventions and support group) produced significant improvement for caregiver burden, depression, subjective well being, perceived caregiver satisfaction, ability/knowledge, and care receiver symptoms (Sorensen, Pinguart & Duberstein, 2002). They conclude that psycho educational and psychotherapeutic interventions showed short-term positive effects that were evident seven months later and that caregivers of dementia patients showed smaller effects that were moderated by setting, number of sessions, age of care receiver and caregiver, gender, relationship between the caregiver and receiver, and the initial burden of care (Sorensen, Pinguart & Duberstien, 2002). This suggests that the burden on dementia caregivers may be greater than the burden on other caregivers who were studied.

A more recent meta analysis of forty-four studies identified from the specialized register for the Cochrane Dementia and Cognitive Improvement Group (<http://www.cochrane.org/Cochrane-reviews>) provided a systematic review of randomized controlled trials that evaluated technology, individual and group interventions, and provision of support and information (Thompson et al., 2007). The investigators report difficulties in measuring depression, unclear method of randomization and poor sample size calculation, among other reported statistical and selection issues, and conclude overwhelming poor quality of evidence and failure to follow “best practice.” They determined that minimal evidence exists to suggest that providing information or support to caregivers is consistently effective (Thompson et al., 2007).

In another large scale study a diverse population of caregivers participants (n=495) were randomly assigned to a structured multi-component intervention targeting five areas including self-care behaviors or to a control group. They applied pre-test and post-test intervention measures using standardized tools. The authors found improved self-reported health status, decreased burden and bother thereby reducing the impact of care giving burden on mental and physical health, and improvements in self-rated health, sleep, mood and physical health. They believe that caregivers changed their self perceived health status, rather than there being an actual change in health status, and this lead to lower levels of depression. They speculate that caregivers may experience less depression and burden when there is a focus on improving their health (Elliot, Burgio & DeCoster, 2010).

Prominent authors in the field of caregivers of persons with dementia published the results of another Meta analysis of 127 studies with dementia caregivers between 1982 and 2005. They reviewed AD support including practical assistance (respite), education, emotional support,

and multi-component interventions. The authors report the following results: on average interventions had significant but small effects on burden, depression, subjective well-being, ability/knowledge and symptoms of care recipient but they cite that better effect has been shown in more recent interventions. Given the fiscal concerns about long term care it is interesting that they found no significant effect on reducing risk of institutionalization but they report that respite care delayed institutionalization (Pinquart & Sorensen, 2006) which has fiscal implications.

Pinquart and Sorenson (2006) conclude, consistent with others (Thompson et al., 2007), that there is little evidence of the effect of interventions, however this is contradicted by Cooke et al. (2001) who report that 30% - 40% of studies they reviewed have an effect on caregiver burden and psychological health. Earlier publications report that problem and behavior management is most effective (Pusey & Richards, 2001). These differences are likely due to increasingly more rigorous approaches to the research process. Of great significance is the conclusion that the higher quality the study the less the improvement in caregiver burden with more recent studies showing better effect. They also report that some effects were stronger on women than men including depressive symptoms; ability/knowledge and delay of institutionalization, and that longer interventions had stronger effects (Pinquart & Sorensen, 2006). Male/female differences in response to interventions were also identified by others (Koerner & Kenyon, 2007).

Different personality traits were reported by some to impact negatively or positively on the caregiving experience (McQuire, Andresen, Brumback, & Anderson, 2009). No difference was found by age, race/ethnicity, sex, level of education, annual household income, healthy days, self-rated health, social support, or life satisfaction between caregivers of people with and without cognitive impairment (DeFries, McQuire, Andresen, Brumback, & Anderson, 2009).

This suggests that the broader caregiver research may also apply to those providing care to cognitively impaired persons.

Two important findings: monitoring of caregivers depressive symptoms may assist in identifying interventions that reduce caregiver burnout and distress; and support and counseling groups for caregiver reduces symptoms of depression (Sorensen, Pinquart, & Duberstein, 2002). Of the caregivers of persons with cognitive impairment who responded to the 2005 North Carolina Behavioral Risk Factor Surveillance System (n= 668), 41% reported higher levels of disability. The authors found no significant differences in frequent mental distress, social support, or life satisfaction between caregivers of those with cognitive impairment and those without cognitive impairment (DeFries et al., 2009).

Leisure activities and interventions like Yoga and Reiki, although not studied extensively, deserve attention. If we are to improve the lives of caregivers we need to take a holistic approach to determine what interventions or combination of interventions offer the most promise.

### **Leisure activities and Complementary Medicine for caregivers**

An experimental design study focused on physical health and coping of informal caregivers, not specifically those of Alzheimer's or dementia patients, found diminished or absent leisure activities placed caregiver's physical health at risk (Van Puymbroeck, Payne & Hsieh, 2007). Caregiver health behaviors that may be influenced negatively by the caregiving experience include alcohol and drug consumption, exercise, sleep, smoking and weight maintenance. The importance of keeping caregivers healthy, both physically and psychologically, is essential to their performance as caregivers.



Yoga is known to have many benefits and has many followers. The authors evaluated an 8-week yoga program for otherwise healthy caregivers who were stratified by age, randomly assigned and who agreed to not initiate any other physical activity during the study period. Their results show that participation in Hatha yoga (n=8), a combination of postures, breathing and meditation, reduced anxiety and improved physical fitness as measured in strength, endurance and flexibility when compared with a control group (n=9) (Van Puymbroeck et al., 2007). The Sense of Coherence Questionnaire (Antonovsky, 1993) was used to measure the ability to mobilize adaptive coping resources along with a physical fitness test with follow-up interviews. After the 8-week intervention the authors report that a 5% increase in coping ability and improved lower body strength was reported by the Yoga group while the control group had decreased findings in all areas (Van Puymbroeck et al., 2007). This research supports the positive effects of Yoga for caregivers. The small sample size suggests further study is needed for this potentially promising intervention. Applying these findings to caregivers of persons with Alzheimer's requires further targeted study.

A mixed model design to analyze an adapted leisure education program developed to provide support for caregivers of people with dementia (n=49), applied pre-test and post-test measures and follow-up that included an open-ended interview. The subjects of the experimental group were caregivers and their loved ones who had dementia. The authors note that not only is there a loss of autonomy for those with dementia but also for their caregivers. The value of significant others in the lives of those struggling with dementia is noted and the goal of this study was to determine how to support and encourage continued involvement of the caregivers with the care receivers. The authors focused on identifying positive aspects of caregiving and reinforcing and strengthening those aspects for the caregivers. They theorized that leisure activities that

included those being cared for will positively affect the relationship through maintenance and strengthening of the bond. The authors used standardized scales to measure the well-being of the caregiver and the quality of the relationship between the caregiver and the care receiver including the General Well-Being Schedule (Dupuy, 1978) and the Relationships in Elder Care Scale (Lyonette and Yardley, 2003). Caregiver participants reported having more pleasant moments facilitating their interactions with their loved ones. The authors conclude that their intervention modified caregivers' perception of their caregiving experience assisting them in perceiving their role as more positive rather than as a burden (Carbonneau et al., 2011).

The effectiveness of Tai Chi, Yoga, Meditation and Reiki in promoting health and enhancing problem solving abilities of another group of caregivers, registered nurses at a university hospital setting (n=35), was studied by Raingruber & Robinson, (2007). Although their findings cannot be generalized to caregivers in other settings or family caregivers with no formal training, they can inform us of transferable techniques for further study. Nurses were asked to keep a journal and to select one of the four interventions, Tai Chi, Yoga, meditation or Reiki health. They found these interventions to be of value to participants with reports of feeling calm, having enhanced problem solving abilities, increased ability to focus on patient need and overall increased positive self care behaviors (Raingruber & Robinson, 2007).

Leisure activities and interventions like Yoga and Reiki, although not studied extensively, deserve attention. If we are to improve the lives of caregivers we need to take a holistic approach to determine what interventions or combination of interventions offer the most promise. In addition to finding time for self-care, caregivers struggle with managing the behaviors of those they care for.

**Caregivers and behavior problems of care receivers**

A promising evaluation tool has been published citing daily diary design to examine day to day variations in caregiver well being in order to measure two stressors; number of caregiving tasks and behavior problems of care recipients (Koerner & Kenyon, 2007). Participants for this study (n=63) were recruited from flyers posted at sites such as family practice clinics. The sample included mostly non-Hispanic white women (n = 46). In their attempt to understand good and bad days for caregivers, the authors discovered that caregivers experience depressive as well as physical symptoms and feelings of burden when faced with more tasks, more problematic behaviors and/or more family disagreements. They also found “with-in person variation” described as “how and why caregivers vary around their own mean in terms of psychological and physical well being” (Koerner & Kenyon, 2007, p. 1). Their research sought to identify those caregivers who are most susceptible to fluctuations around causative factors: increased tasks; increased problematic behaviors; and increased family discord. The author’s review of the literature explores premorbid personality characteristics such as neuroticism, extroversion and conscientiousness and report that they are negative in the case of increased tasks and positive in the case of increased problematic behaviors and increased family discord, with the latter two influencing how they react and manage the stress of caregiving. Caregiving burden can noticeably increase with just the addition of one more family disagreement (Koerner & Kenyon, 2007), leading one to wonder about caregiver fragility. Based on their findings they suggest that hotlines and coaches available to speak with caregivers and assist caregivers with planning may increase coping style. They also advocate for the availability of respite care, use of journaling techniques and family programs early in the caregiving process (Koerner & Kenyon, 2007). These all appear to be important components of caregiving support tools.

Age and gender of the caregiver along with behavior problems of the care receiver were predictive of caregiver depression but were not affected by caregiver mastery according to a study of caregivers of persons with brain tumors, who have many behavioral problems similar to those with dementia, (Sherwood et al., 2007). The strongest predictor of distress among caregivers of those with dementia is care recipients problem behaviors as reported by Pinquart and Sorensen, (2004). This points to support groups addressing behavioral interventions as a priority. Some theorize that the distress that caregivers experience has multiple components including belligerence, lack of cooperation, oppositional behaviors and disruption of sleep patterns of the care receiver (Gottlieb et al., 2000). Caregivers struggle with the “apparent sadness, listlessness and vegetative behavior” of their loved one struggling with AD according to Gottlieb et al., (2000, p. 29).

### **Caregiver stress and functional ability**

The relationship among caregiving stress and caregivers’ functional ability as they relate to self-care behaviors responding to physical and psychological symptoms was studied by Lu and Wykle (2007). The investigators used a correlational cross functional design along with a mailed survey sent to caregivers (n=99). They found that caregivers who reported poorer self-health also reported higher levels of caregiving stress. Secondly, they examined the mediating function of the relationship between caregiving stress and self-care behavior in response to symptoms using a 42-item Caregiving Hassles Scale (Kinney & Stephens, 1989a). Applying descriptive statistics they found caregiver stress to correlate to self-rated health at a statistically significant level ( $r = .30$ ,  $p = .003$ ), (Chronbach’s alpha = .95). The investigators also found that the more negative symptoms family members reported (depression, poor health,) the more self-care behaviors they used and further determined that depressed mood was a strong mediator between

caregiver stress and response to the symptoms with self-care behaviors. The subjects reported that the “most frequent self-care behaviors were; using medication (37%); taking no action (34%); asking for professional help (19.1%); praying (12.6%); and using home remedies (11.2%). Caregivers who report greater levels of depression, and the poorest health and physical function also reported using a larger number of self-care behaviors in response to symptoms (LU & Wyle, 2007). The findings of this study are limited due to the participants being mostly white women, however a large number of caregivers in this country fall into this category.

A study of primary care interventions to alleviate psychological stress for caregivers of those with Alzheimer’s found that those who received both patient behavior management and stress-coping assistance did better than those who just received the behavior management component (Burns et al. 2003). This further supports the need for a multi-faceted approach to supporting caregivers in their complex and demanding role.

### **Issues of institutionalization on caregivers**

An article that addressed family caregivers dealing with transitions and issues of long-term care focused on policy issues as they relate to the impact on decreased hospitalizations and cost through the provision of training and support to caregivers. They estimated that 34 million caregivers in the U. S., predominantly women, provide 75%-80% of long term care (Levine, Helper, Peist, & Gould, 2010). Rather than seeking ways to relieve the burden of caregivers these authors and others (Kelly, Reinhard & Brooks-Danso, 2008) seek to enhance their role in the care delivery system and move care away from institutions into home and community-based care. This approach is anticipated to have enormous impact on the rapidly expanding number of caregivers and demands that we find ways to support our caregiver community physically,

psychologically and financially. Use of valid and reliable assessment tools can assist professionals in focusing their interventions on the identified needs of the caregivers.

The New York University School of Medicine randomized controlled study of intervention for spousal caregivers produced a wide array of results and multiple publications. One such publication reported that counseling and support interventions delayed placement in nursing home and 61.2 % of this delay was attributed to social support, response to patient behaviors and reduced depression (Mittleman, Haley, Clay & Roth, 2006).

Another study focused on counseling as an intervention to reduce burden and depression in caregivers who were in the process of placing their relative in an institution (Gaugler, et al., 2008). They enrolled caregivers (n=406) in a randomized control study over a nine and one half year period. They offered six-sessions of family and individual counseling, support group and phone counseling. Participants (n= 385) were followed for up to 15.9 years with a longitudinal sample. They found that these interventions reduced burden and depressive symptoms for the intervention group and that the control group also experienced positive outcomes for placing their loved one, concluding that placement has a positive effect but counseling and the expanded interventions have additional long-term impact. Comprehensive counseling and support provided during the progression of AD patients transitioning to institutionalization can be beneficial to spouses and may translate more broadly to caregivers in general (Gaugler et al., 2008).

### **Caregiver Assessment Tools for measuring Caregiver Burden, stress, depression and self-care.**

Assessment tools are commonly used to identify problems that can be addressed in a targeted manner and to evaluate effectiveness of interventions. Many assessment tools exist in

the field of Alzheimer's caregivers. Often the tools share common elements as they seek to measure the common issues known to effect caregivers. Recent efforts have focused on blending content areas (depression, burden, health behaviors and quality of life) to establish a single screening instrument, rather than the standalone tools that measure only one domain like depression or burden of care. Some are self-assessments tools and others are professionally administered and scored (<http://www.caregiver.org>).

Review of the many assessment tools available sought to identify appropriate tools that are easy to administer, reliable and valid to be applied to screen for known negative effects and monitor change post intervention (Antonovsky, 1993; Bedard et al., 2001, Czaja et al., 2009; Gort et al., 2010; Kinney & Stephens, 1989a; Locke et al., 2009; Picot, Youngblut & Zeller, 1997; Radloff & Teri, 1986& 1997, Seng et al., 2010). This review and critique examines tools that address the areas of burden, depression and self care with a focus on brief and easy to administer tools that are in the public domain. Many other topic specific tools have been studied in relationship to caregivers such as the Picot Caregiver Rewards Scale developed by Picot, Youngblut & Zeller (1997) and quality of life assessments like SEIQoL studied by Scholzel-Dorenbos, Draskovic, Vernooij-Dassen & Olde Rikkert (2009). These however are beyond the scope of this review.

Consensus Guidelines on development of screening tools suggest four criteria for caregiver assessments recommending that they be; multidimensional; driven by a theoretical framework; culturally relevant and easy to administer (Family caregiver alliance, 2006). Many tools fail to meet these guidelines and were therefore not selected for this intervention.

The Michigan Dementia Coalition Caregiver Assessments (2009) reviewed and catalogued nineteen scales that measure caregiver burden, stress, quality of life, memory,

behavior and perceptions of care giving tasks among others. Tools range from simple to complex with some having yes/no answers and others have 4 or 5 point Likert scales.

Those that meet the criteria for brevity and were in the public domain are the Zarit Burden Interview developed by Zarit, Reeve & Bach-Petersen (1980). This was initially a 29-item tool that was then reduced to 22-items (Bedard et al. 2001) and now has a version with 12-items and a brief screening version with only four-items. Correlations between the reduced length versions were .92-.97 for the short version and .83-.93 for the screening version. The screening version has a sensitivity of 98.5% and a specificity of 94.7% (Gort, 2010). The Zarit Burden Interview is a frequently applied tool to assess burden; is cited in many studies (Bedard, 2001); and has been validated for use in other languages (Miyamoto, Y., Seng, et al., 2010; Tachimori, H. & Ito, H., 2010). It measures subjective burden, distress and perceptions of social, physical health, financial and emotional burden and relationship with caregiver. It is commonly embedded into other blended assessment tools like the California Caregiver Resource Centers Uniform Assessment Tool. (<http://www.caregiver.org>).

The Pearlin Caregivers Stress Scales (Pearlin et al., 1990, 1994) is based on a conceptual model of the Alzheimer's Caregiver Stress tool, an eight-item scale developed by the Alzheimer's association that links yes answers to helpful websites (<http://www.alz.org>). The Pearlin Caregiver Stress Scale includes issues of cognitive status, problem behaviors, overload, relational deprivation, family conflict, job-caregiving conflict, and economic strains among others (Pearlin et al., 1994). The American Medical Association (AMA) published a brief caregiver assessment tool in 2002 encouraging health care professionals to identify the needs of caregivers (AMA, 2002). This tool is most appropriate for use in physicians and nurse practitioners offices.



A study to develop and validate the Risk Appraisal Measurement Tool (RAM) was done using data from the REACH II study (Czaja et al., 2009). RAM is a 16-item assessment that takes five to seven minutes to administer and identifies risk areas for caregivers offering the potential to guide interventions. The six domains of caregiver risk that are potentially amenable to intervention are; burden, self-care, health behaviors, social support, safety, and patient problem behavior. In a study of 642 participants (white n=219, Black n=211, Hispanic n=212), to determine the reliability and validity of RAM, the authors report acceptable internal consistency across racial and ethnic groups and concurrent validity (Chronbach's alpha = .65). The authors acknowledge that this is a relatively low score but explain that it is expected due to the six distinct domains it attempts to measure. This highlights the challenge of maintaining reliability and validity in blended screening tools.

The Geriatric Depression Scale ([http://www.char.brown.edu/GDS\\_short\\_form.PDF](http://www.char.brown.edu/GDS_short_form.PDF)) is a broadly used, well known tool in the public domain and the only tool specifically designed for assessment of depression in the elder population. The Center for Epidemiology Studies Depression Scale (CES-D) is a 20-item self-report scale that takes five minutes to administer and measures depressive feelings and behaviors over the past week (Radloff, 1977). It is reportedly the most frequently used instrument to assess depression in caregivers (Pinquart & Sorenson 2003). A study of distress responses and self-care behaviors in dementia family caregivers with high and low depressed mood, reports Chronbach's alpha for the CES-D as .90 (Lu & Austrom, 2005). Others expressed concerns about this tool when applied to caregivers, many of whom are elderly. They inform us that the questions are oppositely worded where one part asserts and the other denies the content to avoid a tendency to give positive responses to questions, known as acquiescence. These researchers raise the concern of this method distorting

the reliability of the scale and in proposing such recommend against the use of this tool with the elderly (Matschinger, Schork, Riedel-Heller & Angemeyer, 2006).

The Caregiver Burden Scale, adapted version from the Family Practice Notebook (fpnnotebook.com), is a brief 12-item version of the longer Caregiver Burden Interview. This scale was incorporated into the Risk Appraisal Measure and in that format was reported to have internal consistency reliability (Chronbach's alpha =.85). The Self-Care Scale (<http://www.apsnetowrk.org>) was also one of the tools imbedded in RAM with a reported Chronbach's alpha =.62 (Czaja et al., 2009).

An on line Self-Care Scale allows users to assess their well-being and offers advice for managing caregiver challenges (<http://www.arcrom.com/users/alzheimers/ca7a.html>).

Assessing caregiver challenges is only half of the task of seeking to improve their lives.

The challenge is getting caregivers to complete an assessment and reach out for help needed as identified by the results. We must also understand models for change if we are to have an effect on caregivers with structured, well thought out interventions.

### **A Model for change for Caregivers**

Identifying a theoretical change model to apply to the process of improving self care activities for Alzheimer's caregivers is important to the process and outcome of this intervention.

Although no one model fit perfectly, adaptation of a model provides the needed framework.

The six domains of caregiver risk that will be addressed in this intervention are; burden, self-care, health behaviors, social support, safety, and patient problem behavior.

The REACH project, a joint effort between the National Institute on Aging, National Institute of Nursing Research and the National Institute of Health (NIA/NINR-Reach II), applied the Stress-health Process Model (Schulz, Gallagher-Thompson, Haley & Czaja, 2000) as the

theoretical framework for their six different interventions carried out in Birmingham, Boston, Paulo Alto, Philadelphia, Memphis and Miami. The common interventions applied to caregiver research are often not based on theory or designed with a theoretical construct (Coon, Ory & Schultz 2003). For those that do apply a theoretical framework it is commonly the Stress-health Process Model (Coon et al., 2003). While the Stress-health Process Model offers a way to understand the effect on caregivers of someone with Alzheimer's diseases it does not offer a model for changing caregiver behaviors. Schultz et al., (2000) recommend that new models as well as modification to existing models are needed. Some raised the question as to whether caregiver interventions should be informed by environmental-press theory, emphasizing change in living situations; by psychological theories of behavior that focus on caregiver emotional distress and care receiver's behaviors; or by family systems theory that incorporates others beyond the caregiver and care receiver (Coon et al., 2003). They advocate for the active involvement of providers, administrators and policy makers to develop new and refine existing models for this area of practice. There are also models that have been applied to individual home visit interventions such as the Progressively Lowered Stress Threshold (PLST) model that focuses on modifying environmental demands to reduce anxiety and stimulation in care receivers (Stolley, Reed and Buckwalter, 2002).

A review of other theoretical models for change, including predictive theories that address nursing therapeutics and consequences of interventions, and mid- range theories noted for having a limited number of variables and being moderately abstract (<http://www.nursingtheory.net>), revealed many that identify behavior change as the key factor (Prochaska, 1997, Sutton, 2005, Weinstein, 1988, Weinstein and Sandman, 1992). Among those reviewed the Precaution Adoption Process Model (PAPM), as defined by the National

Cancer Institute (<http://www.cancer.gov>), provides a theoretical framework for change and has the potential to address the complex needs of caregivers.

The Precaution Adoption Process Model defines seven stages in the journey of awareness to action and is well suited to the challenge of caregiver awareness, empowerment and action (<http://www.cancer.gov>). The PAPM has seven distinct stages; unaware of the issue, aware of the issue but not personally engaged, engaged and deciding what to do, planning to act but not yet having acted, having decided not to act, acting, and maintenance. Stage theory emphasizes the need to tailor interventions based on the audience, barriers to action, and changes that occur in the process of transitioning from one stage to another (Weinstein & Sandman, 1992).

A more in-depth analysis of the stages of PAPM is offered by Weinstein and Sandman. With stage one the intent to act is key to acting, with stage two they differentiate between people who never thought about acting from those who have, with stage three the variables that influence action are not necessarily the variables that influence the decision, stage four has similarities to stage three with different variables that determine decision versus carrying out the decision, and with stage five the perception of there being a problem is predictive of action. They note the influence of social proof, in the case of Alzheimer's disease, social media and the opinions and actions of others (Weinstein & Sandman, 1992).

Overlapping the PAPM theory with the three identified stages of the progression of Alzheimer's disease (<http://www.alz.org>), has the potential to target the change process to the disease stages to allow us to gain a greater understanding of the link between interventions and expectations of response. This creates an opportunity to target the interventions by mapping the seven stages of PAPM to the three stages of AD (Table 1). Sutton (2005) reports that effective

interventions need to be matched to stage, targeting the change process to the stage of disease, thereby having the potential to produce the most effective outcome.

Prior to a family member being diagnosed with AD, most future caregivers are unaware of the issues and may remain unengaged through the early stages of the disease. As the disease progresses caregivers are faced with deciding about acting. Few have the choice to decide not to act, leading to action, often without the support or tools to do so effectively. The opportune time for professional intervention is early in the process. Educating caregivers in the early stages and providing increasing services and support as the care receiver progresses in the disease process should reduce caregiver burden and physical and psychological distress.

Dietz (2011) points out that people in the same stage may experience barriers to change that are similar and likewise those in different stages experience different barriers. If one looks at the stages of progress of the disease for persons with Alzheimer's and then links those stages to the PAPM model, a greater understanding may be gained of linking interventions and expectations of response. Table 1 outlines the linkage of the behavior model to the stages of disease model. Following the logic of Table 1 the barriers to change for caregivers of AD will likely be influenced by their own stage of change and the stage of AD of the person for whom they provide care.

This combined model provides an effective strategy for public health professionals as we design programs to reduce burden and stress and improve quality of life and self-care for caregivers. Applying a systematic approach to the problem of lack of supportive services, burden of providing care and lack of respite services for caregiver's of persons with Alzheimer's disease provides a logical and effective strategy for public health professionals to begin to address this growing problem.

### **Program Plan**

This project was delivered under the umbrella of Martha's Vineyard Community Services (MVCS) a Department of Public Health licensed mental health facility. MVCS is well known for its role in responding to identified needs on Island and building sustainable programs to meet those needs. MVCS is a HIPAA compliant agency, accredited by the Council on Accreditation of Rehabilitation Facilities (CARF). All activities within the scope of this project were subject to all agency policies of consumer rights and followed the Council on Accreditation of Rehabilitation Facilities framework of acknowledging strengths, needs, abilities and preferences (<http://www.carf.org>). This intervention did not require IRB approval. Participants were advised of confidentiality in accords with HIPAA and they signed a confidentiality statement.

#### **Identification of Candidates**

Caregivers were identified through a social marketing approach including flyers, advertising, posting on the internet and presentations at the Councils on Aging (COA'S), the elder services day care program, the Visiting Nurse Association (VNA), Hospice providers, primary care physicians and nurse practitioners. The day care program introduced the availability of the group to family caregivers who have their loved ones attending the daycare program. Flyers were faxed to the hospital, churches, chiropractors, hospice, private mental health practitioners, podiatrists, departments of public health, police departments, emergency services, pharmacists and others who had contact with elders in need. A current program of outreach to elders to provide mental health and case management services in the home or community also identified three caregivers who they thought might benefit from a support group.

### **Criteria for Participation**

In order to participate in group members had to meet established criteria. Priority was given to spousal or partner primary caregivers for someone with a diagnosis of Alzheimer's disease or another dementia. Other caregivers who were not spouses or older age friends, such as adult children or professional caregivers were considered and the group expanded to accommodate those who expressed a need. There were no restrictions in terms of the AD stage of the care receiver. Caregivers identified that they were able to leave the care receiver safely by themselves. One participant identified a need for respite services in order to attend and this was provided through a stipend. Participants were asked to complete pre and post-assessment tools and a satisfaction survey at the last group.

Participants were informed that a less structured ongoing support group would be available when the structured group ended. As the group progressed it became evident that there was also a need for psychotherapy services for some of the members and out of that came the plan to development a psychotherapy group focused on loss and what the members referred to as "the long goodbye."

### **Membership**

Although initially there were concerns that due to the stigma issues and resistance to acknowledging the struggles, it would be challenging to recruit potential caregivers for a support group, in fact we were overwhelmed with referrals. Requests came from family caregivers including spouses and adult children, professional caregivers and a staff member at one of the Councils on Aging. The demographics section and Table 9 provides details of the participants.

**Plan for individualized program intervention**

In order to recruit caregiver's letters and brochures were faxed to providers who were in contact with elders who may be caregivers. The program concept was presented at multiple meetings made up of a broad range of providers of elder services. The Vineyard has two local newspapers and they provided notification through their "free" section on services for those over age 55. The Martha's Vineyard Times did a long article on caregivers just prior to the group's inception. MVTV scheduled an interview of the group leader and that will be streamed available on demand.

Potential members called the group leader to discuss the group and register to attend. Some just showed up despite not registering and were accepted for membership. The first meeting was used as an orientation and introduction. Everyone talked about why they were there and we reviewed the group agenda. Name tags were used to help people get to know each other. At the end of the first session participants were asked to take home and complete evaluation tools including the Caregiver Burden Scale adapted version from the Family Practice Notebook ([fpnnotebook.com](http://fpnnotebook.com)), the Self-Care Scale (<http://www.apsnetowrk.org>) to assess the well-(being of the potential attendee and the Geriatric Depression Scale ([www.char.brown.edu/GDS\\_short\\_form.PDF](http://www.char.brown.edu/GDS_short_form.PDF)) for those 65 and over and the Zung Scale for those under sixty-five (<http://www.depressiontreatmentnow.com>).

The caregiver burden tool initially seemed to be straight forward and some of the group members completed it readily, other raised questions about double negative questions and other issues. Some chose to not complete it and some who did only partially completed it. The depression screening tool for those 65 and older had several questions left unanswered, the question of sex and constipation was mostly often left blank. This may represent a generational



discomfort with sharing personal information. The third tool, the Self-Care tool, was confusing and the directions were perceived by the caregivers as unclear. When the leader was asked for clarification of the directions, the clarification raised questions and debates about how the tool should be used and analyzed. The responses were inconsistent and not always clear whether they were about the person attending the group or someone else who they considered the primary caregiver. Some selected more than one choice when only one was to be selected. It was determined that the data integrity was compromised and this tool was not used in the final analysis.

The support group was lead by an experience nurse practitioner, DNP candidate. The group met weekly for 12 weeks for one and one-half hours each week in a handicapped accessible conference room. Transportation was available through *The Lift*, a community funded van that is handicap accessible. However, all who attended provided their own transportation. Paid respite care was requested by one participant who had hired her neighbor to care for her husband who could not safely be left unattended.

The group sustained a supportive environment where caregivers could learn to manage their loved ones' behaviors, share their concerns about their role as caregiver and be introduced to complementary therapies. Coffee, tea and other refreshments were served and a casual atmosphere maintained. Each meeting began with a welcome followed by a check in with everyone as to how their prior week has been. At the first session every member was given a loose leaf notebook in which to file program handouts and a separate journal to record thoughts, concerns and questions. Every session included an educational component that addressed the many challenges that caregiver's face. Materials of relevance to the program were collected

throughout the process and a resource library was developed. Materials selected were culturally sensitive and appropriate to the educational level of participants.

The objectives were accomplished through a psycho educational approach using evidence-based materials from the U.S. Department of Health and Human Services, the National Alzheimer Association, The National Caregivers Alliance, The Center for Disease Control and Prevention and the Kimberly-Clark Corporation RE-AIM Framework and other identified resources. The group leader was available before and after the group to answer questions and provide additional referral information. Many participants took advantage of this opportunity to get personal advice. Caregivers requiring additional support or assistance were advised of the services of the mental health center and other community supports.

Didactic topics of the 12-week program are presented in Table 3. Guest speakers and topical experts were invited to present including the police who presented GPS bracelets to track patients who wander, a Yoga teacher, and a holistic medicine provider. Participants requested additional topics and they were incorporated when possible. The group leader maintained a journal about the group. Employing pre-tests and post-test evaluations (Issel, 2009) at the first group participants were asked to complete three well known reliable and valid assessment tools available to be used in the public domain. They included the Caregiver Burden Scale adapted version from the Family Practice Handbook (<http://www.fpnnotebook.com>), the Self-Care Scale (<http://www.apsnetowrk.org>), and the Geriatric Depression Scale ([www.char.brown.edu/GDS\\_short\\_form.PDF](http://www.char.brown.edu/GDS_short_form.PDF)). For caregivers under the age of 65 the Zung depression scale available complimentary from depression treatment now (<http://www.depression-treatment-now.com>) was used. In addition to the pre-test and post-test caregivers participants were asked to complete a demographic survey. At the last session a satisfaction survey form

along with post tests was completed. Anyone not attending the last session did not complete this final survey.

### **Outcome/Evaluation**

The outcome evaluation followed an effect evaluation model to answer the question “did the program make a difference?” The effect size of this small convenience sample, initially estimated to be 12-14 participants but in actuality had a larger participant group with 27 people seeking to join the group and 19 coming to the first session. Of those 19 initial attendees and 3 people added in the first two weeks, 13-20 attended each session with an average attendance of 16. Eleven people attended at least 75% of sessions and nine people attended less than half the sessions, 2 people attended one session only. It is interesting to note that three of those with limited attendance were males of which there were only 5 in the group. One session that had all females had a different tone to it with far more emotional conversation exchanged. This might speak to having separate sessions on occasion to address the needs of males versus females. Many of the males struggle with doing tasks they have never done before like cooking. Often females struggle with managing finances or repairs to the home. This is particularly true for the generation of older adults who had more traditional roles and may be less true for the aging baby boomers.

This intervention was intended to reduce depression and burden (negative aspects of caregiving) and increase skills for managing care receiver behaviors thereby improving positive aspects of care giving and increase self care. In order to demonstrate that the Alzheimer’s caregiver group intervention reduces burden; reduces depression; and improves self-care, inferential statistics were considered.

## **Demographics**

Nineteen participants partially completed the demographic information form therefore totals do not equal nineteen on all questions (Table 9). Nine participants were spouses, four were adult children, and one was a sibling or other. One participant was 49 or younger, eight were 50-64, 2 were 65-75 and six were 75-85. Sixteen participants were females and three were males. However two other males attended sporadically but did not complete the demographics form. Seventeen attendees identified as being white and one as African American. One other attendee who was Brazilian did not complete the form and attended sporadically. Eight were employed, six retired and three reported being unemployed. Three had high school or less education, nine had an AA or Bachelor's degree and five had advanced degrees. Thirteen of those receiving care lived with the caregivers, one lived alone, two with others and one in a facility. Two caregivers are adult children who do not live near parents but provide support to the other parent caregiver.

Of the caregivers providing daily care ten reported providing personal care, ten reported providing household help and 11 reported that they arranged for transportation services, with some caregivers reporting in more than one category. Thirteen people reported that their loved one had Alzheimer's disease or dementia, two reported definitive dementia, and two Parkinson's' disease. Caregivers reported the extent of memory loss of their loved one, seven reported mild, six reported moderate, one reported severe with two people noted that moderate to severe was more accurate but had not been offered as a choice.

## **Attendance**

Thirty one people registered for the caregivers group but not all followed through with one never attending, three dropping out after one session, and others attending sporadically as their schedule allowed. Nineteen people came for the first session. Another came as a guest of an

attendee for one session only and yet another came as the sibling of a group member who was absent that day. Six males attended a range of 3-8 sessions with an average of five. Twenty-two females averaged seven sessions each with a range of 3-10 excluding those who only attended one time. The professional caregivers did not vary from the family caregivers in attendance.

The ongoing group was comprised of 26 individuals almost none of whom could attend every week. Weekly attendance for the group ranged from 13-20 people with an average attendance of 16. The group was comprised of 21 family caregivers (six husbands, nine wives, and 6 adult children), 4 professional caregivers, and one observer from the Council on Aging in training to lead future support groups,

One of the group members was disruptive in group, talking incessantly to the leader and not easily redirected. She was a therapy client of the co-leader who addressed her anxiety and compulsive talking in an individual session and she never returned to the group. She did send her brother in her place for one session only. Several members had off Island doctor appointments one of the days of the group, appointments made months in advance related to the care receiver. Several missed sessions due to planned vacations to escape the winter weather and two missed due to family issues off Island. One attendee was the son of the care receiver. He attended the first meeting with his mother and then dropped out. His mother reported it was too emotional for him to be there, however she continued to attend.

### **Caregiver Burden Scale**

The caregiver burden scale was completed by many participants and is considered a reliable measure of the impact of the caregiver intervention however data collection problems including incomplete responses compromised this measure (<http://www.fpnnotebook.com>).

The Caregiver Burden Scale is comprised of three sections, on a five-point Likert scale from 0=never to 4=nearly always. Each section is scored separately and then scores are combined for a total score. The higher the score the more severe the burden. The first section focuses on burden experienced by caregiver including loss of control, lack of time and too many responsibilities. The next section focuses on needs of relatives and fears of the caregiver regarding meeting those needs. The last section focuses on negative feelings about caring for someone (anger, embarrassment) and their impact on the caregiver's own health. Scores range from 0-68, with the following indications; 0-20 no or minimal burden; 21-40 mild to moderate burden; 41-60 moderate to severe burden; and 61-68 severe burden (<http://www.fpnotebook.com>).

Six of those who responded both pre and post reported greater burden at the end of the sessions than at the beginning. The other three of those who responded to both pre and post tests reported reduced burden. Three people reported reduced scores in all three areas and one reported increased scores in all three areas. All others reported a mix of scores. The write in comments indicated that the screening tool was confusing and not client friendly. The professional caregivers were ambivalent about how best to answer questions and left some blank. The reduction of negative aspects of caregiving was not supported by the limited data collected. Only nine people completed both the pre and post test completely and the mix of attendees of professional versus family caregivers and spousal versus adult children caregivers further skewed the results.

The Caregiver Burden Scale was criticized by the participants for have confusing questions of which two were double negatives that were interpreted differently by participants compromising those results. The last group discussion spent some time focusing on their

concerns about the Burden tool, reporting that the sessions increased their awareness of the issues and lowered their defenses allowing them to acknowledge more of the impact of caring for a loved one. This may have increased their anxiety and feelings of depression. Therefore they feel that they face the burden more honestly but also that they now have some tools to manage the issues that contribute to burden. This finding may indicate that participants have moved into stage three of the Precaution Adoption Process Model in which they are engaged and understand there is a problem. These results point to the need for further research to identify client friendly, easily understood tools that yield more reliable results.

### **Self Care Scale**

It was determined that the results of the self care tool were compromised during the pre test phase and therefore not included in the final analysis. The self care tool selected turned out to be ambiguous and frustrating to the participants. Some reported completing it for themselves, others for the person they cared for as they stated it did not make sense to complete for themselves despite the directions to do otherwise. Two participants answered as if they were their parents who are the full-time caregivers and several answered as professional caregivers with one answering how she thought the family caregiver might answer. Most responses were incomplete or had qualifying statements added. Others expressed frustration with trying to figure it out and did not return it. It was therefore eliminated.

### **Geriatric Depression Scale**

Data available from the Geriatric Depression Scale (GDS) for the caregivers group was inadequate due to inconsistent attendance of participants some of whom did not provide both pre and post test information; some participants not wanting to complete a depression scale, and others being under the age of 65 for which this scale was not appropriate and an alternative scale

was offered ([http://www.char.brown.edu/GDS\\_short\\_form.PDF](http://www.char.brown.edu/GDS_short_form.PDF)). For the three people who reported both pre and post test, all reported a higher score for depression in post session than pre session. This is a minimal sample and therefore it is difficult to draw conclusions. It is likely that pre test participants felt less comfortable sharing sensitive information and therefore underreported their depression symptoms. It is also possible that information in the program that addressed symptoms and destigmatized depression allowed participants to more honestly and openly report their depression.

### **Zung Self Rating Depression Scale**

Five people reported both pre and post data for the Zung depression scale. Among those were professional caregivers and children of parents with Alzheimer's. All spousal caregivers were 65 or older and completed the Geriatric Depression Scale (GDS). Of the five, four reported reduced depression with point reduction on a scale of 80 from 5 to 21 with one person not answering all questions on both the pre and post test. One reported increased depression. It is possible that for some people learning about the future challenges of managing a love one with Alzheimer's might increase depression and for others just the awareness of what the symptoms are may increase their acknowledgement of those symptoms. Though not statistically significant one participant reported that after completing the depression rating scale she realized that she has been depressed for a long time and was going to seek treatment. Although quiet throughout most of the group sessions this caregiver announced at the last session that the group had been "life changing for her and for her mother, the care receiver." The depression screen samples were determined to be too small to be reliable, but important tools none the less.



**Satisfaction Survey.**

The results of the satisfaction surveys (Table 10) offered the most information about the effect of the caregiver group with participants reporting increased skills to manage those they were caring for and the situations they face as caregivers. One member stated “I come to this group every week to be reminded that I have to give up control in order to survive the many situations I face each day and I appreciate all the advice I get here...it really really helps.”

Fourteen people completed the Satisfaction with Services Survey. All reported that the group helped them in their caregiving role. Members identified the following helpful aspects of the intervention; taught them new strategies that reduced their stress; that they were taking better care of their own needs (one answered both yes and no); that they were better able to manage problematic behaviors; and better able to talk with family and friends about their situation and that of their loved one. All but one participant found the educational materials provided to be helpful. All reported that the length of sessions and the number of sessions were just right with one saying the length was too short and another reporting that the group should only run for 10 not 12 sessions. Three people reported that the size of the group was too big and two reported that the room was too small.

When asked on a Likert scale of 1=not helpful to 4=very helpful to rank the interventions 11 participants found the written materials to be helpful (n=5) or very helpful (n=6) while three reported they were somewhat helpful. Twelve participants found the group discussion to be helpful (n=4) or very helpful (n=8) while one found it somewhat helpful. The respondents ranked presentations as very helpful (n=8) and somewhat helpful (n=3). Journals were used

inconsistently by members with four finding them helpful, four stating somewhat helpful and two not helpful. Connecting with others in similar situations was ranked very helpful (n=9) and helpful (n=5). Community resource information was found to be very helpful (n=7) and helpful (n=4) and likewise websites were ranked very helpful (n=5), helpful (n=3) and somewhat helpful (n=3). Eight people found examples given of AD and dementia very helpful and five found them helpful.

Despite the poor return, failure to complete most evaluation tools and the negative comments it is interesting to note that the satisfaction survey results shows that six respondents found the tools to be very helpful, four helpful and one somewhat helpful. However, since several other tools were used in the intervention, like the home safety evaluation tool, the attendees may be referring to those tools and not the pre and post tests.

The participants gave mixed reviews to the Yoga, Reiki and stress exercises with younger participants being more familiar with and feeling more comfortable participating in complementary medicine techniques. When combining the 3 questions about Yoga, Reiki and Stress Management more found it helpful n= (9) than not (n=2). People liked Reiki the least and Stress exercises the most. Perhaps the laying on of hands by strangers was uncomfortable for members who were just getting to know each other.

Future groups might consider introduction to these techniques to include more information about the value of them for the caregiver and more time allocated to learning the techniques. Satisfaction surveys should expand to address satisfaction with social support networks as these are believed to contribute to alleviating caregiver emotional distress (Roth et al. 2005). For more detailed results and participant comments see Caregiver Group for Alzheimer's and other dementias Satisfaction with Services Survey (Table 8).

## Results

Judging from the overwhelming response to this offering there is clearly an unmet need on Martha's Vineyard for support services for caregivers. The large size of the group allowed many people to participate and while this may not have met everyone's needs, the majority of the group found the size to not be a problem. The group size was more of a problem for the leaders in terms of managing dynamics, redirecting when needed, and collecting and tracking data when so many people had sporadic attendance due to the demands on them. Fortunately the participants were very collegial and formed a cohesive group. They shared a common concern, caring for a loved one in challenging situations. While they came from all walks of life, some Islanders their entire lives and others "wash ashores" who chose to retire here and then wonder how they will manage with families far away and few services to support them. Some have family members who attend the day center and others provide the care themselves. Most have not had respite workers and struggle with the decision to trust the care to a stranger. Others expressed concerns about their ability to afford such care. Caregiver's reactions and attitudes towards the person they care for seem to reflect that those who report positive relationships with the care receiver are less negative than those caring for someone with whom they have negative feelings about the relationship prior to the illness. Many stories told strike a note with all; loved ones behaving inappropriately in a restaurant or other public place; eating problems, loss of relationships with friends who no longer want to be around them, physicians who give conflicting advice or no advice at all, decisions around safety and driving, and daily survival in

challenging situations. A common thread was best stated by one attendee who said “my spouse would never have wished to have this disease or wished it on anyone else.”

The results of this study support two findings in the literature; support groups provide emotional support, information and problem-solving skills to caregivers but do not reduce caregiver burden (Thompson et al., 2007) and for caregivers of those with dementia the strongest predictor of distress is care recipients problem behaviors (Pinquart and Sorensen 2004). Understanding the stage of Alzheimer’s that the caregiver was facing allowed for the leaders to understand the responses of the caregivers and their readiness to change. Those caring for someone in the early mild stage became engaged in understanding the problem. Others caring for someone in moderate stage were in varied stages of denial, feeling overwhelmed, having to deal with family, medical issues of their loved one and their own health issues. Those managing severe stage were reaching out for more help and offering advice to those managing earlier stages of the illness.

Participant’s responses to situations helped the leaders to identify where they were in the change process. Leaders were then able to offer responses (support, information) that were targeted to the stage of AD of the caregiver’s loved one and the caregiver’s stage of change.

### **Discussion**

Despite extensive planning for this program and research to identify meaningful, valid and reliable and user friendly pre and post tests many problems were encountered in the implementation process for the latter. There is a need to identify more useful measures of self care and burden for overwhelmed and often anxious caregivers. It appears that the elder caregivers struggled with forms in ways that were not evident for the younger caregivers. It is important to take into consideration that the challenges that overwhelm elders in their caregiving

role should not be exacerbated by complicated or frustrating pre and post tests. It would be useful in the future to meet one on one prior to group participation to assist participants in completing pre tests and again to meet one on one to complete post tests at the culmination of the group.

Data collection and interpretation was compromised by several aspects of the process: membership of the caregivers group was not a randomly selected sample; sample size for pre and post test data was nine or fewer; attendance at group was inconsistent due to caregiver responsibilities; scales were confusing even after being explained; totals did not add up as some respondents did not answer all questions and others offered two answers for questions for which only one was requested.

This research translation project demonstrated a model grounded in evidence-based research, currently available in the professional literature, which can be replicated on the Island of Martha's Vineyard. The Vineyard, a designated rural health area, experiences some unique and not easily addressed public health issues including lack of adequate resources for a rapidly expanding elderly population. It is hoped that this implementation will contribute to families being able to manage their loved ones at home for longer periods of time with more positive outcomes. Given that the results of each of the screening tools have fewer than ten sample sizes and the respondents are a mix of professional and family caregivers the results are not statistically reportable. The results gathered in pre and post tests may not be related to the meaningful significance of this intervention. The satisfaction survey may offer the most informative data about the effect of the support group on the caregiver's lives. Future initiatives should consider qualitative methods such as journaling and storytelling. Some attendees suggested that role playing might be a useful activity once a group becomes comfortable with

each other. Content analysis of the satisfaction data might also be useful for future groups.

Just like the REACH study this author concluded that “multiple challenges of caregiving are not easily addressed” (Schultz et al., 2003).

### **Plan for post-project continuation and implications for future practice and translational research**

A grant proposal submit to the Tufts Foundation, focusing on community partnerships to address caregiving among elders, has received an initial positive review and we hope to receive an award in June. This grant proposes to replicate this 12-week model two times in one year.

At the completion of this structured 12-week program, caregivers were invited to join an ongoing support group scheduled to meet every other week, year round. A psychotherapy group that addresses loss and grieving was also offered. If successful this grant will create a much needed ongoing support for the rapidly growing number of caregivers on Martha’s Vineyard. It is important to note that pure replication of this model is not realistic as new information becomes available and material are updated they must be integrated into the model.

### **Lessons learned**

Although this group managed in a large group setting, a smaller group would likely be more effective and more personal to those attending and would offer each member more opportunities for active participation and questions. While inconsistent attendance created some challenges for continuity, the group members greatly appreciated the flexibility and many would have been eliminated if we had not offered that. While some homework assignments seemed like a good idea (i.e. home safety evaluation checklist) most caregivers were not able to complete them outside of the class and these important tools should be incorporated into the structured time.

Seeking new tools to measure Caregiver Burden and self-care for future groups would be important. Also applying a tool like the Functional Assessment Staging Test (<http://www.mccare.com>), a validated measure of the course of AD, would allow the leaders to target information to group members based on where they are in the process of adapting based on an accurate measure of their loved ones stage of disease.

Future groups should develop a protocol that follows up with those who drop out to learn from them and refer them to alternative services if needed. There is also a need to develop an easily accessible document of a network of support services available on Island (respite, daycare, hospice, VNA) as well as off Island (memory clinics, neuropsychologists, neurologists) for these of times isolated caregivers. Those who missed sessions were able to get the materials at the next session they attended. Several members “buddied” to get materials for each other and fill them in on the group. The most profound learning was that many times the simplest suggestions are very powerful and bring about positive change in both how the caregiver experiences caregiving and how the person they care for responds. One such suggestion was to never offer the AD patient a plate of food that required more than one way to eat it (fingers, fork, spoon) so that they would not become confused and frustrated. As second suggestion was not to argue and always to distract in stressful moments. This is perhaps the most important outcome of a support group.

**Table 1. Precaution Adoption Process Model stages as they relate to the Stages of Alzheimer’s disease**

Precaution Adoption Process Model			Alzheimer’s disease stages
Stage 1 Unaware of health risk			Stage 1: Mild AD disease not yet diagnosed but minor early signs  preconscious thoughts that something is wrong but not yet ready to address the issue  end of stage one, symptoms may allow one to deny anything but routing old age has occurred requiring no specific action but many now understand there is a problem
Stage 2 Aware of the issue but no thoughts of adapting precautions			
Stage 3 Engaged and understand there is a problem			
Stage 4 Adopters who act (go to stage 6)	Stage 4 Adopters but do not yet act (go to stage 5)	Stage 4 Non adopters (go to stage 4)	Stage 2: Moderate AD  Increased memory loss  Confusion  Agitation, restless, wandering  Difficulty organizing thoughts
Stage 5 Having decided not to act			
Stage 6 Acting			Stage 3: Severe AD  No recognition of family/friends  Seizures  Difficulty swallowing
Stage 7 Maintenance			

*Note.* Adapted from “Theory at a Glance: A Guide for Health Promotion Practice,” National Cancer Institute <http://www.cancer.gov/cancertopics/cancerlibrary/theory.pdf> and “Alzheimer’s disease Unraveling the Mystery,” NIA/NIH, p.30-31. Copyright 2007 by Alzheimer’s disease education and referral center.



**Table 2. Pre and post test standardized scales**

Scale	Reference
Zarit Burden Interview Short Version	Bedard et al., 2001 adapted version from the Family Practice Handbook <a href="http://www.fpnnotebook.com">http://www.fpnnotebook.com</a>
Self-Care Scale determined to have unreliable responses and not included in the results	<a href="http://www.apsnetwork.org">http://www.apsnetwork.org</a>
Geriatric Depression Scale (65 and above)	<a href="http://www.char.brown.edu/GDS_short_form.PDF">http://www.char.brown.edu/GDS_short_form.PDF</a> <a href="http://www.stanford.edu/~yesavage/GDS.english.short.html">http://www.stanford.edu/~yesavage/GDS.english.short.html</a>
Zung Depression Scale (<65)	<a href="http://www.depressiontreatment.com">http://www.depressiontreatment.com</a>
Satisfaction with services survey.	Developed by the leader for Martha's Vineyard Community Services

**Table 3. 12 week schedule of Caregiver Group**

Week	Didactic topic	Informational materials	Source	Journal activity	Self-care activity
1	Welcome and outline of plans for group	Stages of AD  Confronting reality  how to screen a personal hire	Alz.org and NIH reference  Caretocareprogram.com	Begin journal of daily activities	Intro to the concept of complementary medicine
2	dementia and AD	Understanding memory loss  Role changes in moderate AD National AD organizations  Decision making and dementia	National Institute on aging  Caretocareprogram.com  Hartford Institute for Geriatric Nursing	Caregiver self assessment Identify areas of concern	Intro to Chair Yoga
3	Caring for someone with dementia and caring for yourself	Caring for a person with AD or other dementia  Home safety inventory for older adults with dementia  Activities for you and your loved one	National Institute on aging  Hartford Institute for Geriatric Nursing	Identify safety concerns at home	Intro to Reiki
4	Home safety for people with AD, driving and operating machinery	Home care handout  Suggested safety precautions for the home	National Institute on aging	Identify medication concerns	Concepts in stress reduction
5	Medication management	Medications using them safely	National Institute on aging	Identify issues with ADL's	Continue chair yoga

		Managing depression  Talking with your doctor	NIH and Wyeth depression information  Caretocareprogram.com		
6	Dressing and activities of daily living	Assessing pain in older adults with dementia	fpnnotebook.com  Hartford Institute for Geriatric Nursing	Identifying eating and sleep issues Identifying pain issues	Reiki
7	Sleep and eating problems	Eating and feeding issues	fpnnotebook.com  Hartford Institute for Geriatric Nursing	Identifying concerns about wandering	Yoga and Reiki
8	Wandering behaviors	Working with professional caregivers	fpnnotebook.com  Caretocareprogram.com	Identifying concerns about behavior	Relaxation exercises
9	Managing challenging behaviors	Avoiding restraints De-escalation, disengagement  Assessing pain	fpnnotebook.com  Hartford Institute for Geriatric Nursing  Caregiver.org	Identifying issues with family or friends in helping them understand about AD	Relaxation and yoga
10	Talking to family and friends about AD Financial and legal planning	Improving communication /c your family And connecting with others	Alz.org  Caretocareprogram.com	Identifying concerns about the future	Relaxation and Reiki
11	When your loved one is hospitalized  When to consider a Nursing home	Working with families of hospitalized older adults  Nursing Homes: making the right choice  Getting Help and	Hartford Institute for Geriatric Nursing  National Institute on aging  Caretocareprogram.com	What next?	More yoga

		how to screen a Financial and legal planning	“		
12	Wrap up and discussion of possible continuance of the support group	Staying positive	Caretocareprogram.com		Refresher of all self care activities

**Table 4. Costs and plan to obtain resources**

Budget	Mental Health Center (MVCS) grant funded	COA In-kind	Project Total
Clinician – 1 ½ hr group, and ½ hr travel x 12 groups 64 hrs at \$50 per hour	1,200.00		1,200
2 hr interview and ½ hr travel x 16 potential group members	2,000.00		2,000
Clinician 2 hr prep = 24 hrs at 50 per hours	1,200.00		1,200
Clinician individual meetings with group members as needed 1 hr per member 12 @ \$50.00	600.00		600.00
COA directors time to support project Estimated at 4 hrs each x 4 directors @ 28 per hour		448	448
COA directors time for support and collaboration 1 hr per week. 4 COA's at 28 per hr		1,344	1,344
Outreach worker recruitment and meeting with potential referrals 50 hrs at 20 per hr		1,000	1,000
Subtotal Personnel Expense	5,000	2,793	7,792
15% overhead expenses	750	418.80	1168.80
<b>Total Personnel</b>	<b>5,750</b>	<b>3,211.80</b>	<b>8,961.80</b>
<b>Non personnel expenses</b>			
Advertising	No charge in 55 over column of newspapers		n/a
Color printed Brochure preparation 250 @ .43 each			107.50
Mailing to providers 60 @ .44			44.00
Space at COA or MVCS to be determined	*in kind	In kind	
Travel @ .55 per mile est. miles 600	330.00		330.00
Program Materials copying at .05 cents per copy estimated copies 720 and notebook @ 4.00 each	84.00		84.00
Administrative Support	*In-kind		
<b>Total Project Costs</b>			<b>9,527.30</b>

Partially funded by Title III E Grant from Elder Services of Cape Cod and the Islands, CORE, Counseling, Outreach Referral and Evaluation for elders funded by the MV Hospital Community Initiatives, in kind funding from Martha's Vineyard Community Services and voluntary contributions.

**Table 5. Time line of intervention**

<b>Project Month</b>	<b>Activity</b>
January pre group	<p>Meet with COA leadership to finalize details of collaboration to establish this program</p> <p>Training of COA staff on identification of AD and recruitment strategy</p> <p>Development of social marketing plan</p> <p>Creation of flyer</p> <p>Distribution of materials</p> <p>Identify evidence- based resources</p> <p>Develop schedule of psycho educational presentations in conjunction with COA's</p> <p>Develop notebooks of all materials for group for group leader</p> <p>Organize materials for participants</p> <p>Respond to all phone calls of inquiry</p> <p>Obtain space</p> <p>Mailing to community providers/faxing/posting announcements</p> <p>Develop advertising plan with newspaper and agency newsletters</p> <p>identify and register participants</p> <p>finalize group participants</p> <p>arrange for respite reimbursement as needed</p> <p>collaborate with co leaders coming to learn the program</p>
January first session	<p>Distribute assessment forms using and collect information</p> <p>Distribute note books, journals</p>
January second session	Collect pre test assessment forms
Feb/Mar	Group sessions, weekly post group meeting with co leaders, and preparation meeting for following week. Follow up with individuals in need.
12 <sup>th</sup> and final session	Complete post test assessments
April post last session	Analyze data of pre and post test
April	Final report of intervention
May	<p>Presentation at UMass</p> <p>Presentation at Health Care Council MV</p> <p>Presentation at CORE community meeting</p> <p>Presentation Elder services workers Martha's Vineyard</p>

**Table 6 Caregiver Burden Scale**

Rank these statements on how true they are for you as a caregiver, using a scale of 0 to 4 with 0 =Never and 4 = Nearly Always.

**Section 1**

\_\_\_\_\_ I don't have enough time for myself.

\_\_\_\_\_ I am over-taxed by responsibilities.

\_\_\_\_\_ I have lost control over my life.

\_\_\_\_\_ I am uncertain about what to do for my relative.

\_\_\_\_\_ I should do more to help my relative.

\_\_\_\_\_ I could do a better job caring for my relative.

\_\_\_\_\_ I feel burdened by caring for my relative.

\_\_\_\_\_ Total Points for Section 1

**Section 2**

\_\_\_\_\_ My Relative needs help all the time.

\_\_\_\_\_ My relative depends on me to help him/her complete daily tasks.

\_\_\_\_\_ I fear what may happen to my relative in the future.

\_\_\_\_\_ I fear I will not be able to continue to care for my relative.

\_\_\_\_\_ I wish someone else would take over my caregiving responsibilities.

\_\_\_\_\_ I feel a sense of strain when I'm with my relative.

\_\_\_\_\_ Total Points for Section 2

**Section 3**

- \_\_\_\_\_ I sometimes feel anger toward my relative.
- \_\_\_\_\_ I am sometimes embarrassed by my relative.
- \_\_\_\_\_ I feel uncomfortable about having friends over.
- \_\_\_\_\_ Caring for my loved one has a negative impact on my social life.
- \_\_\_\_\_ Caregiving has a negative impact on my relationships with other family Members and friends.
- \_\_\_\_\_ Caregiving has affected my health.
- \_\_\_\_\_ Being a caregiver impacts my privacy.
- \_\_\_\_\_ Total Points for Section 3
- \_\_\_\_\_ **Total Points for All 3 sections**

**Interpretation**

- No or minimal burden: 0 to 20 points
- Mild to moderate burden: 21 to 40 points
- Moderate to severe burden: 41- 60 points
- Severe burden: 61 to 84 points

Adapted from The Family Practice Handbook <http://www.fpnotebook.com>



**Table 7. Geriatric Depression Scale****MOOD SCALE  
(short form)**

Choose the best answer for how you have felt over the past week:

1. Are you basically satisfied with your life? YES / NO
2. Have you dropped many of your activities and interests? YES / NO
3. Do you feel that your life is empty? YES / NO
4. Do you often get bored? YES / NO
5. Are you in good spirits most of the time? YES / NO
6. Are you afraid that something bad is going to happen to you? YES / NO
7. Do you feel happy most of the time? YES / NO
8. Do you often feel helpless? YES / NO
9. Do you prefer to stay at home, rather than going out and doing new things? YES /  
NO
10. Do you feel you have more problems with memory than most? YES / NO
11. Do you think it is wonderful to be alive now? YES / NO
12. Do you feel pretty worthless the way you are now? YES / NO
13. Do you feel full of energy? YES / NO
14. Do you feel that your situation is hopeless? YES / NO
15. Do you think that most people are better off than you are? YES / NO

*Note.* (<http://www.stanford.edu/~yesavage/GDS.english.short.html>)

**Table 8: Zung Depression Self rating scale**

This depression test is based on Zung's Self-Rating Depression Scale. It is being provided by *Depression Treatment Now* for informational purposes only. The results of this depression test should not be used as a replacement for assessment by a qualified health care professional.

- |   |   |
|---|---|
| <p>1. I feel down-hearted and blue</p> <p><input type="checkbox"/> A little of the time</p> <p><input type="checkbox"/> Some of the time</p> <p><input type="checkbox"/> Good part of the time</p> <p><input type="checkbox"/> Most of the time</p>         | <p>11. My mind is as clear as it used to be</p> <p><input type="checkbox"/> A little of the time</p> <p><input type="checkbox"/> Some of the time</p> <p><input type="checkbox"/> Good part of the time</p> <p><input type="checkbox"/> Most of the time</p>      |
| <p>2. Morning is when I feel the best</p> <p><input type="checkbox"/> A little of the time</p> <p><input type="checkbox"/> Some of the time</p> <p><input type="checkbox"/> Good part of the time</p> <p><input type="checkbox"/> Most of the time</p>      | <p>12. I find it easy to do the things I used to</p> <p><input type="checkbox"/> A little of the time</p> <p><input type="checkbox"/> Some of the time</p> <p><input type="checkbox"/> Good part of the time</p> <p><input type="checkbox"/> Most of the time</p> |
| <p>3. I have crying spells or feel like it</p> <p><input type="checkbox"/> A little of the time</p> <p><input type="checkbox"/> Some of the time</p> <p><input type="checkbox"/> Good part of the time</p> <p><input type="checkbox"/> Most of the time</p> | <p>13. I am restless and can't keep still</p> <p><input type="checkbox"/> A little of the time</p> <p><input type="checkbox"/> Some of the time</p> <p><input type="checkbox"/> Good part of the time</p> <p><input type="checkbox"/> Most of the time</p>        |
| <p>4. I have trouble sleeping at night</p> <p><input type="checkbox"/> A little of the time</p> <p><input type="checkbox"/> Some of the time</p> <p><input type="checkbox"/> Good part of the time</p> <p><input type="checkbox"/> Most of the time</p>     | <p>14. I feel hopeful about the future</p> <p><input type="checkbox"/> A little of the time</p> <p><input type="checkbox"/> Some of the time</p> <p><input type="checkbox"/> Good part of the time</p> <p><input type="checkbox"/> Most of the time</p>           |
| <p>5. I eat as much as I used to</p> <p><input type="checkbox"/> A little of the time</p> <p><input type="checkbox"/> Some of the time</p>  | <p>15. I am more irritable than usual</p> <p><input type="checkbox"/> A little of the time</p> <p><input type="checkbox"/> Some of the time</p>   |

- Good part of the time
- Most of the time

6. I still enjoy sex
- A little of the time
  - Some of the time
  - Good part of the time
  - Most of the time

7. I notice that I am losing weight
- A little of the time
  - Some of the time
  - Good part of the time
  - Most of the time

8. I have trouble with constipation
- A little of the time
  - Some of the time
  - Good part of the time
  - Most of the time

9. My heart beats faster than usual
- A little of the time
  - Some of the time
  - Good part of the time
  - Most of the time

10. I get tired for no reason
- A little of the time
  - Some of the time
  - Good part of the time
  - Most of the time

- Good part of the time
- Most of the time

16. I find it easy to make decisions
- A little of the time
  - Some of the time
  - Good part of the time
  - Most of the time

17. I feel that I am useful and needed
- A little of the time
  - Some of the time
  - Good part of the time
  - Most of the time

18. My life is pretty full
- A little of the time
  - Some of the time
  - Good part of the time
  - Most of the time

19. I feel that others would be better off if I were dead
- A little of the time
  - Some of the time
  - Good part of the time
  - Most of the time

20. I still enjoy the things I used to do
- A little of the time
  - Some of the time
  - Good part of the time
  - Most of the time

**Table 9 . Profile of class participants who attended four or more classes and completed the demographics form.***(N = 19)\**

Demographic Characteristic	data
Age of class participants by range	
<50	1
50-64	8
65-74	2
75-85	6
Caregivers' relationship to care receiver	
Spouse	9
Adult Child	4
Sibling	1
Professional	3
Caregiver Gender	
Male	3
Female	16
Caregiver Ethnicity	
White	17
Latino	1
African American	1
Employment Status of Caregivers	
Employed	8
Unemployed	3
Retired	6
Educational Level	
High School or less	3
AA or Bachelors' degree	9
Graduate degree	5
Care receiver's living arrangement	
Lives with caregiver	13
Lives alone	2
Lives in a facility	1
Adult children supporting a parent caregiver	2
Amount of Care provided	
Personal care	10
Household help	10
Transportation	11
Illness condition of care receiver	
Alzheimer's/dementia	13
Parkinson's disease	2
Post stroke dementia	2
Extent of Memory Loss***	
Mild	7

Moderate	6
Severe	1
Comorbid medical conditions	
Cardiac	
Diabetes	
Hypertension	

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Adapted from “Empowerment of Family Caregivers,” by L. Boise, 2005. *Educational Gerontology*, 31, p. 582.

\*not all participants completed the demographic form and not all respondents answered all questions

\*\*participants were instructed to select all that apply

\*\*\*Two participants wrote in moderate to severe, a choice not offered

**Table 10. Caregiver Group for Alzheimer’s and other dementias; Satisfaction with Services Survey**

Martha’s Vineyard Community Services  
Winter/Spring 2012

**Please circle yes or no in response to the following questions.**

Did the caregiver support group help you in your caregiving role?	Yes	<b>14</b>	No	<b>0</b>
Did the support group teach you new strategies to reduce your stressed?	Yes	<b>14</b>	No	<b>0</b>
Are you taking better care of you own needs?	Yes	<b>14</b>	No	<b>1*</b>
Were the educational materials helpful to you in your role as a caregiver?	Yes	<b>13</b>	No	<b>1</b>
Are you better able to manage problematic behaviors as a result of these services?	Yes	<b>14</b>	No	<b>1</b>
Are you better able to talk with your family and friends and help them understand your situation and that of your loved one?	Yes	<b>14</b>	No	<b>0</b>

\*one person answered yes and no

**Please rate the following by checking the appropriate box**

	Too short	Just right	Too long
The number of sessions for this program were		<b>12</b>	<b>1</b>
The length of each session was	<b>1</b>	<b>10</b>	

	Too small	Just right **	Too large
The size of the group was		<b>11</b>	<b>3</b>
Space in which program occurred	<b>2</b>	<b>10</b>	

\*\* one said room a bit too small and group a bit too large

**Caregiver Group for Alzheimer’s and other dementias  
Satisfaction with Services Survey  
Page 2**

**Using the following scale please rate how helpful the following activities of the Caregiver support group were for you in your caregiver role.**

	1 = not helpful	2 = somewhat helpful	3 = helpful	4 = very helpful
Written materials		<b>3</b>	<b>5</b>	<b>6</b>
Journals	<b>2</b>	<b>4</b>	<b>4</b>	
Presentations			<b>3</b>	<b>8</b>
Self-evaluation tools		<b>1</b>	<b>4</b>	<b>6</b>
Group discussion		<b>1</b>	<b>4</b>	<b>8</b>
Connecting with others in similar situations			<b>5</b>	<b>13</b>
Community resource information		<b>1</b>	<b>4</b>	<b>7</b>
Websites	<b>1</b>	<b>3</b>	<b>3</b>	<b>5</b>
Examples of AD/dementia issues			<b>5</b>	<b>8</b>
Yoga	<b>2</b>	<b>2</b>	<b>2</b>	<b>5</b>
Reiki	<b>3</b>	<b>1</b>	<b>3</b>	<b>4</b>
Stress exercises	<b>2</b>	<b>4</b>	<b>2</b>	<b>5</b>

Numbers do not equal 14 respondents due to blank responses and some noted not applicable

**Please write a statement about what this program has meant to you.**

I feel better prepared to meet challenges I’ve yet to experience.

Exposure to all of the information needed to prepare for what my mother will be going through.

Periodic reminders of approaches and strategies.

It has meant a great deal to exchange ideas; to have others ask questions I forgot to ask!! I know I’m not alone.

I like very focused format and this program was very focused each week on a specific topic. A lot of information was dispensed in each presentation.

I have found this incredibly helpful. Mom and I are doing so much better, so quickly, since I

**Caregiver Group for Alzheimer's and other dementias**  
**Satisfaction with Services Survey**  
**Page 3**

started using some of the approaches. I feel better.

A social time with the people with similar problems.

The caregivers program enabled me to feel more competent and confident.

Felt well educated as well as supported, a combination hard to beat!

All information is helpful. Meeting others who are family caregivers is helpful.

As a professional caregiver I liked the contact with family caregivers, to see what their lives are like – and my heart goes out to them in their struggles.

As the classes progressed the increasing confidence among participants led to great conversations/sharing about mutual concerns. These in later stages of caregiving shared experiences/resource info – so very helpful.

**What in this program has been most helpful to you in your caregiver role?**

Essential information that was not known but became known allowed me to relax.

Information about what to expect.

Reminders of approaches and strategies

Realizing, he my husband, doesn't know some of the things he says about me.

Understanding just what some of the Alzheimer's behaviors represent has enabled me to better understand what my husband is experiencing.

I have looked forward to these classes each week. Learning new things and being with people who are doing the same thing. Very Helpful!!

The interaction with the people doing the same thing and all of the information!

Techniques on how to talk to mom, and how to prevent upsets before they start.



**Caregiver Group for Alzheimer's and other dementias**  
**Satisfaction with Services Survey**  
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The information provided by my self assessment that I needed to address my own problems.

Support from others.

Presentations.

Wonderful educational tool and well structured which kept a positive flow going.

Connecting with others.

Relax – be calm.

Reminders of a practical nature to be more objective in my reactions to everyday frustrations.

Also, resources to the island were helpful.

Helpful.

**As a caregiver what do you consider to be the greatest problem you face in this role?**

Having access to the people and institutions who interact with my loved one as a daughter.

Distance from my mother and ability to assist from a distance

Shutting up and Self care

If my husband ever/or when has to go to a nursing home.

The lack of hope that a terminal illness represents.

The same thing every day and the constant repeating.

Lack of patience, lack of ingenuity and lack of sleep.

Understanding the changes are not his fault (which I know)'

Confrontation with behavior different than what the Dr. Recommends.

When he (*the care receiver*) can't explain the reason why he doesn't feel well.

Constant work. Rarely a day off. Little time for myself.

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**Satisfaction with Services Survey**  
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The greatest problem is being overwhelmed both physically and emotionally.

Constantly modifying my approach – day by day – to the challenges of my client's needs.

Finding a location for possible future placement that satisfies me, as a former professional in the field.

**What can we do to improve this program for future participants?**

Encourage everyone to share their thoughts.

Increase information segment, sharing segment and relaxation session.

Smaller group size and better organization and distribution of paper work.

I appreciate the program as is.

Perhaps the volume of paperwork can be condensed.

I believe the program was run well and covered everything.

Maybe smaller groups, but otherwise I thought the mix and the information AND THE LEADERSHIP were incredibly fabulous.

Great job, Thank you.

The program leaves little room for improvement!

Somewhat larger room.

**Other comments**

Thanks for your work.

Loved it! Thank you!

The leaders have done a superb job.

Thank you so much. You have given me so much more direction than I have had.

**Caregiver Group for Alzheimer's and other dementias  
Satisfaction with Services Survey  
Page 6**

Bravo

Thank you for sharing your valuable time. We gained a lot from your enthusiasm and knowledge of the topic.

I would like to see an organization of a respite caregivers – volunteer – to give free care to family caregivers.

Location for the island is good. Parking was great and time in the morning was exceptional for me. Thanks so very much. I like the idea of an ongoing support group.

**Other recommendations from participants noted on satisfaction survey.**

Would be great to create a calendar of events for us to go to with our patients.

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**Letter of support for the development of a caregivers support group for those caring for  
elders with Alzheimer's or other dementias**

Martha's Vineyard Community Services, in conjunction with two elder services grants at the agency, is pleased to support the development of a caregiver intervention group for persons caring for elders with Alzheimer's disease or other dementias. The Vineyard is designated as a rural health area and as such suffers from lack of professional resources to deliver the needed services in our community. We also have a greater number of elders when compared with the rest of Massachusetts and the projected need far exceeds current resources.

MVCS works closely with the Island Health Council, the mental health and addictions committee and the councils on aging on the Vineyard to develop and seek funding for programs to respond to identified need. Caring for caregivers is a priority need on the Island and we have secured funding to meet the need of a caregiver support group.

The proposed intervention by Nancy Langman ARNP, MS, MPH, DNP (C) is fully supported by MVCS. If I can be of further assistance do not hesitate to contact me.

Julia Burgess  
Executive Director, MVCS