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Adapting the Resources for Enhancing Alzheimer's Caregivers Health (REACH) program for use in a nursing home setting

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*Adapting the Resources for Enhancing Alzheimer's Caregivers
Health (REACH) program for use in a nursing home setting*

OCT 7003 Capstone Paper

Project Submitted in Partial Fulfillment of the Requirements
for the Degree of Doctor of Occupational Therapy
(Concentration: Allied Health Science)

by

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Table of Contents

List of Tables 6

Executive Summary 8

Chapter

I. Introduction 9

 Purpose of the Project 10

 Problem Statement 11

 Significance of the Problem 11

 Research Objectives 13

 Research Question 14

 Definition of Terms 14

 Limitations 15

II. Literature Review

 Alzheimer’s disease 17

 Preclinical Stages of Alzheimer’s Disease 17

 Mild Cognitive Impairment Due to Alzheimer’s Disease 18

 Dementia Due to Alzheimer’s Disease 20

 REACH Program: Development and Implementation 21

 REACH Program: Cost Effectiveness 22

 REACH Program: translation to practice settings 23

 REACH-Like interventions: caregiver and care recipient focus 24

 Occupational Therapy and Dementia Management 25

Translation studies	26
Summary	29
III. Methodology	
Design	31
Participants	31
Inclusion Criterion	32
Exclusion Criterion	33
Recruitment of Participants	33
Consent Process	34
Materials	35
Procedure	37
Phase I	38
Phase II	40
Risks, Discomforts, and Inconveniences	41
Psychological discomfort	41
Emotional discomfort	42
Inconvenience related to time investment	43
Breach of confidentiality	44
Protection of confidential information	46
Benefit to subjects	46
Data Analysis	46
Data Analysis: Process	48
Scientific Benefit	50

Risk/Benefit Ratio	51
IV. Results	
Persistent or Recurrent Challenges	53
Support and Resources	55
Usefulness of Information	58
Interaction with Providers and Management	62
V. Discussion	65
REACH Program: Features and Structure	70
REACH Program: Support Group Component	71
REACH Program: Adaptation for Nursing Home Use	73
Summary	79
Recommendations	82
References	84
Appendixes	
Appendix A	90
Appendix B	94
Appendix C	98
Appendix D	102
Appendix E	106
Appendix F	107
Appendix G	109
Appendix H	111
Appendix I	113
Appendix J	114
Appendix K	115
Appendix L	118
Appendix M	120
Appendix N	124
Appendix O	125

Appendix P 126

List of Tables

Table

1. Proposed Framework for Preclinical Alzheimer’s Disease	18
2. Summary of Clinical and Cognitive Assessment for Mild Cognitive Impairment.	19
3. Caregiver Profile Questionnaire	32
4. Data Analysis Categories and Codes	49

List of Figures

Figure

1. Capstone Project Qualitative Data Analysis Stages 47

Executive Summary

*Adapting the Resources for Enhancing Alzheimer's Caregivers
Health (REACH) program for use in a nursing home setting*

By Edward Golden

The number of persons with Alzheimer's disease (AD) has increased considerably in the United States. This phenomenon has caused significant problems for caregivers related to physical, cognitive, behavioral, and functional deficits of persons in the moderate and/or severe stage of Alzheimer's disease. Family members typically provided unpaid care for persons with AD and were at higher risk for negative health outcomes associated with the role and responsibility of primary caregiver for the person with AD. These problems or concerns related to issues such as caregiver anxiety, depression, guilt, social isolation, and perceived burden. Moreover, such caregiver problems/concerns persisted even after nursing home placement of their relative due to progression of Alzheimer's disease.

The capstone project revealed that family member education and training about AD could be helpful to address problems or concerns associated with the role/responsibility of primary caregiver. The Resources for Enhancing Caregivers Health (REACH) Program had proven effective in assisting family caregivers of persons with AD in the home and other community settings. Therefore, the Principal Investigator (PI) conducted focus group interviews with family caregivers and paid caregivers to determine the feasibility of adapting REACH for use in the nursing home setting. The results of the capstone project would be used to facilitate such adaptation of REACH and potential implementation of the program following Phase II project completion.

Chapter 1

The topic of this capstone project was an investigation of the feasibility of adapting an education and training program for family caregivers of persons with Alzheimer's disease (AD) for use in a nursing home setting. Although nursing home placement may alleviate stressors associated with direct care for persons with dementia, experiences of subjective burden and stress continues for some family caregivers (Majerovitz, 2007).

Dementia is defined as a set of symptoms that identify deficits in brain functioning (McLay & Young, 2007). Key symptoms of dementia include loss of memory, problems with speech and communication, deficits in judgment and reasoning, problems with motor activities, difficulties with basic daily activities (e.g., cooking, managing medications or finances), and deficits in self-care tasks such as dressing, feeding, and toileting (Mace & Rabins, 2011; McLay & Young, 2007; Voigt-Radloff, 2011). Alzheimer's disease, the most common form of dementia, is a progressive, irreversible condition that accounts for approximately 60 to 80 percent of all forms of dementia (Alzheimer's Association, 2012).

Seventy percent of persons with Alzheimer's disease live in the home environment where family and/or friends provide the majority of care related to activities of daily living (ADLs) and basic daily living tasks. Nearly 11 million caregivers in the United States provide 69 to 117 hours per week of unpaid care to persons with Alzheimer's disease each year – or, 12.5 billion hours annually (Alzheimer's Association, 2011; Elliott, Burgio & DeCoster 2010). It is reported that caregiving for persons with dementia can have negative psychosocial and physical effects; particularly for various segments of the population such as women, spouses, and people in lower socioeconomic communities (Sorensen & Conwell, 2011).

Adverse health outcomes for caregivers of persons with dementia include increased risk of stress, burden, depression, and anxiety (Burgio, Collins, Schmid, Wharton, McCallum, & DeCoster, 2009; Falk-Kessler, 2011). Caregiving for persons with Alzheimer's disease can affect the carer's physical health, mental health, quality of life, and hasten placement of the care recipient in a nursing home. It is of note that nursing home placement is a primary clinical indicator of dementia progression (Devor & Renvall, 2008; Gaugler, Mittleman, Hepburn & Newcomer, 2010). The risk of placement in a nursing home is five times greater for a person with dementia than for individuals without dementia-related health concerns. However, nursing home placement does not always relieve family caregiver stressors such as guilt, concerns about quality of care provided, and tension or conflict with nursing home staff (Coehlo et al., 2007; Mittleman, Haley, Clay, & Roth, 2006).

Purpose of Project

The purpose of this project was to determine feasibility of adapting the Resources for Enhancing Alzheimer's Caregivers Health (REACH) program, an education and training program for family caregivers of persons with Alzheimer's disease, to address needs or concerns of family caregivers and explore the feasibility of implementation of the program in a nursing home setting.

The REACH program consists of four sessions that can be provided either in person (home or facility) or by telephone to assist caregivers with issues related to problem solving and skills building techniques. Additionally, the REACH program focuses on caregiver's safety, health, social support, physical and emotional well-being, stress management, and addressing care recipient's problem behavior(s). Focus group interviews were conducted with family caregivers and paid caregivers of persons with Alzheimer's disease that live (or had lived) in a

nursing home. The focus group interviews were conducted to understand components of the REACH program that need to be adapted to address current issues of caring for self and family member with Alzheimer's disease in a nursing home.

Statement of the Problem

Given that family caregiver's roles and responsibilities often change following placement of a loved one with Alzheimer's disease in a nursing home, there was need for investigation of the feasibility of adapting an existing education and training program for use in the nursing home.

Significance of the Problem

Of the nearly 5.4 million individuals with Alzheimer's disease (AD) in the United States, over 70% live in the home environment where family and/or friends provide about 75% of informal care related to activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Given that caregivers expend from 69 to 117 hours per week providing informal care to people with dementia, they are at increased risk for detrimental effects to physical and psychological health, quality of life, and general well-being (Elliott, Burgio, & DeCoster, 2010).

According to Nichols and colleagues (2008), the number of people with Alzheimer's disease in the U.S. is projected to increase to 13.2 million by the year 2050. The authors estimated that national costs, with respect to medical care and lost caregiver productivity would exceed \$350 billion per year by 2050. They also noted that caregivers often "lack the skills to manage patient behaviors and their own stress, both of which are critical to caregiving in the home" (Nichols et al, 2011, p. 353). Therefore, it was hypothesized that approaches which helped caregivers to improve coping skills and manage care recipient's dementia-related behaviors could facilitate life skills acquisition, improve quality of life (CG and CR), and

decrease costs associated with caring for people with Alzheimer's disease. In particular, \$18,408/year for mild AD, \$30,096/ year for moderate AD, and \$36,132/year for severe AD; and, the estimated \$61 billion per year for U.S. businesses in terms of CG absenteeism and lost productivity (Nichols et al., 2008). The current national expenditure for Alzheimer's and other dementias is \$172 billion but the cost is projected to increase to over \$1 trillion in 2050 (Alzheimer's Association, 2011).

With respect to global impact of dementia, it was reported that approximately 35.6 million individuals worldwide would be affected by dementia in 2010. That number was projected to increase to 67.5 million in 2030, and 115.4 million in 2050 (Alzheimer's Disease International, 2010). Given that Alzheimer's disease accounts for up to 80 percent of all cases of dementia, there is significant concern for adverse personal and economic consequences that result from this global health care epidemic (Gitlin & Vause Earland, 2010). Moreover, the authors noted, "...developing testing and implementing nonpharmacologic approaches in clinical settings to manage the disease and that support or enhance quality of life for individuals with dementia and their families, is a public health imperative both in the United States and worldwide" (Gitlin & Vause Earland, 2010, p. 1).

According to Gaugler, Mittleman, Hepburn and Newcomer (2010), nearly 69% of all residents in nursing homes have some form of dementia. Average life expectancy following a diagnosis of Alzheimer's is four to six years – however, some individuals may live as many as 20 years after diagnosis (Alzheimer's Association, 2011; Silverberg, 2007). A person with Alzheimer's will typically experience the severe stage of disease for about 40 percent of the dementia process. Given that 75 percent of people with Alzheimer's are placed in a nursing home by age 80, many older adults with such dementias will be transitioned to an institutional

setting; this statistic is in comparison with the only 4 percent nursing home placement for the general 80-year-old American populace (Alzheimer's Association, 2012).

Dementia can have adverse effects for the entire family in terms of physical, emotional, spiritual, and financial well-being. Caregivers of persons with Alzheimer's disease are at greater risk for stress and depression than are non-caregivers (Tennessee Commission on Aging & Disability, 2009). Interventions that address family caregiver concerns include respite (e.g., adult daycare), education, counseling/case management, emotional support, and multicomponent programs (Pinquart & Sorensen, 2006). Traditional case management approaches that address caregiver concerns following nursing home placement do not always provide desired outcomes when used in isolation. However, multicomponent psychosocial approaches that emphasize client-specific consultation and ongoing professional support provide better results with respect to caregiver health outcomes (e.g., burden, stress, depression), postponing nursing home placement, and improving caregiver experiences associated with eventual transition to the nursing home setting (Gaugler et al., 2010).

Research Objectives

The REACH program was initially designed to be used with caregivers in the home environment. Thereafter, the REACH program was successfully implemented in other settings such as hospitals, universities, and area agencies on aging (Burgio et al., 2009; Nichols et al., 2011)). The objectives of this capstone project were to identify specific concerns of stakeholders (i.e., family members and nursing assistants) in order to determine what component(s) of the REACH program need to be adapted for use in a nursing home. And, subsequently, to engage in discussion with a nursing home administrator to identify barriers and facilitators in order to determine feasibility of implementing the REACH program in nursing homes. However, because

of time limitation, objective number two could not be accomplished during this phase of the capstone project.

Research Question

1. Can the REACH program be adapted to for use in a nursing home to address family caregiver needs or concerns following placement of a loved one with Alzheimer's disease in a nursing home? And if so, how can such adaptation of the REACH program be accomplished?

Definition of Terms

1. Activities of Daily Living (ADLs) – actions that are directed towards an individual taking care of his or her body, including the following tasks: a) bathing, showering; b) toileting and toilet hygiene; c) dressing; d) swallowing/eating; f) feeding; g) functional mobility; h) personal device care; i) personal hygiene and grooming; and j) sexual activity. Also referred to as basic activities of daily living (BADLs) and personal activities of daily living (PADLs) (American Occupational Therapy Association, 2014).
2. Alzheimer's disease – the most common form of dementia, accounting for 60 to 80 percent of all types of dementia. Early symptoms of AD include problems with memory (remembering names or recent events). As the disease progresses symptoms include impaired judgment, disorientation, confusion, behavioral changes, and problems with speaking, walking, and swallowing (Alzheimer's Association, 2012).
3. Basic Activities of Daily Living (BADLs) – see above definition of activities of daily living (ADLs) also referred to as personal activities of daily living (PADLs) (American Occupational Therapy Association, 2014).

4. Centers for Medicare and Medicaid Services (CMS) – the government agency that administers the Medicare, Medicaid program, and Children’s Health Insurance Program (U.S. Department of Health and Human Services, 2014).
5. Focus group – research method that uses discussion and interaction among group participants to investigate and reveal viewpoints that would be difficult to investigate through one on one interview techniques (Liamputtong, 2011).
6. Instrumental Activities of Daily Living (IADLs) – tasks that support daily existence in the home or community but are more complex than basic ADLs. These IADL tasks include the following: a) care of others; b) care of pets; c) child rearing; d) communication management; e) driving and community mobility; f) financial management; g) health management and maintenance; h) home establishment and maintenance; i) meal preparation and cleanup; j) religious and spiritual activities and expression; k) safety and emergency maintenance; and l) shopping (American Occupational Therapy Association, 2014).
7. Self-Care – actions people take to care for themselves or their family member(s) such as bathing, feeding, dressing, toileting, home management, health management, financial management, and community mobility that allows for interaction within the person’s social and environmental contexts (Chambers, Wakley, & Blenkinsopp, 2006).
8. Third-Party Payer – payment provided by anyone except the patient (or, beneficiary) it is considered third-party reimbursement or third-party payment (for example, Medicare, Medicaid, and private insurance companies) (Buff & Terrell, 2014).

Limitations

1. The project was limited to a small number of focus interview respondents.

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2. The project was limited to participation of Alzheimer's disease caregivers that resided in the Memphis Metropolitan region of Southwestern, Tennessee.

Chapter 2

Review of the Literature

The literature review examined studies and opinions from experts who had written or spoken about the effect of Alzheimer's disease on health, well-being, and quality of life for persons with the dementia and their family caregiver(s). Professional journals, trade publications, textbooks, and the internet provided essential contribution to the capstone project.

Alzheimer's disease

Alzheimer's disease was described as "age-related brain disorder" associated with decline in cognitive and physical abilities of the person with the disease. A detailed review of Alzheimer's disease also included description of neuronal damage and significant reduction in brain size (atrophy) due to progression of the disease (National Institute on Aging, 2011). Specific clinical symptoms of AD included problems with memory, cognition, communication and language, and executive functions. Because of significant impairment in cognition and functional ability in the final stages of AD, affected individuals often needed help from caregivers to perform self-care and other basic activities of daily (National Institute on Aging, 2011).

Preclinical Stages of Alzheimer's disease

The problems associated with Alzheimer's disease often develop over a period of years to decades before an individual received a diagnosis of Alzheimer's disease dementia. Because of lack of a standard definition for Alzheimer's disease, the term was used by some to describe pathophysiological processes of the disease (e.g., amyloid beta deposition, tau protein tangles, neuronal depletion) while others use it to describe clinical symptoms such as cognitive and behavioral problems indicative of AD dementia. The authors suggest that the progressive

physiological and neuronal pathology of Alzheimer's disease and clinical symptoms associated with the disease occur on a continuum that that can happen in similar patterns or differ in terms of course of development symptoms over time (Sperling et al., 2011).

A list of the proposed research criteria for defining preclinical AD and describing individuals at increased risk of developing clinical symptoms of AD can be seen in Table 1.

Table 1

Proposed Framework for Preclinical Alzheimer's Disease

Stage 1	Asymptomatic cerebral amyloid development	-high A β load on PET -low CSF A β
Stage 2	Amyloid positivity + synaptic dysfunction and/or neurodegeneration	-neuron abnormality on FDG-PET/fMRI -high CSF tau/p-tau -decreased cortical mass/ decreased hippocampal mass on structural MRI
Stage 3	Amyloid positivity + neurodegeneration + mild cognitive deficits	-minor change from baseline measure in cognition -decreased ability on demanding cognitive tests -not yet at criterion for MCI -last stage of preclinical AD nearing clinical criteria for MCI

(Adapted from Sperling et al., 2011)

Mild Cognitive Impairment Stage of Alzheimer's disease

The term 'mild cognitive impairment due to AD' is used to define the predementia stage in which individuals experience progressive decline in cognitive ability due to Alzheimer's disease (Albert et al., 2011). The authors noted lack of clearly defined standards for identifying specific points at which individuals changed from the being without symptoms of Alzheimer's

disease through progression to the symptomatic predementia stage. Mild cognitive impairment (MCI) is a health condition that can be detected through clinical evaluation, cognitive assessment, and observation of individual performance by a skilled clinician (Albert et al., 2011). Measures used in to determine cognitive ability include memory tests (immediate and delayed) and evaluation of executive functioning ability (e.g., interpretation, problem solving, planning). Additional measures include communication and language comprehension tests (verbal and/or written), assessment of visual and perceptual ability, and evaluation of ability to concentrate or maintain attention on a task (Albert et al., 2011). A summary of the proposed clinical and cognitive assessment for MCI due to AD can be seen in Table 2.

Table 2

 Summary of Clinical and Cognitive Assessment for Mild Cognitive Impairment

Determine clinical and cognitive standards

Concern regarding change in cognitive status on the part of the individual, caregiver/informant, or clinician based on decline from previous level of performance or observed decrease in cognitive ability over time

Evidence of decreased ability in one or more cognitive areas such as memory, language, attention and executive function

Maintenance of independence in self-care and functional abilities

No evidence of dementia due to Alzheimer's disease

Investigate cause of MCI associated with Alzheimer's disease processes

Eliminate other potential causes for cognitive impairment such as vascular problems, traumatic head injury due to falls or accidents, and/or medical problems resulting in cognitive deficits

Establish proof of long-term decrease in cognitive ability, if possible

Indicate presence of personal/familial genetic risk factors for Alzheimer's disease

(Adapted from Albert et al., 2011)

Dementia Due to Alzheimer's disease

McKhann and colleagues (2011) described the efforts of a select workgroup assigned the tasks of updating diagnostic standards for Alzheimer's disease and promoting effective interventions for dementia. The workgroup recommended use of the updated standards in clinical settings to address cognitive or behavioral problems associated with dementia. The workgroup underscored the importance of further research directed at changing standards for evaluation and treatment of AD and increasing global knowledge of dementia-related health conditions (McKhann et al., 2011).

The workgroup identified issues that influenced the task of updating diagnostic standards such as focusing on work-related or routine tasks, assessing functional ability by comparison with previous levels of function, and understanding the influence of other health conditions that are not attributable to delirium or psychiatric condition. They also looked at other important issues, including assessing deficits in cognition effectively and awareness of the influence of cognitive and behavioral problems related to Alzheimer's disease (McKhann et al., 2011).

Lastly, the workgroup recommended adoption of separate standards for categorizing persons with dementia due to Alzheimer's disease. The updated diagnostic categories proposed by the workgroup included: 1) Probable AD dementia, 2) Possible AD dementia, and 3) Probable or possible AD with associated AD pathophysiological progression. Moreover, the classifications of 'Probable AD dementia' and 'Possible AD dementia' were intended for use in clinical settings and the category of 'Probable or possible AD with AD pathophysiology' was intended for use in research settings (McKhann, et al., 2011).

REACH Program: Development and Implementation

The National Institute on Aging (NIH) and the National Institute of Nursing Research funded development of the Resources for Enhancing Alzheimer's Caregiver Health (REACH) program to investigate multicomponent intervention for caregivers of people with Alzheimer's disease. The program was conducted in two stages from 2002 to 2004. The first stage focused on intervention development and testing (REACH I). The second stage involved evaluation of the program at five separate sites around the U.S. (REACH II). The overall project was designed to help dementia caregivers with issues or concerns and encourage their active involvement throughout the intervention process (Belle et al., 2006).

The researchers suggested that participants in the REACH program had better health outcomes in measures of quality of life and management of care recipient dementia-related problem behaviors than control subjects. Strengths of the study included randomized controlled trials, cultural sensitivity, and format adaptability format. The limitations to the study included having only one follow-up assessment which hindered analysis of long-term effect of the intervention; lack of inclusion of people of mixed ancestry and Asian-Americans in the study; and concerns about control methodology (Belle et al., 2006).

Elliott and colleagues (2010) described REACH II as the only multiethnic, multisite randomized controlled trial funded by the NIH to study caregiver issues (e.g., stress and burden) related to Alzheimer's disease. The authors studied the differences in caregivers' health from baseline to completion of the intervention. They reported significant improvement in quality of life, burden, social support, self-care, and management of care recipient dementia-related problem behavior for participants. The researchers found more notable improvement among Hispanic and Caucasian participants than was observed for African American study participants.

Limitations identified by the authors included concern for influence of mediating factors on study outcomes and difficulty ensuring study participants accurately represented the intended research population; for example, informal caregivers who provided care to a person with AD for an extended period of time (Elliott et al., 2010).

REACH Program: Cost Effectiveness

An analysis of the cost effectiveness of the REACH II program was conducted by Nichols and colleagues (2008) at the Veterans Affairs research site in Memphis, Tennessee. The researchers investigated the time individuals spent caregiving and specific components related to cost of intervention delivery including staff salary costs, staff training time and costs, staff intervention time and costs, supervision cost, travel expenses, material costs, and caregiver time and cost. They reported a total cost for the 6-month intervention of \$1,214 per caregiver participant that was distributed among the costs associated with the components noted above. For example, the authors indicated staff intervention time and costs of \$871, supervision costs of \$105, material costs of \$30, and caregiver time and cost of \$167 for the program (Nichols et al., 2008).

The researchers noted that the REACH II intervention had a positive effect on caregiver quality of life as measured by indicators such as caregiver burden, depression and emotional well-being, self-care and healthy behaviors, social support, and care recipient problem behaviors. The researchers also commented on the benefit of the intervention to informal caregivers in terms of time saved. That is, they suggested that the program saved informal caregivers an extra one hour per day in which they did not have to provide direct unpaid care. This would represent a savings in unpaid care of \$1,478 over a 6-month period based on the Department of Labor estimated hourly cost for informal caregiver's time of \$8.12 per hour (Nichols et al., 2008).

REACH program: translation to practice settings.

Burgio and colleagues (2009) modified the REACH II program for Area Agencies on Aging in Alabama to address concerns related to caregiver burden and well-being. The program, REACH OUT (Offering Useful Treatments), was developed with funding from the Alabama Department of Senior Services. The program was based on the original REACH II program but was modified and eliminated two of the seven REACH II components. Therefore, REACH OUT participants received instruction and education about dementia, health maintenance, home safety, behavior management, and stress management (Burgio et al., 2009).

Strengths of the Burgio et al. study included consistency of data across study domains related to acceptability, traditional outcomes, and risk profiles. Limitations of the study included lack of random dyad selection, lack of a control group, and concerns regarding data collection and data analysis methodology (Burgio et al., 2009).

Nichols, Martindale-Adams, Burns, Graney, and Zuber (2011) reported on the second clinical translation study of the REACH II that was conducted from September 2007 through August 2009. The intervention, REACH VA, was similar to the original REACH II program and focused on caregiver education, support, and life skills training. The study addressed caregiver safety, social support, and management of problem behaviors, depression, and health. However, REACH VA interventions were adapted and addressed issues related to problem solving, active engagement in setting goals, and management of caregiver stress. The notable changes in the REACH VA program included elimination of computer-assisted screen telephone component; increased flexibility in adapting intervention sessions; and reduction of risk assessment items from fifty-one down to sixteen items (Nichols et al., 2011).

REACH-Like interventions: caregiver and care recipient focus.

Gitlin, Winter, Dennis, & Hauck (2007) conducted a study to determine the effectiveness of multi-component intervention in addressing environmental and behavioral concerns related to dementia. The program, Project ACT (Advancing Caregiver Training), consisted of a four-month occupational therapy intervention phase (13 in-home sessions) and, thereafter, a two-month follow-up phase. The interventions included education about Alzheimer's disease, life skills training, modification of physical and social environments, and instruction on stress management. The ACT protocol involved active collaboration between interventionists (i.e., occupational therapist or nurse) and caregivers throughout the program (Gitlin et al., 2007).

Gitlin, Winter, Dennis, Hodgson, and Hauck (2010) reported findings of a randomized controlled trial that studied the effectiveness of intervention for caregivers of people with Alzheimer's disease. The program, COPE (Caring for Persons with Dementia in their Environments), consisted of twelve in-home sessions and telephone contacts that were conducted over a four-month period. The COPE program addressed modifiable environmental factors that influence physical and cognitive abilities of the client and reduce caregiver burden.

COPE interventions included home, environmental assessments, caregiver education, and training to address identified concerns. At 4-month outcome, the authors reported statistically significant improvement in care recipient instrumental activities of daily living and caregiver confidence. They also reported clinically significant improvement in care recipient engagement the environment. Limitations of the study included vague definition of active treatment components, lack of generalizability, and concern for skewed data due to possible placebo effect (Gitlin et al., 2010).

Occupational Therapy and Dementia Management

Graff and colleagues noted the effectiveness of occupational therapy to address concerns related to daily function, autonomy, and health for people with dementia and their caregivers (Graff et al., 2006; Graff et al., 2007). The authors conducted a randomized controlled trial that examined effectiveness of occupational therapy intervention and presented findings in two articles that were individually published in 2006 and 2007. The 2006 study examined effectiveness of occupational therapy on functional ability of people with AD, as well as, the caregivers' sense of role competence. They reported that participants who received occupational therapy intervention had significant improvement from baseline in quality of life, health status, mood, and sense of autonomy (Graff et al., 2006). In the 2007 article, the authors studied the effectiveness of occupational therapy interventions in addressing concerns related to quality of life and emotional and physical health of people with dementia and their caregivers. They found that occupational therapy interventions developed with input from participants resulted in improved quality of life, physical function, and emotional well-being of study participants (Graff et al. 2007).

Robinson and colleagues (2009) studied the effectiveness of occupational therapy and multicomponent interventions for persons with AD and their caregivers. The authors conducted a systematic review of psychosocial interventions for caregivers of persons with dementia and found them effective in addressing concerns related to Alzheimer's disease. The study found occupational therapy intervention for cognitive and behavioral problems associated with AD cost effective. The authors also noted improvement in quality of life and health for care recipients and family caregivers related to participation in occupational therapy interventions (Robinson et al., 2009).

Arbesman and Lieberman (2011) studied effectiveness of occupational therapy for people with AD and family caregivers focused on occupation, perception, and routines. The authors reviewed twenty-six articles that met inclusion criterion for occupation; thirty-one articles for perception; and twenty-four articles on routines. They indicated that strong evidence supported the effectiveness of occupational therapy and multicomponent dementia management approaches for people with AD and related dementias (Arbesman & Lieberman, 2011).

Thinnes and Padilla (2011) investigated the effectiveness of occupational therapy interventions on self-care, functional mobility, communication, and psychological and behavioral health of people dementia and their informal caregiver. The authors reviewed forty-three articles and developed eight research categories that addressed concerns of care recipients and caregivers. The research categories consisted of occupational therapy interventions, direct interventions with caregivers, joint interventions with caregivers and patients, family interventions, combination of strategies involving interventions in the home, technology-based intervention, and respite care. Based on study findings, the authors recommended occupational therapists incorporate interventions that aligned with concerns identified by the client and their informal caregiver into the treatment regimen (Thinnes & Padilla, 2011, p. 542).

Translation Studies

Gitlin, Jacobs, and Earland (2010) conducted a 2-year study of an existing intervention, Environmental Skill-building Program (ESP). The program addressed issues related to caregiver burden and functional status of people with dementia. The researchers studied the feasibility of translating ESP for use in the home health setting and obtaining payment for program participation through Medicare Part B reimbursement. They found in the study that certain

interventions could be combined with existing occupational therapy treatment plans and qualify for Medicare Part B reimbursement (Gitlin et al., 2010).

Through the successful implementation of ESP, the authors highlighted the importance of matching interventions for caregivers with the established functional goals of the person with dementia. They also commented on the significant restriction to Medicare Part B reimbursement for caregiver training after completion of occupational therapy services (Gitlin et al., 2010). The authors identified pertinent issues such as the ability or willingness of to pay for programs like ESP from personal resources of care recipient or caregiver and advocacy regarding expanding Medicare coverage for caregiver training “independent of patient therapeutic goals”. They also discussed the importance of facilitating increased referral to occupational therapy for physical and cognitive concerns related to dementia (Gitlin et al., p. 854).

Maslow (2012) authored a white paper that reviewed over forty non-pharmacological interventions that demonstrated positive outcomes for persons with dementia and family caregivers. The researchers received funding from the Alzheimer’s Disease Service and Supports Program, U.S. Department of Veterans Affairs, and the Rosalyn Carter Institute for Caregiving (Maslow, 2012). The author recommended further research to determine effective treatments and care practices for early and late stages of Alzheimer’s disease. He also suggested increased focus on dementia-related concerns of racial and ethnic minority populations and more detailed examination of other types of dementia (Maslow, 2012).

The recommendations pertained only to non-pharmacologic interventions designed for people with Alzheimer’ disease or other dementias that lived in community settings. Therefore, the work group did not examine interventions intended for use in settings such as nursing homes,

assisted living centers, adult day care centers, hospitals, or inpatient rehabilitation facilities. (Maslow, 2012).

Altpeter, Gwyther, Kennedy, Patterson and Durence (2013) studied the community translation of the REACH II program conducted through a grant from U.S. Administration on Aging that was provided to the North Carolina Division of Aging and Adult Services. The researchers indicated that fifteen Interventionists (family consultants and coaches) employed by three different organizations reported satisfaction with the program and the certification requirements. The Interventionists also reported approval regarding the ability to create a treatment plan, tailor the intervention to the needs of the client, and develop action plans using the REACH II program. The authors noted that Interventionists expressed a desire to keep on with the REACH II program but they also offered several recommendations for program adaptations, including: addressing the role and accommodation ability of the family consultant (Interventionist), taking participant skill and experience level into consideration, use of role play to address problem solving concerns, assessing caregiver readiness, and streamlining family consultant and caregiver guides and tools (Altpeter et al., 2013).

Gitlin and colleagues (2008) studied effectiveness of activity-based interventions to reduce caregiver distress, depression, and burden. The program, Tailored Activity Program (TAP), was carried out by occupational therapists and involved six home sessions (90-minutes) and two telephone contacts (15-minutes) over a 4-month period. Researchers suggested that designing activity programs that incorporated existing capabilities and previous roles/interests of people with dementia would have positive effect on care recipient problem behaviors and caregiver burden and role competence. The authors identified specific study limitations such as small sample size, lack of attention control group, and use of caregiver self-report on behavioral

issues. The authors noted that tailored activities were effective for helping people with dementia and caregivers by decreasing behavioral problems that lead to nursing home placement and improving quality of life (Gitlin et al., 2008).

Tompkins and Bell (2009) studied the effectiveness of individualized intervention to address problem behaviors and alleviate caregiver burden or stress. The researchers evaluated three intervention approaches provided to caregivers of persons with dementia in Colorado. The interventions consisted of a psychoeducational program known as the Savvy Caregiver Program (SCP), a respite grant program (adult daycare, in-home care, or other respite services), and combination of both SCP and respite. According to the authors, results of the study suggested that psychoeducational programs and respite grant programs can have a positive effect on dementia caregiver's health outcomes (e.g., depression scores and self-reported health) (Tompkins & Bell, 2009).

According to the authors, both intervention approaches (SCP and respite program) were effective in helping participants with problem behaviors or caregiver burden and stress. Strengths included a 6-month follow from baseline to determine long-term effect of interventions, partnership with a community organization, and having a training manual and educational material. Limitations of the study included lack of randomization, no control group, and lack of ethnic diversity among study participants. The authors suggested that the above interventions could be used in various settings to help people with dementia and their caregivers (Tompkins & Bell, 2009).

Summary

The literature review provided relevant information about Alzheimer's disease and other related dementias and identified concerns of people with Alzheimer's disease and informal

caregivers. Several articles reported the importance of non-drug interventions to help clients and caregivers deal with the range of issues that arise throughout the course of Alzheimer's disease. The review also pointed to the benefit of occupational therapy interventions for concerns related to health and well-being of persons with Alzheimer's disease and their caregiver.

Occupational therapy interventions that addressed functional, psychological, and environmental concerns of people with Alzheimer's disease and caregiver were found effective in the literature review. Some review articles discussed effectiveness of multicomponent occupational therapy interventions in addressing client and caregiver concerns. There was evidence of successful adaptation and implementation of the REACH program in different clinical and community settings. Therefore, the literature review provided support for the decision to conduct the capstone project on adapting REACH for use in a nursing home setting.

Chapter 3

Methodology

Design

A qualitative design that consisted of focus group interviews was conducted with family caregivers and paid caregivers of persons with Alzheimer's disease that resided (or had resided) in a nursing home.

Participants

There were a total of four separate focus group interviews with individuals from two main groups of stakeholders: a) family caregivers, which comprised three separate types of caregivers, i.e., husband or wife (n=3), son or daughter (n=3), and brother or sister (n=2) of a person with Alzheimer's disease who resided (or, had resided) in a nursing home; and b) paid caregivers, in which certified nursing assistants (n=2) that provided care to nursing home residents with Alzheimer's disease participated.

The number of potential participants initially noted in the Institutional Review Board protocol consisted of twelve family caregivers, four paid caregivers, and one nursing facility administrator. However, the recruitment process yielded only eight family caregivers and two paid caregivers (i.e., certified nursing assistants) that agreed to participate in the focus group interviews. The completion of an individual interview with a nursing home administrator could not be accomplished due to time constraint in completing the capstone project (A listing of participant demographic information can be seen in Table 3).

Table 3

Caregiver Profile Questionnaire

Participant Demographic Data (n=10)		
Age	Mean \pm SD	54.70 \pm 14.33
	Range	34-73
Gender	Female	8 (80%)
	Male	2 (20%)
Race	White/Caucasian	4 (40%)
	Black/African American	6 (60%)
Role	Spouse/Significant Other	3 (30%)
	Sibling	2 (20%)
	Son/Daughter	3 (30%)
	Nursing Assistant	2 (20%)

Inclusion Criterion

The inclusion criterion for family caregiver participants in focus group interviews consisted of providing care for a person with Alzheimer's disease or dementia-related condition for at least four hours each day during the previous 6 months and perceived or reported stress or burden related to caregiver role. Other criteria were requirement that participants be 18 years of age or older and provided unpaid caregiver for a person with Alzheimer's disease for a person who lives (or had lived) in a nursing home. Additional inclusion criterion consisted of helping with basic care and instrumental care and emotional assistance and having English-speaking ability and reading ability of fifth grade level or above. Potential respondents were asked during the initial telephone conversation about the inclusion criterion and the PI determined if they met the inclusion requirements during this discussion.

The inclusion criterion for paid caregiver participants in the focus group interview included being a certified nursing assistant (employed or retired) with experience providing care for persons with Alzheimer's disease or dementia-related condition in a nursing home, be at least 18 years of age or older, and have English-speaking ability and reading ability of fifth grade level or above. As noted above, potential respondents were asked during the initial telephone conversation about the inclusion criterion and the PI then placed them in respective focus groups if they met the inclusion requirements.

The inclusion criterion for the nursing home administrator included being a director or administrator of nursing home that provided services people with Alzheimer's disease and, have English-speaking ability and reading ability of fifth grade level or above.

Exclusion Criterion

The exclusion criterion for family caregiver and paid caregiver focus group interviews included a health condition that prevented active engagement in the focus group discussion and inability to participate due to current participation in a study on caregiver intervention program for Alzheimer's disease. Participants were asked during the initial telephone contact if they had concerns or other factors that would keep them from taking part in the focus group.

The exclusion criterion for the nursing home administrator consisted of being director or administrator of a nursing home that did not have people with Alzheimer's disease as residents in the facility.

Recruitment of Participants

Potential paid caregiver participants were recruited from the Gardens of Germantown Memory Care Center located in Memphis, Tennessee. Additionally, paid caregiver respondents were recruited through distribution of recruitment flyers in the above facility (see Appendix E).

The recruitment flyers were distributed during a presentation in a conference room at the facility and placed on a bulletin board in an employee area designated by the facility administrator.

The family caregiver recruitment letter was developed for submission to Tennessee Occupational Therapy Association (TOTA) for placement on the association's website. In the recruitment letter, the PI included a statement to occupational therapists informing them of the need to print and distribute the recruitment letter to potential respondents for the group interviews. The PI distributed recruitment letters to therapists working in the Memphis-Metropolitan region to request nomination of potential caregiver participants for the focus group interviews. The recruitment letters would be distributed to potential caregiver participants by therapists that agreed to refer caregivers for the focus group discussions. The PI also recruited potential participants through referrals from local support group coordinators and contacts in the community. The family caregiver recruitment letter is listed in Appendix F.

The PI will recruit the nursing home administrator during the phase II of the project. This will be conducted with a facility administrator from the Gardens of Germantown Memory Center located in Memphis, Tennessee following the potential adaption of the REACH program. The individual interview recruitment letter for the nursing home administrator is listed in Appendix G.

Consent Process

The focus group interview and individual interview recruitment materials contained statements that informed potential respondents that participation in the project was voluntary and of their right to withdraw at any time before or during the focus group or individual interview session. The family caregiver consent form, paid caregiver consent form, and individual interview consent form are listed in Appendix B, Appendix C, and Appendix D, respectively.

In the first telephone conversation with potential participants, the PI described the purpose and format of the focus group interview and provided information about site/facility, location, and time of the focus group interview. The PI also informed potential respondents of the incentives for participants (i.e., gift card to cover transportation expenses and refreshments provided during interview session).

On the date of the focus interviews, the PI handed out consent forms and allowed participants to read the document silently while the PI read the document aloud. The consent form specified the capstone project purpose, contact information of the PI and Institutional Review Board, and data collection (i.e., note taking and digital voice recorder and note taking). The respondents were given the opportunity to ask questions and determine if they wanted to participate in the respective focus group interview session. Participants were asked to sign the informed consent form and the PI then collected the signed consent forms. The PI provided each participant an original copy of their signed consent form. The PI also placed an original signed consent form in a folder to be kept in a locked file cabinet in the home office of the PI for a period of 36-months. Additionally the PI verbally informed respondents of their right to opt out of participation at any time during the session.

Materials

The capstone project involved participation of human subjects. The principal investigator (PI) was therefore required to submit appropriate documentation in order to gain approval from the Nova Southeastern University (NSU) Institutional Review Board (IRB). The NSU Protocol Number 02071405 Expedited, was approved by the IRB on February 12, 2014. Additionally, the PI completed a tutorial provided by the Collaborative IRB Training Initiative (CITI) which consisted of instructional modules for researchers that satisfied the “Protection of Human

Subjects” requirement mandated by the Nova Southeastern University Institutional Review Board.

Materials used in development and completion of the capstone project include the Interview Guide which contained questions used by the PI to conduct focus interviews with the respective stakeholder groups. The focus group questions for spouse/significant other, son/daughter, and brother/sister of an individual with Alzheimer’s disease are located in Section I of the interview guide. The focus group questions for nursing home direct care staff (i.e., certified nursing assistants) are located in Section II of the interview guide. Lastly, individual interview questions for the nursing facility administrator are located in Section III of the interview guide. However, as noted above, the individual interview with a nursing home administrator was not conducted in this phase of the capstone project due to time constraint in project completion. The interview guide with specific questions posed to the respective participant groups is listed in Appendix A.

As noted above, the focus group interview and individual interview recruitment materials contain statements that inform potential respondents that participation in the interview process is voluntary and of their right to withdraw at any time before or during the focus group or, individual interview session. The informed consent documents for the respective focus group participants are listed in Appendixes B, C, and D. As previously noted, the individual interview with a nursing home administrator was not conducted during this phase of the capstone project. The consent form (Appendix D) is included to maintain continuity with the IRB protocol document.

The recruitment materials for the capstone project consisted of a recruitment flyer for paid caregivers, a family caregiver recruitment letter, an individual interview recruitment

letter, and an electronic mail (email) attachment family caregiver recruitment letter submitted to Tennessee Occupational Therapy Association (TOTA). The recruitment documents for the respective participants are listed in Appendixes E, F, G, and H. Additionally, documents authorizing the PI to place recruitment materials within the Gardens of Germantown Memory Care facility located in Memphis, Tennessee facility and on the Tennessee Occupational Therapy Association organizational website is attached to Appendixes I and J, respectively.

Demographic information from participants (e.g., caregiver role, gender, age, race or ethnicity, and duration of caregiving experience) was collected for each focus interview on the Caregiver Profile Questionnaire. The demographic information document for the respective participants is listed in Appendix K.

The PI provided resource material to participants in the form of a document that contained the names and contact information for community and governmental agencies that provided assistance for persons with Alzheimer's disease. The resource information describing community and governmental agencies is listed in Appendix L.

Lastly, participant's responses during the focus group interviews were collected by means of digital audio recording (Sony Digital Voice Recorder ICD-PX333) and note taking by the PI.

Procedure

The capstone project was designed to be conducted in two phases. In Phase I, the PI will conduct focus group interviews with three separate family caregiver groups and one paid caregiver group as noted above in the Participants section. In Phase II of the project, the PI will conduct an individual interview with a nursing home administrator to determine feasibility of implementing an adaptation of the REACH program for use in the nursing home setting.

Phase I.

The focus group interviews were conducted in a conference room in the Memphis Central Library and the Alford Executive Offices Suites Building. Specifically, one focus group with paid caregivers took place at the Alford Executive Offices Building and three separate focus groups with family caregivers took place at the Memphis Central Library. The sites were selected because they are located on well-known streets in the City of Memphis and each facility provided adequate accessibility for participants with potential mobility or ambulatory concerns. Participants in each focus group were seated around a table in the conference room. The first name of each participant was written on an index card (name tent) and placed on the table in the conference room to specify seating arrangement for the respective focus group interviews.

At the start of each session, the PI welcomed participants and established the guidelines/ground rules for the focus group interview (i.e., respect for other participants, maintaining confidentiality by not disclosing comments made by other participants, and allowing every respondent the opportunity to engage in topics of discussion). The PI then stated the capstone project purpose, provided contact information for the PI and IRB, described data collection methods (i.e., digital voice recorder and note taking), and informed participants of their right to withdraw from involvement at any time during the focus group interview session.

The interview guide listed in Appendix A (Section I) was used to conduct the focus group interviews with family caregivers of individuals with Alzheimer's disease. The interview guide contained questions that sought family caregiver's input on issues of caring for a person with Alzheimer's disease and change(s) in caregiver roles or responsibilities following nursing home placement of their family member (see questions 2, 3, 4, 5, and 6). The interview guide also contained questions that sought information regarding participation in caregiver education

programs in the nursing home setting and potential barriers or facilitators to family member's participation in such programs (see questions 7, 8, and 9).

The interview guide listed in Appendix A (Section II) was used to conduct the focus interview with paid caregivers. The interview guide contained questions that sought paid caregiver's input on observations of common problems or concerns that were experienced by family members of persons with Alzheimer's disease after placement in a nursing home (see questions 2 and 3). The interview guide also contained questions that elicited paid caregiver responses about issues or topics that should be included in an education program for family members of clients/residents and explore potential barriers or facilitators to family caregiver's participation in such a program (see questions 4, 5, 6, and 7).

Additionally, the PI used prompt and probe questions to generate detailed discussion on key issues raised during the focus group interviews. The focus group participants were encouraged to respond to questions posed by the PI and interacted in discussions with each other during the group interview session. Throughout the focus group interviews, the PI ensured that all participants were given the opportunity to provide input and express opinions on topics of discussion.

The PI concluded the focus group interviews by asking participants if they had additional questions regarding issues discussed during the session. The PI then thanked participants for providing input and contributing to the capstone project. Respondents were then given the twenty-dollar gift card incentive for focus group participation. The funding for incentives (i.e., gift cards) came directly from the personal resources of the PI and no other funding for incentives was sought or utilized in the capstone project.

The responses from participants during the focus group interview were recorded by means of a digital voice recorder and note taking by the PI.

Phase II.

The individual interview with a nursing home administrator was not conducted during the capstone project but will be completed at a later date to gather views and opinions on feasibility of implementation of an adapted REACH program in the nursing home setting. This will occur as phase two (Phase II) of the investigation.

In phase II of the project, the individual interview will take place to engage in dialogue and discussion with the nursing home administrator to determine factors that could facilitate or inhibit implementation of the REACH program in a nursing home setting. Based on data from the focus group interviews conducted in Phase I, the PI will present the results and potential adaptations of the REACH program to the nursing home administrator for his or her review. The individual interview will be conducted at a location preferred by the nursing home administrator.

The PI will use the interview guide listed in Appendix A (Section III) to conduct the individual interview with the nursing home director. The individual interview guide will contain questions that seek input on education program(s) currently offered by the facility and input on barriers to implementing such programs if none exist (see question 1). Additionally, the individual interview guide will seek feedback on potential adaptations to the REACH program and potential barriers or facilitators to program implementation in a nursing home setting (see questions 2, 3, and 4). The individual interview guide will ask about the feasibility of occupational therapists using the adapted REACH program to address caregiver education and support group functions in the nursing home setting (see questions 5, 6, and 7).

The PI will use prompt and probe questions to elicit detailed explanation from the nursing home administrator on key issues raised during the individual interview. The PI will conclude the individual interview by asking the respondent if there are additional questions or issues that need to be further discussed.

The responses of the nursing home administrator during the individual interview will be recorded by means of digital voice recorder and note taking.

Risks, Discomforts, and Inconveniences

Psychological discomfort.

Family caregivers could experience psychological discomfort due to thoughts or conversation about potentially stressful events related to the role of family caregiver for a person with Alzheimer's disease that might arise during the focus group interview. Paid caregivers could experience psychological discomfort due to thoughts or conversation about potentially stressful events related to the role of nursing assistant for a person with Alzheimer's disease that might arise during the focus group interview. However, the likelihood of occurrence of psychological discomfort and the magnitude or duration of psychological discomfort to participants in the focus group interviews was considered to be minimal.

To address the issue of psychological discomfort due to involvement in focus group interviews, respondents were informed of potential psychological discomfort associated with participation in the focus group discussion at the outset of the interview session. The PI provided information about community resources that assist in dealing with psychological discomfort related to caregiving for a person with Alzheimer's disease or other dementia-related condition at the beginning of the interview session. Participants were provided a list of community and governmental agencies (e.g., Alzheimer's Association and Mid-South Aging Commission) that

assist caregivers with dementia-related concerns. The respondents were also encouraged to discuss with their primary health care provider any lingering psychological discomfort related to thoughts or conversations about their role as caregiver for a person with dementia. As noted previously, participants were informed of their right to withdraw from involvement at any time during the focus group interview.

Emotional discomfort.

Family caregivers could experience emotional discomfort due to participant's feeling of grief, loss of meaningful relationship(s), social isolation, anger, or perceived burden that resulted from thoughts or conversations that might occur during the focus group interview. The paid caregivers could experience emotional discomfort due to feeling of burden or sense of perceived conflict with family caregivers following placement of a person with Alzheimer's disease in a nursing home that resulted from thoughts or conversations that might occur during the focus group interview. However, the likelihood of occurrence of emotional discomfort and the magnitude or duration of emotional discomfort to participants in the focus group interviews was deemed to be minimal.

To address the issue of emotional discomfort due to involvement in focus group interviews, respondents were informed of potential emotional discomfort associated with participation in the focus group discussion at the outset of the interview session. The PI provided information about community resources that assist in dealing with emotional discomfort related to caregiving for a person with Alzheimer's disease or other dementia-related condition at the beginning of the interview session. Participants were provided a list of community and governmental agencies (e.g., Alzheimer's Association and Mid-South Aging Commission) that assist caregivers with dementia-related concerns. Participants were informed of opportunities to

join in support groups that are sponsored by the above agencies and in addition to other community sources of support for caregivers of persons with Alzheimer's disease. The respondents were also encouraged to discuss with their primary health care provider any lingering emotional discomfort related to thoughts or conversations about their role as caregiver for a person with dementia. As noted previously, participants were informed of their right to withdraw from involvement at any time during the focus group interview.

Inconvenience related to time investment.

Family caregivers could experience inconvenience related to time requirement involved in getting to/from the meeting site and the approximately one-hour participation in the focus group interview. Paid caregivers could experience inconvenience related to time requirement involved in getting to/from the meeting site and the approximately one-hour participation in the focus group interview. The nursing home administrator could experience inconvenience related to time involved in reviewing the adapted REACH program and the approximately one-hour participation in the individual interview. However, the likelihood of the inconvenience and the magnitude or duration of inconvenience to participants in the focus group interviews or individual interview was deemed to be minimal.

To address the issue of time inconvenience related to involvement in the focus group interview, the PI scheduled the interviews for weekday and on weekends through direct communication with respondents in the respective focus groups. To address the issue of time inconvenience related to involvement in the individual interview, the PI will schedule the interview at a time and location recommended by the nursing home administrator following adaptation of the REACH program.

Additionally, family caregiver participants were provided a twenty-dollar gift card to minimize the inconvenience of transportation expenses to/from the focus group interview. Paid caregiver participants were provided a twenty-dollar gift card to minimize the inconvenience of transportation expenses to/from the focus group interview. The nursing home administrator will be allowed to schedule the individual interview at a time and location that is convenient to him or her, therefore no twenty-dollar gift card or other incentive will be provided for participation in the individual interview.

Breach of confidentiality.

Family caregivers could experience a risk for breach of confidentiality due to potential for other focus group participant(s) to talk about issues/topics discussed in the interview outside of the interview session. Family caregivers could experience discomfort related to concern about unwanted disclosure of personal or sensitive information discussed during the focus group interview. Paid caregivers could experience a risk for breach of confidentiality due to potential for other focus group participant(s) to talk about issues/topics discussed in the interview outside of the interview session. Paid caregivers could experience discomfort related to concern about unwanted disclosure of personal or sensitive information discussed during the focus group interview. The PI and nursing home administrator will be the only individuals involved in the individual interview following adaptation of the REACH program in Phase II, therefore the risk of breach of confidentiality and potential for discomfort related to interview participation will be significantly diminished. Moreover, the likelihood of breach of confidentiality and the magnitude or duration of discomfort related to concern for breach of confidentiality to participants in the focus group interviews or individual interview was deemed to be minimal.

To address the issue of risk for breach of confidentiality the PI informed participants of the need to protect confidentiality by not discussing the issues or comments made during the interview outside of the focus group session. The PI informed participants that effort would be taken on his part to protect confidentiality of information of focus group members such as storing the capstone project data in a locked file cabinet in the home office of the PI for a period of 36-months following completion of the project. As noted previously, other ground rules that highlighted the importance of confidentiality were discussed at the outset of each focus group interview.

Family caregivers were advised to be mindful of possible consequences related to divulging particularly personal or sensitive information during focus group discussions. The PI then restated the purpose of the capstone project for family caregivers participants, which was to understand stakeholder concerns in order to adapt a family caregiver education and training program for use in the nursing home setting. Similarly, paid caregivers were advised to be mindful of possible consequences related to divulging particularly personal or sensitive information during focus group discussions. The PI then restated the purpose of the capstone project for paid caregiver participants, which was to understand stakeholder concerns in order to adapt a family caregiver education and training program for use in the nursing home setting.

Following determination of the feasibility of adapting the REACH program in Phase I, the PI will advise the nursing home administrator in Phase II that his or her personal disclosure of issues or comments made during the individual interview could lead to potential breach of confidentiality if he or she were to disclose information addressed during the individual interview outside of the interview session.

Protection of confidential information.

The consent forms, audio recording, and interview transcripts will be stored in a locked file cabinet in the home office of the PI for 36-months and then destroyed. At the end of the three-year period, the consent forms and interview transcripts will be destroyed by mechanical shredding. The interview audio recordings will be destroyed by erasing the audio file from the built-in memory and reformatting internal memory on the digital voice recorder. The interview audio files will also be deleted from the external memory by reformatting the microSD card that contains information from the interviews. All information obtained from participants in the capstone project was strictly confidential unless disclosure was required by law.

Benefit to Subjects

There were no direct benefits to capstone project participants. However, the respondents were provided a listing of resource organizations that assisted caregivers of persons with Alzheimer's disease. The listing was compiled by the PI through Internet search for community and governmental agencies that supported individuals with Alzheimer's disease or other dementia-related conditions and their caregivers. The file of community and governmental agencies provided to project participants is listed in Appendix J.

Data Analysis

The PI recorded the family caregiver and paid caregiver focus group interviews by means of a digital voice recorder and field notes. The audio recordings from capstone project interviews were then transcribed by the PI to produce a written account of comments made by participants during the respective focus group interview sessions.

The PI reviewed the focus group transcript to look for recurrent themes or developing issues that were presented during the interview sessions. Following the example suggested by

Creswell (2009), data analysis included organization and preparation of the research material and reading and re-reading the transcript to developing codes that identify specific categories or sets of transcript data. Additionally, the author indicated that data analysis strategies consisted of searching for topics or issues that developed and connecting themes or descriptions that emerged with the research question (Creswell, 2009). The data analysis process also required interpretation of the meanings associated with themes or descriptions generated from the focus group transcript. A framework of the data analysis procedure can be seen in Figure 1.

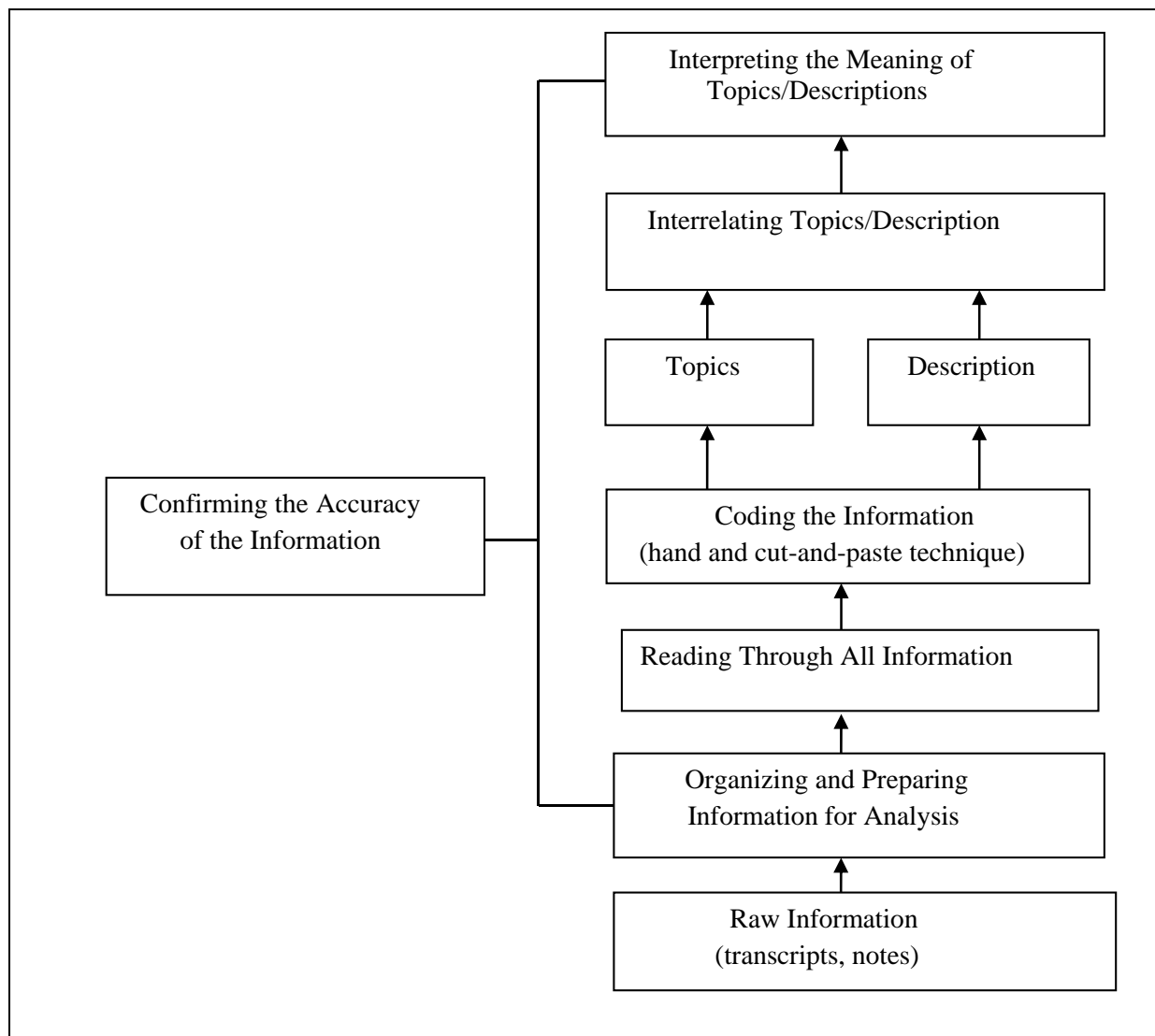


Figure 1: Capstone Project Qualitative Data Analysis Stages (Adapted from Creswell, 2009)

The PI used the process of thematic analysis that consisted of identifying, analyzing, and reporting patterns (themes) in the focus group transcript (Creswell, 2009). The PI also used thematic analysis methods suggested by Liamputtong (2011) that consisted of transcribing each focus group session and reviewing across the respective transcripts for “repeated patterns of meaning” (p. 173). The PI used a data-driven coding strategy that identified key words and phrases from respondents and allowed for analysis of statement(s) from focus group participants. To detect recurring themes or patterns of agreement in participant responses the PI used a meaning condensation strategy. This involved rephrasing long comments into smaller sections of words for data analysis. The PI interpreted the data from the interview transcripts and identified four major themes that were pertinent to the capstone project question.

Data analysis: process.

Following the strategy suggested by Creswell (2009) and Liamputtong (2011), the PI read the transcript data of the responses from participants and thought about the overall meaning of the information. This was done to look for common ideas of respondents and gain insight into the nature of those ideas in relation to the capstone project question. Additionally, the reading and re-reading of the transcript was done to gain even more familiarity with the information contained in the focus group transcript. The PI made notes in the margins of the transcripts (i.e., individual focus group transcripts and combined focus group transcript) and on index cards that documented recurring words, thoughts, and subject matter.

Creswell (2009) and Liamputtong (2011) noted that thematic analysis consisted of first reading each focus group transcript to gain insight into participant responses and then analyzing the combined transcript to understand the views of respondents as a group. Therefore, the PI used this thematic analysis strategy to develop categories for major topics or issues and identify

representative information in the transcript related to the capstone project question.

Tesch (as cited in Creswell, 2009) described eight steps to the coding process and recommended that researchers utilize such strategies in the analysis of qualitative focus group data. For example, Tesch suggested that the transcript be read, developed into topics, coded by topic, and described and categorized. Additionally, Tesch advised that researchers assign an abbreviation to the categories and “alphabetize these codes” (p. 186). Therefore, the PI used the system of reading the transcript and developing categories and codes for relevant topics and identified twelve categories that were used for the data analysis process. The PI then coded the twelve categories coded alphabetically, for instance, planning and support (code A), stress and coping (code B), role and responsibility (code C), information and training (code E) and so on. These, and other, codes were used in the margins of the transcript to identify words, sentences, or exchanges that related to the issue of caregiver concern(s) following placement of a loved one with Alzheimer’s disease in a nursing home. (A listing of the categories and codes can be found in Table 4).

Table 4

Data Analysis Categories and Codes

Categories	Code Letter
Planning and Support	A
Stress and Coping	B
Role and Responsibility	C
Information and Training	D
Emotional and Mental Health	E
Repeated Issues and Problems	F
Transition and Adjustment	H
Nursing Home Interaction	I
Nursing Home Regimen	J
Community Interaction	K
Change and Adaptation	L
Unpaid Caregiver Schedule	M

According to Creswell (2009), hand coding of qualitative transcripts could be accomplished through use of a color-coding system and implementing the cut and paste technique to place focus group responses onto the combined transcript. The PI used this method to assemble the combined transcript by respective focus groups as follows: 1) focus group one yellow, 2) focus group two green, 3) focus group three blue, and 4) focus group four purple. The PI arranged the combined transcript by interview guide question and respective color-coded focus group participant response. The PI developed topics and categories from the transcript and looked for emerging categories and codes for interview guide questions and participant responses related to the capstone project question. The PI then cut out and arranged the coded focus group transcript into categories of specific topics and issues to be reviewed (i.e., interpreted) for underlying ideas in participant's responses.

The PI analyzed the data using the categories and letter codes developed from the transcript and identified recurrent themes or topics that related to the question of adapting the REACH program for use in a nursing home. The four main themes identified by the PI included: 1) persistent or recurrent challenges, 2) support and resources, 3) usefulness of information, and 4) interaction with providers and management. The narratives contained in the Results section below and in the Data Analysis Table located in Appendix P provide relevant comments from participants that support placement of the statements in the respective category/categories and the subsequent development of the major themes related to the capstone project question.

Scientific Benefit

The information obtained from the capstone project could contribute to scientific knowledge regarding interventions for family caregivers of persons with Alzheimer's disease. Previous research on the REACH program was funded by the National Institute on Aging and

the National Institute for Nursing Research and involved quantitative methodology that highlighted the effectiveness of the program in different health systems and community environments. In the instance of this capstone project, the benefit related to contribution to adaptation and potential implementation of an evidence-based program that has been used to address needs or concerns of family caregivers in other community settings for use in the nursing home environment. Further scientific benefit lies in the notion that an adapted REACH program has the potential to be used by occupational therapists and other health care providers in a nursing home setting to support family caregivers of residents with Alzheimer's disease.

Risk/Benefit Ratio

It was believed that the capstone project had a positive benefits-to-risks ratio. Although there was a minimal risk for respondents to experience psychological discomfort, emotional discomfort, time inconvenience, and breach of confidentiality the potential benefit was maximal in that participants sharing of viewpoints and experiences would help to develop a program that addressed the specific needs or concerns of family caregivers related to nursing home placement of a loved one with Alzheimer's disease. Family caregivers reported stress, burden, and emotional problems even after placement of the family member with Alzheimer's disease in a nursing home. Therefore, the widespread application of an adapted REACH program held the potential to improve the quality of life and well-being of family caregivers and promote the best possible outcome for care recipients in nursing home settings.

The minimal risk of psychological discomfort to focus group participants was outweighed by the greater benefit of providing family caregivers with an effective program that addressed anxiety and/or depression related to nursing home placement of their family member. The minimal risk of emotional discomfort to respondents was outweighed by the greater benefit

of developing an education and training program that addressed specific needs or concerns of family caregivers associated with stress or perceived burden in the nursing home setting. The minimal risk of inconvenience due to time expenditure was outweighed by the greater benefit of providing family caregivers with an adapted program that provided strategies that dealt with the change in roles and responsibilities after placement of their family with Alzheimer's disease in a nursing home. The minimal risk of breach of confidentiality to focus group participants was outweighed by the greater benefit of supporting family caregivers with a program that provided education and training strategies that dealt with challenges of caring for self and care recipient in the nursing home setting.

Chapter 4

Results

Participant responses were gathered from two groups of caregivers, family and nursing home caregivers; the responses from each of these two groups will be reported under each of the themes that resulted from the data analysis. The themes from focus group participant responses related to four main concerns as follows: 1) persistent or recurrent challenges throughout the course of Alzheimer's disease, 2) availability of support and resources for caregivers, 3) usefulness of information about Alzheimer's disease, and 4) interaction with healthcare providers and/or facility managers. A list of representative focus group responses, categories, and themes is contained in the Data Analysis Table located in Appendix P.

Persistent or Recurrent Challenges

The theme "recurrent challenges" addressed the repetitive nature of problems that were encountered at each stage of Alzheimer's disease. Participants in the family caregiver focus groups indicated that recurrent challenges related to adjustment to the care recipient's diminishing health status at each stage of AD. Family caregivers described these recurrent challenges as seemingly continuous cycles of denial, frustration, anxiety, stress, and coping throughout the Alzheimer's disease process. There was discussion among family caregivers of difficulty in adjustment to changed roles/responsibility following nursing home placement of their family member with Alzheimer's disease:

- ...more like having a nervous feeling, especially after time went along... feeling that something was happening over again just at a different point in my wife's condition (Participant 03/FG2/ p.12).

Family caregivers stated that adjusting to nursing home schedules or routines was particularly challenging for themselves and their relative with AD (care recipient). For example, they reported that family members with AD seemed to do better with feeding, dressing, or toileting/incontinence care during certain shifts or with particular nursing home staff members. They indicated that such observations increased their feeling of recurrent stress or anxiety related to ongoing change in health status of their family member with AD in the nursing home:

- ... you know and things like the morning schedule... and the evening schedule and him sometimes not wanting to go along with the routine... so yeah, it took me some time getting used to it (Participant 05/FG2/ p.14).

The male focus group participants described relative comfort with allowing nursing home staff to assume primary caregiving responsibilities for their family member with AD. This was contrasted with focus group discussions of female participants that described greater difficulty in relinquishing their role and responsibility as primary caregiver. The female focus groups participants expressed a feeling of distress if they were not actively involved in care for their family member with AD during nursing home visits. They commented that feelings of doubt about caregiving roles/responsibilities became more persistent as the disease progressed to the late stages of AD within the nursing home:

- ... my mother was up and kind of doing ok and getting treated well in the nursing home, that was enough for me... and doing what I could do to help (Participant 06/FG3/ p.21).
- ... you have to get used to having somebody else in the process and as long as everybody is communicating and getting along, then well enough (Participant 04/FG2/ p.20-21).
- ... to let him know we were there and hadn't just put him in there and forgot about him (Participant 10/FG4/ p.23).

Paid caregivers described their observations of adjustment difficulties on the part of family members of nursing home residents with AD during periods of change in level of function related to progression of the AD. They discussed their experiences providing paid care for residents with Alzheimer's disease and assisting their family members with information or instruction:

- ... I was on that side of it, of the you know wishing I had some help that I didn't have you know... and not accepting it too well, your family member getting worse... I kind of understood where they were coming from (Participant 02/FG1/ p.4).
- ... confused and distressed looking, at least at first anyway... getting used to it and learning their way around in the nursing home (Participant 01/FG1/ p.5).

Paid caregivers indicated that nursing home residents with co-existing health conditions, in addition to AD, increased the experience of recurrent challenges throughout the progression of Alzheimer's disease. They also stated that problems with communication and/or interaction with family members of residents with AD was a common experience that created an additional sense of persistent or recurrent challenges related to paid caregiving for persons with Alzheimer's disease:

- ... getting used to having to maybe wait a few minutes for the CNA or the nurse to help their family member... they just want you right there when they hit the call button... that caused a kind of ongoing issue between them and the staff (Participant 01/FG1/ p.4).

Support and Resources

The theme "support and resources" dealt with experiences of family caregivers and paid caregivers regarding access to appropriate support or assistance to help them care for persons with AD. Family caregivers discussed problems getting community or governmental agency

support to assist them during the nursing home placement process. They described being strongly affected by significant changes in their lives related to nursing home placement of their family member with AD. The experience was reportedly made worse by lack of governmental programs or community advocates that could guide them through the process of caregiving in the nursing home environment:

- ... a whole lot more I had to be concerned about with involving the nursing home situation... I was always uneasy about the Alzheimer's and everything else (Participant 07/FG3/ p.38-39).
- ...the forms and paperwork to prove you qualify... I got everything in by myself eventually, it just took up time I could use on something else... all that mattered to them was whether we were eligible or not (Participant 04/FG2/ p.42).

Family caregivers commented that prior strategies that had been useful in their home seemed to be ineffective in the nursing home setting. Additionally, family caregivers discussed being unprepared for the nursing home setting. This was reflected in their comments regarding uncertainty about appropriately assisting their loved one with AD and interacting with facility staff members in the nursing home:

- ... nursing home workers doing their job and me realizing I couldn't deal with it like I could before at home (Participant 08/FG3/ p.33).
- ... getting them to understand that I wasn't trying to be demanding... just doing what I needed to do (Participant 07/FG3/ p.32).

Respondents talked about stress related to constant concern about the nursing home care for their relative with AD. The respondents discussed reluctance to ask for needed social support following nursing home placement of their family member with Alzheimer's disease. They

added that this contributed to their sense of social and community isolation related to family caregiving for a person with Alzheimer's disease:

- ... why burden people with what was happening... I mean the family yeah, but other people we know... didn't want to bother them (Participant 03/FG2/ p.44).
- ... it took her from around people she had been friends with, friends for years, and had done things with (Participant 06/FG3/ p.26).

The paid caregiver participants discussed limited resources in the nursing home, such as inadequate staff-to-patient ratios, that created an environment that made it difficult to provide optimal care for persons with AD. Paid caregivers also commented that the problem was intensified due to heightened expectations of family members of residents with Alzheimer's disease. They noted that some family members had expectations of almost one-to-one care each shift for their relative with AD in the nursing home:

- ... in addition to all the other assignments.... one or two and at the most three with Alzheimer's was hard to work with (Participant 02/FG1/ p.3).
- ... then they expect you to drop what doing already and come straight to their room (Participant 01/FG1/ p.4).

Paid caregivers commented that family members of residents tended to express complaints or concerns regarding resident care towards nursing assistants because they were often the most visible or accessible facility staff members. Paid caregiver respondents indicated that support for family members of residents with AD could also serve to support nursing assistants and other staff members:

- ... when their family member got worse... they get frustrated and go off on us because we're right there (Participant 01/FG1/ p.5).

- ... make it so convenient that it wouldn't make sense not to take part. And if it helps them then it helps us too, because then they won't be so stressed out and everything (Participant 01/FG1/ p.9).

Paid caregivers described consistent support from nursing supervisors and facility managers in the form of daily staff meetings, monthly in-service training sessions, and mandatory certification each year in care and assistance for persons with Alzheimer's disease. However, they also noted that employee suggestions or recommendations regarding job-related support for paid caregivers of persons with AD were frequently disregarded or dismissed by supervisors and administrators:

- ... in-service nearly every month and the dementia class for Medicare too, every year... good about keeping up with training we had to get for the State Inspection... health fairs and all but that's just one side of it... I had all my assigned rooms and like I said, there is just so much you can do (Participant 01/FG1, p.2).
- ... but I mean just having the director and the supervisors and the nursing home staff too, if everybody sees the benefit those kind of situations are what can really help family members. You know, they see people around them talking about it and using it ... so yeah, they would probably feel better about joining in and participating (Participant 02/FG1/ p.9).

Usefulness of Information

The theme "usefulness of information about AD" addressed the ability of respondents to use information that was provided by governmental agencies, healthcare professionals and skilled nursing facilities. According to family caregivers, information about the cause(s), course, and consequences of Alzheimer's disease was often confusing or misunderstood. They indicated

this was a particular problem during transition to—and following—nursing home placement of their relative with Alzheimer’s disease:

- ... not just the orientation they gave me...but something to explain what’s happening with his dementia and how I can stay on top of it and everything, that’s what I needed (Participant 07/FG3/ p.44).

Participants in the respective family caregiver focus groups discussed problems using educational information about AD that was specific to the nursing home setting. They stated that their relative with AD was placed in the nursing home during the moderate or severe stage of the disease. Consequently, information that had been provided to them did not adequately address family caregiver roles, responsibilities, or expectations for the nursing home environment:

- Not that they didn’t help some, but the pamphlets... some of them were a problem understanding sometimes, you know, just reading, or trying to read it, and then trying to understand how to use it in my situation, anyway (Participant 03/FG1, p.53).

Family caregiver participants commented that they did not have effective strategies for coping with behavioral changes, cognitive decline, and decreased functional ability of their family member with AD following nursing home placement. They further indicated that this was distressing because the level of stress, anxiety, and burden seemed to remain high despite the decreased requirement for direct physical care for their relative with AD. Family caregiver respondents suggested that useful educational information for the nursing home setting should be concise and delivered in a manner that is easily understood:

- ... information that help me with all the problems from being in there caused, I’m all for that... but I don’t need it to waste my time (Participant 09/FG4, p.52).

- ... it's not like its stagnant or something when her Alzheimer's got worse that made me more stressed out too... it was more like a constant kind of worry that I felt like (Participant 06/FG3/ p.27).
- ... easy and simple to use, so that it wouldn't be a problem to get to and use in the nursing home.... and even when I'm at my own house too (Participant 07/FG3/ p.65).

The issue of availability of information or training was talked about frequently among the respective family caregiver focus groups. They stated that education and training for family caregivers should be readily available during the morning and evening shifts. Participants commented that time constraints and other family or work-related responsibilities made it difficult to take part in caregiver educational programs or instructional training that might be offered. Additionally, they stated that only being provided booklets or brochures about AD was ineffective because the information was either difficult to understand or poorly retained by the family caregiver:

- ... who had time to take on learning something else, especially if it didn't make sense in the first place... how is going to benefit me and my family? (Participant 06/FG3/ p.61).
- ... hard trying to digest all of that and still take care of things happening everyday (Participant 05/FG2/ p.48).

Family caregivers recommended that nursing home administrators take measures to develop and implement useful education and training programs for family members of nursing home residents with AD. They commented that programs should be flexible as to time and location of presentation and include face-to-face instruction as well as other methods for providing information about AD:

- ... involvement and everybody talking to each other and everything... from the top down... so that I could get questions answered or help or information from everybody in there (Participant 10/FG4/ p.52).
- information and advice I need at one location... efficient on time and easy to get access to... it needs to make sense for my situation (Participant 09/FG4/ p.62).

Paid caregiver focus group participants shared insights about educational and training needs of family members of residents in the nursing home setting. According to paid caregivers, family members of residents were given information about the nursing home and services that were provided to residents during the admission process. They indicated that case managers and nurses supplied informational pamphlets or brochures and instructional material (e.g., video recordings) about AD with family members of residents:

- ... the orientation information is pretty much basic details... not like some in-depth information about dementia, if that's what you mean (Participant 02/FG1/ p.6).
- ... brochures on dementia and diabetes and high blood pressure from the nurses and case managers on the station... you know, instructions and directions and things like that (Participant 01/FG1/ p.6).

Paid caregivers suggested that potential education and training programs for family members of persons with AD be flexible to account for schedules of participants, brief in duration, and presented in a manner that was easy to understand. They added that information should focus on the moderate, severe, and late stages of AD in the nursing home and emphasize strategies for effective coping and care of family members of residents in the above stages of Alzheimer's disease:

- ... if it's not given at a choice of times during the day or else can't be taken at their own pace somewhere, then that might be a barrier to some of them (Participant 01/FG1/ p.8).
- ... what they are dealing with at the end of it, you know... the behaviors and problems and taking care of their own business too (Participant 01/FG1/ p.7).

Paid caregivers recommended that a designated room or other space be made available for family members to briefly relax, meditate, or compose themselves prior to and/or after visiting relatives with AD in the nursing home. They commented that such accommodation could serve as place in which family caregivers could receive education or training about AD pertinent to the needs of themselves and their family member in the nursing home:

- ... for the family members to go and get whatever it is they need to help them cope with their situation (Participant 02/FG1/ p.8).
- ... if there isn't a good effort of promoting and making it accessible and reasonable, and really at no cost at all if possible, they probably won't be willing to take part in (Participant 02/FG1/ p.9).

Interaction with Providers and Management

The theme "interaction with healthcare providers and/or facility management" addressed the views of family caregivers and paid caregivers about problems or barriers to effective communication with the nursing home staff, supervisors, and administrators. Family caregivers discussed their frustration about limited opportunities for conversation with nursing home staff or unit managers. They talked about ongoing concerns such as frequent changes in physical or cognitive status of their relative with AD; and, described problems communicating with nursing home personnel:

- ... most of the time the nurses helped with questions or things like that... I didn't see the managers on the floor as much as I would have liked to... personal conversation would have helped, in my experience (Participant 05/FG2/ p.42).
- ... having somebody in charge there available, more available, to talk to about what I might need to help with my dad's health condition (Participant 07/FG3/ p.45).

Family caregivers also commented on their need for effective dialogue with nursing facility supervisors and managers to help them assist their family member with AD in the nursing home appropriately. The family caregivers talked about difficulties scheduling meetings with nursing staff and facility managers to discuss concerns during the initial period (and, immediately following) nursing home placement of their family member. They commented that lack of meaningful dialogue was particularly troubling because of major changes in their lives and schedules related to nursing home placement of their relative with Alzheimer's disease. Moreover, family caregivers indicated that communication or guidance related to expectations and changed roles/responsibilities in the nursing home came primarily from certified nursing assistants and case managers:

- ... consistent support from the nursing home staff, top to bottom, would be encouragement (Participant 08/FG3/ p.65).
- ... it was hard on everybody in the nursing home to deal with his dementia.... they should plan the schedules and the daily routines and programs and things like that and include me in the decisions about whatever comes up in the nursing home (Participant 05/FG2/ p.37).

Paid caregiver participants discussed their observations of communication and/or interaction problems on the part of family members of residents following admission or

placement in the nursing home. They commented that different schedules or routines within the facility contributed to misunderstanding among family members of residents regarding appropriate contact personnel with whom to express concerns. They acknowledged that it could be difficult for family members to meet with the administrator(s) during the evening shift because most of them were not in the facility past eight in the evening:

- it's not like it's easy to get into a good nursing home to begin with... some of them are a little intimidated by the nursing home, you can tell... they don't really get involved with the managers like some of them do after awhile in there (Participant 01/FG1/ p.10-11).
- ... something like orientation but the information and training would be available year round, you know... just extend the hours so they can reach who they need to when they're in there visiting... that way the managers can see how many residents we have to cover now too (Participant 02/FG1/ p.8-9).

With respect to concerns of paid caregivers about interaction with their own supervisors or managers, they indicated that communication or involvement primarily centered around adherence to requirements or mandates from governmental agencies and other reimbursement entities. Paid caregivers stated that interaction with direct supervisors was, for the most part, positive and effective. However, they also commented that it was sometimes difficult to get managers to understand the challenges of daily work schedules and other tasks related to assisting or instructing family members of nursing home residents:

- ... there's only so much time you have to get everything done everyday... you know with everything required by the State and the inspectors... and family members got tight schedules too, so when they visit they already got things on their mind that need to be taken care of before they leave, too (Participant 02/FG1/ p.8).

- ... the nursing home just has to see the benefits and offer the training program or it probably won't happen. So the staffing level would probably be the biggest barrier for me too (Participant 01/FG1/ p.9).

Paid caregivers commented that supervisors encouraged communication and interaction among nursing home personnel and family members of nursing home residents. They noted however that it was difficult to establish meaningful rapport due to busy schedules and/or time constraints on the part of both paid caregivers and family members of nursing home residents. Paid caregivers stated that family members of residents were often in need of simple information or instruction about the functional or cognitive status of their relative with Alzheimer's disease:

- ... if it's something they see as an extra burden or a hardship... I think that would discourage family members from participating (Participant 01/FG1/ p.9).
- ... it needs different kinds of information and training for whatever issues the family members have in the nursing home (Participant 02/FG1/ p.7).
- ... if they have a good reason to take a training program that might balance out the other obstacles to them taking part in it... but just having the director and the supervisors and the nursing home staff too (Participant 02/FG2/ p.10).

Lastly, paid caregivers discussed the need for effective methods of communication and interaction with family members and staff members beginning at the admissions process and continuing throughout the course of the resident's nursing home placement:

- ... seeming like the same problems with the Alzheimer's disease were happening... just being burned out... so information and training on the disease and living with it... that's what would help them with the stress and the other issues (Participant 01/FG1/ p.7).

Chapter 5

Discussion

In this capstone project, the Principal Investigator conducted focus group interviews with family caregivers and paid caregivers of persons with Alzheimer's disease that resided (or had resided) in a nursing home. Participants in the respective focus groups were asked questions contained in the Interview Guide located in Appendix A. Thereafter, responses from participants were categorized according to their relevance to the capstone project question.

The coding process involved a initially reading through the transcript and bracketing or underlining sections, and sentences. The PI then re-read the transcript to identify meanings associated with participant's responses and also determine if additional categories or codes emerged from the transcript data. The PI combined the four focus group transcripts into one document and color-coded the combined transcript to denote the specific focus group participants and interview guide questions. Specifically, the PI cut-and-pasted participant responses for each interview guide question from the original focus group transcript to the combined transcript document. The PI then color-coded the combined transcript by assigning a different highlighted color for each focus group (e.g., yellow for focus group one, green for focus group two, blue for focus group three, and purple for focus group four).

The PI placed comments from respondents into categories by respective interview guide question. Initial codes related to the caregiver concerns identified in the literature review such as burden, time management, stress, money/finances, health, and coping. The initial codes were changed or revised as categories appeared that related to potential adaptation of the REACH program for use in a nursing home. The PI then developed twelve categories by topic and twelve codes by alphabet to identify representative comments or responses contained in the transcript.

Thereafter, the PI interpreted the transcript and the following themes emerged from the data analysis: repeated problems or challenges, access to help and resources, relevance to caregiving in the nursing home, and involvement and decision-making. More specifically, the four major themes that emerged from the focus group responses are as follows: 1) persistent or recurrent challenges, 2) support and resources, 3) usefulness of information, and 4) interaction with providers and management.

The results of focus group discussions and the literature review were used by the PI to investigate if an existing education and training program for family caregivers of persons with Alzheimer's disease could be adapted for use in the nursing home setting. The Resources for Enhancing Alzheimer's Caregivers Health (REACH) Program was initially developed for use in the home environment to assist family caregivers of military veterans with Alzheimer's disease or other related dementias. As previously noted, the REACH program addressed issues regarding safety, health, social support, caregiver physical and emotional well-being and stress management, and problem solving strategies for identified problems or concerns related to care of persons with AD.

Because of reports in the literature review of family caregiver stress, anxiety, depression, and perceived burden following placement of a relative with AD in the nursing home, the capstone project was conducted to determine if REACH could be adapted for use in such setting(s) (Coehlo et al., 2007; Majerovitz, 2007; Mittleman, Haley, Clay, & Roth, 2006). The comments of paid caregiver and family member focus group participants supported the findings noted in the literature review of emotional or psychological concern (e.g., anxiety, stress, or perceived burden) that was related to placement of a relative with Alzheimer's disease in the nursing home. The focus group responses also guided development of the theme 'persistent or

recurrent challenges' that resulted from reading, categorizing, coding, and interpreting the transcript information by the PI.

According to Nichols et al., the REACH program was designed to have effectiveness in addressing the myriad issues or concerns of family caregivers of persons with Alzheimer's disease. The paid caregiver and family member focus group participants were consistent in their responses that family caregivers had problems adjusting to the nursing home environment. This was revealed by comments that suggested family caregivers needed help or instruction in understanding what to expect for themselves and their relative with AD in the nursing home. They also indicated need for ongoing assistance to adapt to different roles, responsibilities, and stressors after nursing home placement of their family member with AD. The PI used representative responses from focus group participants similar to the above to develop the theme of 'support and resources' from the focus group transcript information.

There was agreement in the respective family caregiver focus groups of being weighted down by the process of transitioning from caregiving in their home setting to the unfamiliar surroundings and routines of the nursing home. However, some respondents did acknowledge positive aspects related to nursing home placement, for example, one focus group participant expressed relief from having the nursing home assume responsibility for the majority of care for her relative with Alzheimer's disease. Another focus group participant commented that the process was made easier by active support from nursing home personnel.

Both family caregiver and paid caregiver respondents indicated that family members of residents often needed information, education, and/or training about effective ways to assist their relative with AD in the nursing home and maintain proper care for themselves. It was also noted that family caregivers expressed concern about participating in education or training programs in

the nursing home due to issues regarding timing, duration, and site of delivery of such programs. Additionally, focus group respondents commented that certified nursing assistants were often the family members' primary source of contact for information or instruction about the physical or cognitive status of their relative with AD in the nursing home.

Paid caregiver focus group participants (i.e., certified nursing assistants) talked about being distressed by additional responsibilities of instruction and training of family members that was beyond their ordinarily assigned duties of caring for residents in the nursing home. Family caregiver participants indicated that information or instruction that had been useful during the early to moderate stages of AD was inadequate following nursing home placement of their relative with AD because of significant changes in physical, cognitive, or behavioral status of their relative.

The issue of ability or willingness to pay for provision of education and training about AD in the nursing home from family caregivers' personal resources produced somewhat mixed results. That is, family caregivers expressed interest in taking part in such programs to help them cope with issues related to nursing home placement of their family member with AD. They also suggested that the 'nursing home' should provide family member education and training programs as part of the admission and orientation process. However, paid caregiver respondents commented that reimbursement sources such as Medicaid or third-party payers (e.g. private insurance companies) would be unlikely to reimburse the nursing facility for interventions or services that did not directly relate to the resident's treatment plan.

Paid caregivers discussed staff meetings with supervisors and managers that detailed problems getting compensation for health care services that were provided in the nursing home. In light of such concerns, paid caregiver participants stated that nursing supervisors and facility

managers might be hesitant to implement education and training programs due to inability to obtain reimbursement or other funding to establish and maintain the program. The above situation represented a potential barrier to implementation of family caregiver education and training programs (e.g., REACH program) for use in the nursing home setting. Therefore, it was considered important to explore alternative methods of payment for family caregiver education and training programs about Alzheimer's disease to facilitate potential adaptation or implementation of the REACH program for use in the nursing home setting.

REACH Program: Features, Components, and Structure

The most recently revised REACH program consists of four intervention sessions with the family caregiver that are conducted over a period of two to three months in the participants home or in a 'facility'. The REACH program interventions could also be delivered either directly with the caregiver (i.e., face to face) or by telephone. Upon determining eligibility for the program, the certified Interventionists (i.e., occupational therapist, nurse, or case manager) provides assessment forms for participant completion (e.g., Demographics Form and Risk Priority Inventory).

Based upon assessment form results, the Interventionist collaborates with the participant to identify and address issues/concerns related to caregiving for an individual with Alzheimer's disease. The program structure consists of an active intervention phase, discharge from the active intervention, and a maintenance intervention phase (e.g., to address additional caregiver issues or concerns). The core features of the REACH program include the following: 1) risk priority inventory; 2) educational activities; 3) problem solving activities related to target behavior/issue; 4) stress management; and 5) closure tasks (Nichols et al., 2013).

According to the Veterans Affairs Caregiver Center, the REACH interventions are implemented by an individual who has attained certification as an Interventionist; this individual can then enroll family caregivers in the REACH program. The Interventionist training and certification had the option of being provided by the Caregiver Center either through classroom presentation or video teleconference. The REACH program intervention sessions followed protocol defined by the Caregiver Center. Specific structure of intervention sessions included the following: 1) discussion about focus and organization of program intervention; 2) description of techniques and instructional materials presented in each session; 3) collaboration between caregiver and Interventionist regarding barriers and new intervention/education techniques; and 4) Interventionist closure of each session that consisted of setting date/time for next meeting, reviewing issues/problems dealt with during session, reviewing intervention strategies which caregiver will focus on prior to next session, and assisting caregiver to problem solve and apply techniques that address identified target /problem behaviors or concerns (Nichols et al., 2013).

REACH Program: Support Group Component

In addition to traditional REACH interventions, the Caregiver Center developed a REACH Community Support Group Program to assist participants with ongoing issues related to the following topics: 1) caregiver self-care; 2) problem solving strategies; 3) communication with the care recipient with Alzheimer's disease; 4) stress management techniques; 5) communication with health care providers; and 6) accessing community resources. The REACH support group component was designed to be delivered monthly by telephone conference call from the Group Leader whom had received training and certification from the VA Caregiver Center. The REACH support group component was designed to accommodate the schedule and

workload of the facility or organization in which it was being considered for implementation (Nichols et al., 2013).

Specifically, the monthly REACH support groups could be conducted with up to 10 participants each session (one hour) in the different delivery methods. These include a closed support group (option 1) in which group participants begin and finish the six monthly sessions together. Support group participants could choose a different option, a closed support group (option 2), in which the group participants begin and finish the six monthly sessions together and includes the option for Group Leader and Caregivers to address other issues/concerns contained in Caregiver Notebook. The support group participants could also choose a third option, an open support group (option 3), in which group members can begin at any stage of the ten monthly sessions. Additionally, the Support Group Leader was responsible for facilitating effective discussion and interaction among support group members (Nichols et al., 2013).

However, according to the program developers the role of Support Group Leader was not ‘mental health’ group therapy facilitation, but “... [encouragement] of the Caregivers to share feelings, concerns, and information in a safe, non-judgmental setting” (Nichols et al., 2013, p. 5). Therefore, the Group Leader used a range of facilitation techniques, such as, active listening; paraphrasing; giving and receiving feedback; supporting; self-disclosure; praising; perception checking; deflecting; use of silence; and summarizing to enable optimal benefit for support group participants. Ideally, support group members would establish rapport and cohesiveness during the sessions to the extent that participants eventually relied more on each other for effective dialogue and interaction and less on the Group Leader (Nichols et al., 2013).

REACH Program: Adaptation for Use in the Nursing Home Setting

The REACH program and REACH Community Support Group Program were designed to accommodate the schedule and tasks/responsibilities of participants. The respective programs could also be adapted to meet the needs of caregivers and/or the facility in which they were presented. However, to maintain fidelity with the program the Interventionist and Support Group Leader are required to follow established guidelines and protocols for the REACH program and Community Support Group Program. That is, adherence to presentation methods and materials (e.g., scripted dialogue) and established delivery sequence of individual intervention sessions that are contained in the Interventionist Notebook and Group Leader Notebook.

In light of responses from focus group participants, this researcher believes that family caregivers of persons with Alzheimer's disease could benefit from an education and training program such as REACH that was provided in the nursing home and/or other setting (e.g., home telephone or web-based intervention session). Additionally, nursing home staff members similar to certified nursing assistants, nurses, medical social workers (case managers), and allied health professionals (e.g., occupational therapists) could also gain important knowledge about family caregiver issues/concerns related to nursing home placement of a relative with AD through training and certification in the REACH program and Community Support Group Leader Program. An adapted REACH program would focus on issues or concerns related to the moderate, severe, and late stages of Alzheimer's disease because the needs of family members and care recipients with AD changed significantly from onset throughout disease progression.

The Risk Priority Inventory (RP) listed in Appendix M was described as a key feature of the REACH program and Community Support Group Program. The Risk Priority Inventory

examines areas of concern through collaboration with the family caregiver to disclose information related to care recipient safety, caregiver health and physical well-being, social support, and caregiver frustration and vigilance. The RP also assessed caregiver emotional well-being (Zarit Burden Index), caregiver mood (PHQ-4/Depression Score), care recipient cognitive score (optional), and care recipient behavioral problems. The Interventionist and/or Support Group Leader then identified problem areas or concerns (e.g., high and moderate risks) of the caregiver of an individual with Alzheimer's disease based on results of the Risk Priority Inventory. The REACH intervention would then be adapted or tailored to address the problem areas or concerns indicated by the family caregiver participant (Nichols et al., 2013). A listing of the Risk Priority Inventory can be found in Appendix M of this document.

To adapt the REACH program for use potential in the nursing home, the Risk Priority Inventory section regarding Safety (items 1-5) would need minor modification to address the caregiving situation in the nursing home environment. Specifically, the questions related to care recipient access to dangerous objects (gun, knife, or sharp items) and care recipient operation of motor vehicle—questions 1 and 2, respectively—would need to be revised or adapted for the nursing home. For example, the RP could be modified to address safety concerns typically found in the nursing home like the potential access to dangerous objects or substances (e.g., razor blades, metal finger nail files, needles, drugs (prescription and non-prescription), cigarette lighter or matches, and other toxic or volatile substances). The RP would also need to be modified to address the issue of mobility within the nursing home, particularly as relates to the potential use of a wheelchair for mobility (manual or power-based).

The RP questions related to supervision required or provided in the nursing home and the resident's behavior(s) of concern, such as wandering and smoking (questions 3, 4, and 5) might

also require modification or adaptation to address the care recipient's nursing home placement. For example, the RP could be modified to identify questions or concerns about level or degree of supervision the individual with Alzheimer's disease receives (or, needs) in the nursing home. The issue of wandering was discussed by focus group participants and the RP could be modified to address noted concerns about wandering or elopement from the nursing home. For example, the RP could contain questions that ask if the resident is (or, has) engaged in wandering or roaming behavior and if plans or interventions have been put in place to monitor the wandering behavior and prevent elopement from the nursing home.

The Risk Priority Inventory questions related to caregiver Health/Physical Well-Being (questions 6-12) could be used in its present form to assess issues or concerns related to dementia caregiver's health and well-being without need for adaptation or modification in the nursing home. However, the Social Support section (questions 13-14) could be modified to address concerns about communication and interaction following nursing home placement. For example, the RP heading could be changed to read Social Support, Communication, and Interaction and contain additional questions that address the issue of dialogue and interaction between the caregiver and nursing home personnel and management.

The Risk Priority Inventory questions related to Caregiver Frustration and Vigilance (questions 15-20) address general caregiver concerns and could be used in its present form to assess dementia caregiver's concerns about frustration and vigilance (watchfulness) in the nursing home environment. Therefore, no modification or adaptation is deemed necessary by the PI for potential use of this section of the RP in the nursing home environment.

The Risk Priority Inventory questions related to Caregiver Well-Being (questions 21-24) addressed caregiver concerns related to time management, caregiver responsibilities, and

personal relationships and interpersonal interaction. Because this section addressed general concerns of caregivers of persons with dementia, no modification or adaptation is deemed necessary by the PI for potential use in the nursing home environment.

The Risk Priority Inventory questions related to Caregiver Mood (questions 2-28) addressed concerns related to caregiver mental health and emotional well-being. This section of the RP addressed general concerns of caregivers of persons with dementia, therefore, no modification or adaptation is deemed necessary by the PI for potential use in the nursing home environment. Lastly, the RP section on care recipient Behavioral Problems (questions 1-25) contained general questions used to assess behavioral issues or concerns of persons with dementia and would require no adaptation or modification for use in the nursing home setting.

Participants in the REACH program received a Caregiver Notebook that contained information about behavioral issues (Section 1) and caregiving issues (Section 2) that could be addressed during the intervention session(s). Based on issues or concerns identified in the Risk Priority Inventory, the Caregiver Notebook provided educational material and stress management strategies that could be used during and following the intervention sessions. The data from the focus group transcript served as the basis for this researcher's belief that the Notebook is an appropriate strategy for the nursing home environment. The Notebook was designed to be adaptable for use in different circumstances or situations therefore no modification of the Caregiver Notebook is deemed necessary by the PI. Additionally, the REACH program emphasis on dialogue and interaction between family caregiver and Interventionist is also noted as an important component that is believed by this researcher to be an acceptable strategy for the nursing home setting. A listing of the topics contained in the Caregiver Notebook can be found in Appendix N and Appendix O, respectively.

Focus group respondents commented on limited time for participation and need for flexibility in program delivery as potential barriers to implementation of an education and training about AD in the nursing home. Therefore, it might be necessary to shorten (or, modify) the intervention sessions in order to adapt the REACH program for use in the nursing home. For example, the adapted REACH program intervention could be structured such that a segment of the session was delivered face to face (e.g., 30 minutes) and the remaining portion completed by telephone or Internet (e.g., virtual chat room or video conference); depending upon collaboration and comfort level with the respective modes of delivery by the Interventionist and Caregiver participant. The adapted REACH program could also incorporate features that allowed two or more Interventionists to conduct the session(s) with the Caregiver in order to facilitate program delivery and participation at various times of the day or week. The above suggestions could assist in adaptation of the REACH program for use in the nursing home by addressing the issue of “flexibility” in delivery of education and training programs for family members of persons with Alzheimer’s disease.

According to the VA Caregiver Center, it could provide training and certification of nursing home personnel (or other organizational staff members) in the REACH program. Thereafter, a lead coordinator (e.g., occupational therapist or medical social worker) could monitor the adapted REACH program to ensure fidelity of delivery and adherence to core principles (i.e., program structure and protocols) of the traditional program by Interventionists. This could allow for comprehensive education and training of family members of residents with Alzheimer’s disease at various levels of physical and cognitive function throughout the disease process in the nursing home environment. Moreover, the nursing facility could incorporate knowledge gained by staff members that received training and certification in the REACH

program into mandatory continuing education requirements regarding care for residents with AD and other related-dementias. The above measures, could also address the issues of “usefulness of information” and “communication and interaction” that were described by family caregiver focus group participants as issues of concern related to nursing home placement of a relative with Alzheimer’s disease.

The issue of reimbursement or payment for education and training programs for family caregivers of persons with AD was the most challenging consideration to potential adaptation and implementation of the REACH Program in the nursing home setting. Because of stringent reimbursement guidelines from entities such as the Centers for Medicare and Medicaid Services (CMS), it would be difficult to obtain payment for caregiver instruction and training that was not directly related to skilled services or maintenance programs as defined in CMS regulations (for example, Pub 100-02 Medicare Benefit Policy). Therefore, it would be necessary to explore alternative payment methods for potential implementation of an adapted REACH program for the nursing home setting.

As previously noted, Gitlin et al. (2010) discussed the strategy of combining caregiver education into existing occupational therapy treatment plans and meeting the qualification requirements for Medicare Part B reimbursement in the home health setting. The researchers referenced the Medicare Benefit Policy Manual chapter 15 that allowed for reimbursement of rehabilitative services related to family training. They further described Medicare reimbursement guidelines in stating, “... education of family should be ongoing through treatment and instructions may have to be modified intermittently if the patient’s status changes” (Gitlin et al., 2010, p.848).

The cost effectiveness of the REACH interventions was studied by Nichols et al. (2008) who indicated the multicomponent intervention was beneficial in terms of enhancing informal caregiver's quality of life and providing them extra time to attend to other matters or concerns.

It is this researcher's opinion that a similar approach could be used to incorporate components of an adapted REACH program into collaboratively developed treatment plans for residents with Alzheimer's disease and their family caregivers in the nursing home and, comply with Medicare guidelines for reimbursement. An alternative solution to the issue of payment for implementation of the REACH program in the nursing home could come from joint participation between the nursing home and family caregivers of persons with Alzheimer's disease. In that situation, the nursing home would provide the adapted education and training program to family members of residents with AD and the family participants would agree to pay a reasonable co-payment to offset the facility's overall expenditures for program delivery and ongoing caregiver education and training. Additionally, the researcher will have to determine the ability and/or willingness of family caregivers to pay for the adapted REACH intervention from personal funds or resources.

This will require discussion and interaction with the nursing home administrator or manager in Phase II of the capstone project to determine the feasibility of implementing the adapted REACH program for the nursing home setting and to get his or her views about contracting consultant Interventionists services (e.g., occupational therapist trained and certified in the REACH Program and Group Leader Program).

Summary

The capstone project was undertaken to determine the feasibility of adapting the Resources for Enhancing Alzheimer's Caregivers Health (REACH) Program for use in the

nursing home setting. A review of the literature into the incidence, prevalence, and cost of providing care to persons with Alzheimer's disease yielded insight into concerns of both the care recipient and family caregivers. It was reported that there were over 5 million people with Alzheimer's disease in the United States in 2013. The literature review also highlighted problems and concerns of family caregivers of persons with Alzheimer's disease related to issues of caring for themselves and their family member with AD. For example, almost 11 million caregivers provided from 69 to 117 hours per week of unpaid care for persons with AD each year (12 billion hours annually).

It was reported that provision of care for persons with AD could have negative health consequences in terms of physical and emotional health of informal caregivers. Specific adverse effects of caregiving for persons with AD included stress, burden, depression, anxiety, and decreased environmental. The above concerns were indicated as primary factors related to nursing home placement of an individual with AD. However, it was noted that nursing home placement of the relative with Alzheimer's disease did not always relieve family caregiver stressors related to guilt, quality of care provided, and tension or conflict regarding communication or interaction with nursing home staff. That is, family caregivers reported that concerns about perceived burden, anxiety, and stress continued even after placement of their relative with Alzheimer's disease in the nursing home.

The REACH Program had shown effectiveness in addressing family caregiver concerns related to safety, health, social support, caregiver physical and emotional well-being and stress management, and problem solving in the home and various community settings. Therefore, the PI thought that the REACH program could potentially benefit family caregivers in the nursing home setting as well. Consequently, to investigate the feasibility of adapting the REACH

program for use in a nursing home the PI conducted focus group interviews with family caregivers (i.e., spouse/significant other, son/daughter, and brother/sister) and paid caregivers (i.e., nursing assistants) of persons with Alzheimer's disease that resided or had resided in a nursing home. The comments of focus group participants were then transcribed, analyzed, and interpreted by the PI which yielded the four major themes as follows: 1) recurrent problems or challenges throughout the disease process; 2) lack of support and resources for caregivers; 3) concern about information pertaining to AD; and 4) concern regarding communication and interaction with health providers and/or nursing home management. Focus group members also provided input regarding factors that could both enable and/or limit family caregiver participation in potential education and training programs in the nursing home setting.

The PI then used focus group findings to determine which components of the REACH program would require modification in order to adapt the program for use in the nursing home. The Risk Priority Inventory that was used to identify problem areas or concerns of the Caregiver was found to require minor adaptations for use in the nursing home setting. Additionally, to adapt the REACH program it would be necessary to modify the length of intervention sessions to accommodate the schedule and responsibilities of both the nursing home and family caregiver participants.

The issue of reimbursement or payment for provision of an adapted REACH program was then addressed by the Principal Investigator. The literature review described the cost effectiveness of the REACH program in terms of decreasing economic costs related to unpaid care and enhancing the quality of life of the caregiver (Nichols et al., 2008). The paid caregiver respondents suggested that it would be difficult for the nursing facility to receive reimbursement from Medicare for education and training of family caregivers that was not directly linked to the

resident's plan of care. However, Gitlin et al. (2010) demonstrated that occupational therapy caregiver training with a multicomponent intervention (RE-AIM) could be incorporated into treatment plans and reimbursed by Medicare in the home health setting. It is the belief of this researcher, that caregiver training in the REACH program could potentially be reimbursed by Medicare in the nursing home setting in a similar manner.

Family caregiver respondents commented on their inability or unwillingness to pay for an education and training program about Alzheimer's disease in the nursing home from personal finances or resources. It is this researcher's belief that possible resolution to the issue of payment for REACH program implementation in the nursing home could come from joint participation, in which, the nursing home provided the adapted education and training program to family members of residents with AD; and, the family participants paid a reasonable co-payment to offset the facility's overall expenditures for program delivery and ongoing caregiver education and training.

Recommendations

One: The Principal Investigator should conduct an individual interview with the nursing home administrator at the Gardens of Germantown Memory Care Center and present the findings of Phase I of the capstone project in order to determine the feasibility of implementing the adapted REACH Program in the nursing home.

Two: The certified Interventionists (e.g., occupational therapists, nurses, case workers, or consultants) within a particular nursing home and the nursing facility administrator(s) should review, and become familiar with, all regulatory guidelines from Medicare and third-party payers regarding reimbursement for education and training programs for family caregivers of persons with cognitive or behavioral health conditions (i.e., Alzheimer's disease and related-dementias).

Three: The Interventionist(s) and nursing facility administrator(s) should explore alternative sources of payment for provision of the adapted REACH program, such as obtaining grants or partnership with an advocacy agency (e.g., Alzheimer's Association) to enable payment or assistance with program implementation in the nursing home.

Four: There should be future capstone project(s) conducted at several sites that investigate adaptation of the REACH program for use in the nursing home.

Five: The future capstone project(s) should include larger sample sizes of focus group participants that are recruited from a broad spectrum of the population in terms of geographical representation, ethnic background, cultural identity, and socioeconomic status.

Six: The findings from the capstone project should be published by the Principal Investigator to contribute to the knowledge base of the profession and provide potential resource material for caregivers of persons with Alzheimer's disease.

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Appendix A

Interview Guide

I. Focus Group Interview Guide for Spouse/Significant Other, Son/Daughter Focus Groups, and Brother/Sister Focus Group Questions

1. What is it like to provide care for your loved one with Alzheimer's disease in the nursing home?
2. What do you do when you visit the nursing home that your family member with Alzheimer's disease lives in?
3. Talk about your concerns related placement of your family member with Alzheimer's disease in the nursing home.
4. What changed in your caregiver role and responsibility after placement of your family member in the nursing home?
5. Discuss challenges or concerns that you experienced that were related to the nursing home placement of your family member.
6. What kind of information or support could have made the transition to the nursing home easier for you as a family caregiver?
7. Tell us about educational program(s) about Alzheimer's disease that you have been involved in the past. Have you participated in caregiver education or training program(s) about Alzheimer's disease since placement of your family member in the nursing home?
8. What kind or educational information or training do you think would be helpful for family caregivers in the nursing home setting?

Appendix A (continued)

Interview Guide

9. If an education program for family caregivers of persons with Alzheimer's disease was offered in the nursing home, talk about things (or, barriers) that might keep you from participating in caregiver education program.
10. What kinds of information or support would get you to take part in an education and training program for family members in the nursing home?
11. Is there anything else you would like to share about concerns after placing your family member in a nursing home?

II. Nursing Home Direct Care Staff Focus Group Questions

1. Talk about common questions or concerns that family caregivers talk to you about following placement of a person with Alzheimer's disease in the nursing home?
2. What are typical problems you observe family members experience after nursing home placement of their loved one with Alzheimer's disease in the nursing home?
3. In your opinion, what would be useful information to include in an education and training program to help family members adjust to the nursing home setting?
4. If an education and training program for family caregivers of persons with Alzheimer's disease was offered in the nursing home, talk about things (or, barriers) that might keep them from participating in such a program.
5. What kinds of information or support do you think would encourage family members to participate in an education and training program for caregivers nursing home?
6. Is there anything else that you would like to share regarding family caregiver needs or concerns that should be addressed in the nursing home setting?

Appendix A (continued)

Interview Guide

III. Nursing Administrator Individual Interview Questions

1. What education program(s) does the facility currently provide for family members of clients with Alzheimer's disease? If none exists, what issues affect the ability to implement an education program about Alzheimer's disease for family caregivers in the facility?
2. After reviewing the proposed adapted REACH program, what is your viewpoint regarding potential benefit(s) of the program for family members of clients with Alzheimer's disease in the nursing home?
3. What factors would make implementation of the adapted REACH program more likely to be implemented?
4. What issues or concerns might function as barriers to implementing the adapted REACH program in the nursing home?
5. What is your view regarding occupational therapists in the nursing home using the adapted REACH program to provide family caregiver education as a reimbursable service?
6. In the adapted REACH program, the telephone support group component can also be conducted in a face-to-face group session format. In your opinion, would the nursing facility be open to hiring certified interventionists in the REACH program to provide this service for family caregivers within the facility (e.g., bi-monthly weekday afternoons or evenings)?

Appendix A (continued)

Interview Guide

7. Is there anything else you want to share regarding the feasibility of implementing the adapted REACH program in a nursing home setting?

Appendix B

Family Caregiver Consent Form



Health Professions Division
College of Health Care Science
Occupational Therapy Department

Funding Source: None.

IRB protocol #

Principal investigator

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Human Research Oversight Board (Institutional Review Board or IRB)
Nova Southeastern University
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Site Information:

Recruitment Site

Tennessee Occupational Therapy Association
P.O. Box 198126
Nashville, TN 37219

Focus Group Site

Memphis Central Public Library
3030 Poplar Avenue
Memphis, TN 38111

Salvation Army Kroc Community Center
800 E. Parkway South
Memphis, TN 38104

What is the study about?

The purpose of this project is to learn about the needs or concerns of caregivers of persons with Alzheimer's disease in order to adapt the Resources for Enhancing Alzheimer's Caregivers Health (REACH) program for use in a nursing home setting. The REACH program is an education and training program for family caregivers of persons with Alzheimer's disease. The project will seek family caregiver input that will support adaptation of the REACH program for use in a nursing home.

Initials: _____ Date: _____

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College of Osteopathic Medicine • College of Pharmacy • College of Optometry • College of Health Care Science
College of Medical Sciences • College of Dental Medicine • College of Nursing

E. Golden

Appendix B (continued)

Family Caregiver Consent Form

Why are you asking me?

I am sending this letter to invite you to participate in a group interview about family caregiver needs or concerns following placement of a loved one with Alzheimer's disease in a nursing home. You are invited to participate in a group interview session because you have experience providing care for a family member with Alzheimer's disease. There will be about four to six individuals in a group who all share similar experiences.

What will I be doing if I agree to be in the study?

You will be participating in a group interview. You will be asked to talk about your concerns and experiences caring for your family member with Alzheimer's disease in the nursing home setting. You will also be asked about your participation in programs that provide education about Alzheimer's disease and to talk about things that might keep you from taking part in an education program in the nursing home setting. You will also be asked to talk about issues or topics that you think should be included in an education program for family caregivers of people with Alzheimer's disease. Additionally, you will be asked to talk about what it is like to provide care for your family member after he or she has moved to a nursing home. You will also be asked to complete a brief demographic questionnaire. The group interview should take approximately one hour. Participation in the focus group interview is voluntary and you have the right to withdraw at any time before or during the focus group session.

Is there any audio or video recording?

This capstone project will include audio recording of the interview. This audio recording will be available to be heard by the PI, Dr. Ariela Neuman, personnel from the IRB. The audio recording will be transcribed by the PI, Edward Golden. The audio recording will be kept securely in Mr. Golden's office in a locked cabinet for three years. The audio recording will be stored in a locked file cabinet for 36-months and then destroyed. The audio recording will be destroyed by erasing the audio file from built-in memory and reformatting the internal memory on digital voice recorder. The interview audio files will also be deleted from the external memory by reformatting the microSD card that contains information from the interviews. Because your voice will be potentially identifiable by anyone who hears the recording, your confidentiality for things you say on the recording cannot be guaranteed although the PI will try to limit access to the recording as described in this paragraph.

Initials: _____ Date: _____

Appendix B (continued)

What are the dangers to me?

Risks to you are minimal, meaning they are not thought to be greater than other risks you experience every day. Sharing your experiences on caregiving for a person with Alzheimer's disease may cause psychological discomfort or emotional discomfort such as feeling anxious or sad from recalling unhappy memories or feelings of grief, loss, social isolation, anger or burden, respectively. To address these concerns, you will be provided with contact information for organizations and community sources that provide support for caregivers of persons with Alzheimer's disease (for example, the Alzheimer's Association and Area Agency on Aging). If you decide to use any of the services provided by the organizations or community sources listed, you will have to pay for these services.

By conducting a group interview there is no guarantee that the information you share in the group will remain confidential. The PI will tell the group participants about the need to protect the privacy of them and other participants by not disclosing any information outside of the interview session. If you have any concerns or questions after the interview session please contact the PI, Mr. Edward Golden, at the following telephone number (901) 324-1384. You may also contact the IRB at the numbers indicated above with questions as to your research rights.

Are there any benefits to me for taking part in this research study?

There are no direct benefits to you for participating in the group interview.

Will I get paid for being in the study? Will it cost me anything?

You will receive a twenty-dollar (\$20 USD) gift card to cover transportation expenses related to focus group participation. There is no fee or cost to take part in this project.

How will you keep my information private?

The consent form, audio recording, and interview transcript will be stored in a locked file cabinet for 36-months and then destroyed. At the end of the three-year period, the consent form and interview transcript will be destroyed by mechanical shredding. The interview audio recording will be destroyed by erasing the audio file from the built-in storage drive on the digital voice recorder. The interview audio recording will be deleted from the external memory card (microSD card) that contains information from the interview by reformatting . To prevent potential data leakage, the reformatted microSD card will be destroyed following the 36-month storage in the locked file cabinet. All information obtained in this project is strictly confidential unless disclosure is required by law. The IRB, regulatory agencies, or Dr. Neuman may review the research records.

Initials: _____ Date: _____

Appendix B (continued)

Family Caregiver Consent Form

What if I do not want to participate or I want to leave the study?

You have the right to refuse participation in this capstone project. You have the right to withdraw participation in the project at any time before or during the group interview. If you do decide to withdraw you will not experience any adverse consequence. However, if you choose to withdraw, any information collected about you **before** the date you leave the project will be kept in the research records for 36 months from the conclusion of the project and may be used as a part of the research.

Other Consideration:

Voluntary Consent by Participant:

By signing below, you indicate that

- this project has been explained to you
- you have read this document or it has been read to you
- your questions about this project have been answered
- you have been told that you may ask the investigator any related questions in the future or contact him in the event of a research-related problem
- you have been told that you may ask Institutional Review Board (IRB) personnel questions about your study rights
- you are entitled to a copy of this form after you have read and signed it
- you voluntarily agree to participate in the project entitled *Adapting Resources for Enhancing Alzheimer's Caregivers Health Program (REACH) for use in a Nursing Home Setting*

Participant's Signature: _____ Date: _____

Participant's Name: _____ Date: _____

Signature of Person Obtaining Consent: _____

Date: _____

Initials: _____ Date: _____

Appendix C

Paid Caregiver Consent Form



NOVA SOUTHEASTERN UNIVERSITY
Health Professions Division
College of Health Care Science
Occupational Therapy Department

Funding Source: None.

IRB protocol #

Principal investigator

Edward Golden, MSA, OTR/L
1046 Railton Road
Memphis, TN 38111
(901) 324-1384

Project Advisor

Ariela Neuman, Ph.D., OTR/L
3200 S. University Drive
Fort Lauderdale, FL 33328
(954) 262-1224

For questions/concerns about your research rights, contact:

Human Research Oversight Board (Institutional Review Board or IRB)

Nova Southeastern University

(954) 262-5369/Toll Free: 866-499-0790

IRB@nsu.nova.edu

Site Information:

Recruitment Site

Gardens of Germantown Memory Care
3179 Professional Plaza Drive
Memphis, TN 38138

Focus Group Site

Memphis Central Public Library
3030 Poplar Avenue
Memphis, TN 38111

Salvation Army Kroc Community Center

800 E. Parkway South
Memphis, TN 38104

What is the study about?

The purpose of this project is to learn about the needs or concerns of caregivers of persons with Alzheimer's disease in order to adapt the Resources for Enhancing Alzheimer's Caregivers Health (REACH) program for use in a nursing home setting. The REACH program is an education and training program for family caregivers of persons with Alzheimer's disease.

Initials: _____ Date: _____

3200 South University Drive • Fort Lauderdale, Florida 33328-2018
(954) 262-1242 • Fax (954) 262-2290

College of Osteopathic Medicine • College of Pharmacy • College of Optometry • College of Health Care Science
College of Medical Sciences • College of Dental Medicine • College of Nursing

Appendix C (continued)

Paid Caregiver Consent Form

Why are you asking me?

You are invited to participate in a group interview session because you have the experience providing paid care for persons with Alzheimer's disease. There will be about four to six individuals in the group who all share similar experiences.

What will I be doing if I agree to be in the study?

You will be participating in a group interview. You will be asked to talk about experiences regarding providing paid care for individuals with Alzheimer's disease in the nursing home setting. You will also be asked about programs that provide education about Alzheimer's disease and to discuss things that might keep family members of clients from taking part in an education and training program in the nursing home. You will also be asked to talk about issues or topics that you think should be included in an education program for family caregivers of people with Alzheimer's disease.

Additionally, you will be asked to complete a brief demographic questionnaire. The group interview should take approximately one hour. Participation in the focus group interview is voluntary and you have the right to withdraw at any time before or during the focus group session.

Is there any audio or video recording?

This capstone project will include audio recording of the interview. This audio recording will be available to be heard by the PI, Dr. Ariela Neuman, personnel from the IRB. The audio recording will be transcribed by the PI, Edward Golden. The audio recording will be kept securely in Mr. Golden's office in a locked cabinet for three years. The audio recording will be stored in a locked file cabinet for 36-months and then destroyed. The audio recording will be destroyed by erasing the audio file from built-in memory and reformatting the internal memory on digital voice recorder. The interview audio files will also be deleted from the external memory by reformatting the microSD card that contains information from the interviews. Because your voice will be potentially identifiable by anyone who hears the recording, your confidentiality for things you say on the recording cannot be guaranteed although the PI will try to limit access to the recording as described in this paragraph.

What are the dangers to me?

Risks to you are minimal, meaning they are not thought to be greater than other risks you experience every day. Risks to you are minimal, meaning they are not thought to be greater than other risks you experience every day.

Initials: _____ Date: _____

Appendix C (continued)

Paid Caregiver Consent Form

Sharing your experiences on paid caregiving for a person with Alzheimer's disease may cause psychological discomfort or emotional discomfort such as feeling anxious or uncomfortable from recalling stressful memories or feelings of burden or perceived conflict.

To address these concerns, you will be provided with contact information for organizations and community sources that provide support for caregivers of persons with Alzheimer's disease (for example, the Alzheimer's Association and Area Agency on Aging). If you decide to use any of the services provided by the organizations or community sources listed, you will have to pay for these services.

By conducting a group interview there is no guarantee that the information you share in the group will remain confidential. The PI will tell the group participants about the need to protect the privacy of the participants by not disclosing any information outside of the interview session. If you have any concerns or questions after the interview session, please contact the PI, Mr. Edward Golden, at the following telephone number (901) 324-1384. You may also contact the IRB at the numbers indicated above with questions as to your research rights.

Are there any benefits to me for taking part in this research study?

There are no direct benefits to you for participating in the group interview.

Will I get paid for being in the study? Will it cost me anything?

You will receive a twenty-dollar (\$20 USD) gift card to cover transportation expenses related to focus group participation. There is no fee or cost to take part in this capstone project.

How will you keep my information private?

The consent form, audio recording, and interview transcript will be stored in a locked file cabinet for 36-months and then destroyed. At the end of the three-year period, the consent form and interview transcript will be destroyed by mechanical shredding. The interview audio recording will be destroyed by erasing the audio file from the built-in storage drive on the digital voice recorder. The interview audio recording will be deleted from the external memory card (microSD card) that contains information from the interview by reformatting . To prevent potential data leakage, the reformatted microSD card will be destroyed following the 36-month storage in the locked file cabinet.

Initials: _____ Date: _____

Appendix C (continued)

Paid Caregiver Consent Form

All information obtained in this project is strictly confidential unless disclosure is required by law. The IRB, regulatory agencies, or Dr. Neuman may review the research records.

What if I do not want to participate or I want to leave the study?

You have the right to refuse participation in this capstone project. You have the right to withdraw participation in the project at any time before or during the group interview. If you do decide to withdraw you will not experience any adverse consequence. However, if you choose to withdraw, any information collected about you **before** the date you leave the project will be kept in the research records for 36 months from the conclusion of the project and may be used as a part of the research.

Voluntary Consent by Participant:

By signing below, you indicate that

- this project has been explained to you
- you have read this document or it has been read to you
- your questions about this project have been answered
- you have been told that you may ask the investigator any related questions in the future or contact him in the event of a research-related problem
- you have been told that you may ask Institutional Review Board (IRB) personnel questions about your study rights
- you are entitled to a copy of this form after you have read and signed it
- you voluntarily agree to participate in the project entitled *Adapting Resources for Enhancing Alzheimer's Caregivers Health Program (REACH) for use in a Nursing Home Setting*

Participant's Signature: _____ Date: _____

Participant's Name: _____ Date: _____

Signature of Person Obtaining Consent: _____

Date: _____

Initials: _____ Date: _____

Appendix D

Individual Interview Consent Form



NOVA SOUTHEASTERN UNIVERSITY
Health Professions Division
College of Health Care Science
Occupational Therapy Department

Funding Source: None.

IRB protocol #

Principal investigator

Edward Golden, MSA, OTR/L

1046 Railton Road

Memphis, TN 38111

(901) 324-1384

Project Advisor

Ariela Neuman, Ph.D., OTR/L

3200 S. University Drive

Fort Lauderdale, FL 33328

(954) 262-1224

For questions/concerns about your research rights, contact:

Human Research Oversight Board (Institutional Review Board or IRB)

Nova Southeastern University

(954) 262-5369/Toll Free: 866-499-0790

IRB@nsu.nova.edu

Site Information: Pending Phase I Completion

What is the study about?

The purpose of this project is to learn about the needs or concerns of caregivers of persons with Alzheimer's disease in order to adapt the Resources for Enhancing Alzheimer's Caregivers Health (REACH) program for use in a nursing home setting. The REACH program is an education and training program for family caregivers of persons with Alzheimer's disease. This phase of the project is intended to determine the possibility of implementing an adapted Resources for Enhancing Alzheimer's Caregivers Health (REACH) program in the nursing home setting.

Why are you asking me?

You are invited to participate in the individual interview because you are a director or manager in a nursing facility that cares for persons with Alzheimer's disease. In your capacity, you have experience providing health care administration in a nursing home for clients with Alzheimer's disease and can provide insight regarding the potential for implementation of an adapted REACH program in a nursing home setting.

Initials: _____ Date: _____

Appendix D (continued)

Individual Interview Consent Form

What will I be doing if I agree to be in the study?

You will be asked to review the adapted REACH program and provide recommendations about the possibility of using the program in the nursing home to help family members of clients with Alzheimer's disease. You will also be asked questions about education programs for family members that are provided in your facility as well as talk about things that could increase or decrease the likelihood of using the adapted REACH program in the nursing home. You will also be asked to complete a brief demographic questionnaire. The time required for you to review the adapted REACH program is about one hour and individual interview will last approximately one hour. Participation in the interview is voluntary and you have the right to withdraw at any time before or during the interview session.

Is there any audio or video recording?

This capstone project will include audio recording of the interview. This audio recording will be available to be heard by the PI, Dr. Ariela Neuman, personnel from the IRB. The audio recording will be transcribed by the PI, Edward Golden. The audio recording will be kept securely in Mr. Golden's office in a locked cabinet for three years. The audio recording will be stored in a locked file cabinet for 36-months and then destroyed. The audio recording will be destroyed by erasing the audio file from built-in memory and reformatting the internal memory on digital voice recorder. The interview audio files will be deleted from the external memory by reformatting the microSD card that contains information from the interviews. Because your voice will be potentially identifiable by anyone who hears the recording, your confidentiality for things you say on the recording cannot be guaranteed although the PI will try to limit access to the recording as described in this paragraph.

What are the dangers to me?

Risks to you are minimal, meaning they are not thought to be greater than other risks you experience every day. Sharing your experience on facility administration regarding provision of care for persons with Alzheimer's disease may result in psychological discomfort by making you feel anxious or stressed. To address this concern, you will be provided with contact information and community sources that provide support for caregivers of persons with Alzheimer's disease (for example, Alzheimer's Association and Area Agency on Aging). If you decide to use any of the services provided by the organizations or community sources listed, you will have to pay for these services.

Initials: _____ Date: _____

Appendix D (continued)

Individual Interview Consent Form

The only persons involved in the individual interview are the PI and the interviewee. Therefore, the risk for breach of confidentiality significantly decreased. The PI will inform you of the need to protect your privacy by not disclosing any information outside the interview session.

If you have questions after the interview session please contact Mr. Edward Golden at the following telephone number (901) 324-1384. You may also contact the IRB at the numbers indicated above with questions as to your research rights.

Are there any benefits to me for taking part in this research study?

There are no direct benefits for participation in the individual interview.

Will I get paid for being in the study? Will it cost me anything?

You will not be paid for participation in the individual interview. There is no fee or cost to take part in this capstone project.

How will you keep my information private?

The consent form, audio recording, and interview transcript will be stored in a locked file cabinet for 36-months and then destroyed. At the end of the three-year period, the consent form and interview transcript will be destroyed by mechanical shredding. The interview audio recording will be destroyed by erasing the audio file from the built-in storage drive on the digital voice recorder. The interview audio recording will be deleted from the external memory card (microSD card) that contains information from the interview by reformatting . To prevent potential data leakage, the reformatted microSD card will be destroyed following the 36-month storage in the locked file cabinet. All information obtained in this project is strictly confidential unless disclosure is required by law. The IRB, regulatory agencies, or Dr. Neuman may review the research records.

What if I do not want to participate or I want to leave the study?

You have the right to refuse to take part in this capstone project. You have the right to withdraw participation in the project at any time; for example, when reviewing the adapted REACH program and before or during the individual interview. If you do decide to withdraw you will not experience any adverse consequence. However, if you choose to withdraw during the interview, any information collected up to the point of withdrawal will be kept in the research records for 36 months from the conclusion of the project and may be used as a part of the research.

Initials: _____ Date: _____

Appendix D (continued)

Individual Interview Consent Form

Voluntary Consent by Participant:

By signing below, you indicate that

- this project has been explained to you
- you have read this document or it has been read to you
- your questions about this project have been answered
- you have been told that you may ask Institutional Review Board (IRB) personnel
- questions about your study rights
- you are entitled to a copy of this form after you have read and signed it
- you voluntarily agree to participate in the study entitled *Adapting Resources for Enhancing Alzheimer's Caregivers Health Program for use in a Nursing Home Setting*

Initials: _____ Date: _____

Participant's Signature: _____ Date: _____

Participant's Name: _____ Date: _____

Signature of Person Obtaining Consent: _____

Date: _____

Initials: _____ Date: _____

Appendix E

Paid Caregiver Recruitment Flyer



NOVA SOUTHEASTERN UNIVERSITY
Health Professions Division
College of Health Care Science
Occupational Therapy Department

Certified Nursing Assistants are Needed Immediately to Participate in a Group Interview

- The purpose of the interview is to learn caregiver's needs or concerns about providing care for persons with Alzheimer's disease who live in a nursing home.
- The group interview is being conducted to understand how to adapt the Resources for Enhancing Alzheimer's Caregivers Health (REACH) program so that it can be implemented in a nursing home. The REACH program is an education and training program for family caregivers of persons with Alzheimer's disease. Participation is voluntary and you will have the right to withdraw at any time before or during the group session. Your input is an essential component to adapting the program.

The focus interview will last about 1 hour

- A \$20 dollar gift card will be given to participants to cover transportation expenses. Hot or cold beverages and a light snack will be provided.

Location/Date/Time

- The group interview will be conducted at either of the following sites:
Memphis Central Library Salvation Army Kroc Center

3030 Poplar Avenue 38111 800 E. Parkway South 38104
- Date and time will be arranged at a convenient time for participants.

What will I be doing if I agree to be in the project?

- You will be asked to talk about your experiences providing paid care for persons with Alzheimer's disease in a nursing home. You will be asked to talk about possible needs or concerns of family caregivers and will discuss the usefulness of education programs for family caregivers. You will also complete a short demographic questionnaire.

What are inclusion criteria for participation?

- Certified nursing assistant with experience providing care for persons with Alzheimer's disease or dementia-related condition in a nursing home
- 18 years of age or older
- English-speaking and reading ability (5th grade level or above)

Contact Information:

- Edward Golden, MSA, OTR/L (Doctoral Student Nova Southeastern University)
Cell: (901) 692-1687 Email: eg503@nova.edu

3200 South University Drive • Fort Lauderdale, Florida 33328-2018
(954) 262-1242 • Fax (954) 262-2290

Appendix F

Family Caregiver Recruitment Letter



NOVA SOUTHEASTERN UNIVERSITY
Health Professions Division
College of Health Care Science
Occupational Therapy Department

Dear Caregiver,

I am sending this letter to invite you to participate in a group interview about family caregiver needs or concerns following placement of a loved one with Alzheimer's disease in a nursing home. This group interview is being conducted as part of my doctoral capstone project. The purpose of the project is to adapt the Resources for Enhancing Alzheimer's Caregivers Health program for use in a nursing home. The REACH program provides education and training for family members of persons with Alzheimer's disease at home and other community settings. Your input is essential to help me understand caregiver's needs or concerns following placement of a family member with Alzheimer's disease in a nursing home. Participation in the group interview is voluntary and you will have the right to withdraw at any time before or during the focus group session. The interview will last about one-hour and will consist of one session with each of three different family caregiver groups. I am particularly looking for individuals 18 years of age or older who:

- Have been providing care for a family member with Alzheimer's disease or dementia-related condition for at least four hours each day during the past 6 months.
- Have a family member with dementia currently residing in a skilled nursing home and provide emotional support and assistance with some Activities of Daily Living (ADL) and/or Instrumental Activities of Daily Living for the care recipient in this setting.
- Feel the burden or stress in their caregiver role for the person with Alzheimer's disease.
- Can speak and read English (at 5th grade level or above)

If you agree to participate, you will be asked to share your concerns and experiences caring for your family member with Alzheimer's disease at home and after he or she moved to a nursing home setting. You will be asked about your experience in programs that provide education about Alzheimer's disease, if you have, and to talk about things that might keep you from taking part in an education program if provided in the nursing home setting

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College of Medical Sciences • College of Dental Medicine • College of Nursing

E. Golden

Appendix F (continued)

Family Caregiver Recruitment Letter

You will be asked to talk about issues or topics that you think should be included in an education program for family caregivers of people with Alzheimer's disease. You will also be asked to complete a brief demographic questionnaire.

The group interview will be held in a conference room at the Memphis Central Library located at 3030 Poplar Avenue or the Salvation Army Kroch Community Center located at 800 E. Parkway South.

The proposed time for interviews will be mornings (9:30 am or 10:00 am), early evenings (4:30 pm or 5:00 pm), or on weekends to accommodate the caregiving and/or work schedules of participants. You will be offered a twenty-dollar (\$20 USD) gift card to cover transportation expenses. Hot and cold beverages and a light snack will be provided.

If you are interested in participating in the group interview, please contact me as soon as possible by phone or email:

Cell: (901) 692-1687

Email: eg503@nova.edu

I thank you for considering this invitation to take part in the group interview.

Sincerely,

Edward Golden, MSA, OTR/L (Occupational Therapy Doctoral Student)

Appendix G

Individual Recruitment Letter



NOVA SOUTHEASTERN UNIVERSITY
Health Professions Division
College of Health Care Science
Occupational Therapy Department

Gardens of Germantown Administrator,

My name is Edward Golden. I am an occupational therapist and doctoral student at Nova Southeastern University. I am sending this letter to ask your assistance in conducting a capstone project that is part of my degree completion requirement. The capstone project is being conducted to complete a doctoral degree in occupational therapy. You are requested to take part in an interview about an education and training program for family caregivers of persons with Alzheimer's disease. Participation in the individual interview is voluntary and you have the right to withdraw at any time before or during the program review or individual interview session.

You are invited to participate in the individual interview because you are a director or manager in a nursing facility that cares for persons with Alzheimer's disease. You have experience providing administration in a nursing home for clients with Alzheimer's disease.

The Resources for Enhancing Alzheimer's Caregivers Health (REACH) program is an education and training program for family caregivers of persons with Alzheimer's disease in the home and community setting. However, because family caregivers continue to have specific needs or concerns after nursing home placement of their love one with Alzheimer's disease, I believe the REACH program can benefit such family caregivers. In Phase I of the project, I conducted separate group interview sessions with family caregivers of persons with Alzheimer's disease and paid caregivers in order to adapt the REACH program for use in a nursing home setting.

To complete Phase II of the capstone project, I am requesting that you review the adapted program and provide input and feedback during the interview in order to determine the possibility of implementing the REACH program in a nursing home environment. The time commitment for reviewing the adapted program will be about one hour. The interview will last about one hour and can take place at a site or location that you prefer.

If you are interested in participating in the interview, please contact me as soon as possible by phone or email:

Cell: (901) 692-1687 Email: eg503@nova.edu

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(954) 262-1242 • Fax (954) 262-2290
College of Osteopathic Medicine • College of Pharmacy • College of Optometry • College of Health Care Science
College of Medical Sciences • College of Dental Medicine • College of Nursing

E. Golden

Appendix G (continued)

Individual Recruitment Letter

I thank you for considering this invitation to take part in the individual interview.

Sincerely,

Edward Golden, MSA, OTR/L (Doctoral Student Nova Southeastern University)

Appendix H

Participant Recruitment Letter Tennessee Occupational Therapy Association



NOVA SOUTHEASTERN UNIVERSITY
Health Professions Division
College of Health Care Science
Occupational Therapy Department

Dear Occupational Therapy Colleague,

My name is Edward Golden. I am an occupational therapist and currently completing a doctoral program at Nova Southeastern University. This message is sent to request your assistance with the capstone project that is required for my degree completion. The purpose of the project is to adapt the Resources for Enhancing Alzheimer's Caregivers Health (REACH) program for use in a nursing home. The REACH program provides education and training for family members of persons with Alzheimer's disease at home and other community settings. However, since family caregivers report specific needs or concerns even after nursing home placement of a loved one with Alzheimer's disease, it is believed that the REACH program could be adapted to support family caregivers in the nursing home setting. Participation in the group interviews is voluntary and participants have the right to withdraw at any time prior to or during the focus group interview.

I will be conducting group interviews with family caregivers to understand specific needs or concerns related to nursing home placement of persons with dementia in order to adapt the REACH program for such an environment. Participants will participate in a group interview. They will be asked to talk about concerns and experiences caring for family member(s) with Alzheimer's disease in the nursing home setting. They will also be asked about participation in programs that provide education about Alzheimer's disease and to talk about things that might keep them from taking part in an education program in the nursing home setting. Participants will also be asked to talk about issues or topics that they think should be included in an education program for family caregivers of people with Alzheimer's disease. Additionally, they will be asked to talk about what it is like to provide care for your family member after he or she has moved to a nursing home. They will also be asked to complete a questionnaire. The family caregiver group interview will last approximately one hour. Your assistance is essential to help me recruit the necessary participants to conduct the group interviews. Your time commitment related to assisting with this request will be approximately two to three hours in total.

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College of Medical Sciences • College of Dental Medicine • College of Nursing

E. Golden

Appendix H (continued)

Participant Recruitment Letter Tennessee Occupational Therapy Association

If you can assist with this request, print copies of the Family Caregiver Recruitment Letter that is attached to the Tennessee Occupational Therapy Association website. Please share the printed recruitment letters with family caregivers of clients with Alzheimer's disease whom you think would be interested in participating in a group discussion about needs or concerns associated with nursing home placement of their family member. I am particularly looking for individuals 18 years of age or older who:

- Have been providing care for a family member with Alzheimer's disease or dementia-related condition for at least four hours each day during the past 6 months.
- Have a family member with dementia currently residing in a skilled nursing home and provide emotional support and assistance with some Activities of Daily Living (ADL) and/or Instrumental Activities of Daily Living for the care recipient in this setting
- Feel burden or stress in their caregiver role for the person with Alzheimer's disease
- Can speak and read English (at 5th grade level or above)

I thank you for considering this request to assist me in recruiting participants for the capstone project for my doctoral degree in occupational therapy.

Sincerely,

Edward Golden, MSA, OTR/L (Doctoral Student)

Cell: 901.692.1687

Email: eg503@nova.edu

Appendix I

Gardens of Germantown Authorization Letter

Gmail -FW:



FW: 1 message

From: Lisa Bobal <lbobal@gardensofgermantown.com> **Sent:** Thursday, December 26, 2013 11:59 AM **To:** Edward Golden **Cc:** asanders8137@gmail.com; Ariela Neuman **Subject:** RE:

This email is to inform the Institutional Review Board that Mr. Edward Golden is granted permission to actively recruit and place recruitment materials in our community, The Gardens of Germantown, requesting participation of certified nursing assistants for a focus group interview at an off-site location. The Gardens of Germantown is an assisted living community that specializes in memory care. Please feel free to contact me if further information is needed regarding this letter of permission or our participation.

Lisa Bobal
Director of Marketing

901-755-5450, office
901-626-9685, cell

www.gardensofgermantown.com
www.facebook.com/thegardensofgermantown



E. Golden

Appendix J

Tennessee Occupational Therapy Association Authorization Letter

Gmail: FW



FW: TOTA Website 1 message

From: TN Occupational Therapy Assoc. <joyce@tnota.org> **Sent:** Thursday, December 26, 2013 3:33 PM **To:** Edward Golden **Subject:** TOTA Website

Tennessee Occupational Therapy Association
P. O. Box 198126 Nashville, Tennessee 37219
www.tnota.org

This message is submitted to inform the Nova Southeastern University Institutional Review Board that Edward Golden is granted permission to place a recruitment letter seeking participation of family caregivers of persons with Alzheimer's disease on the Tennessee Occupational Therapy Association (TOTA) website.

Please contact TOTA if further information is needed regarding this statement of permission for placement of the recruitment letter on the association website.

Sincerely,

Joyce McDaniel
Tennessee Occupational Therapy Association
P. O. Box 198126
Nashville, Tennessee 37219
[615.425.5310](tel:615.425.5310)
www.tnota.org

E. Golden

Appendix K

Caregiver Demographic Questionnaire

Note: All the information collected here will be kept strictly confidential. If you feel uncomfortable answering any question, you can leave it blank.

Caregiver Role (Mark X by selected response)

- Husband / Wife / Significant Other _____
- Son / Daughter _____
- Brother / Sister _____
- Nursing Assistant _____

Gender: (Mark X by selected response)

- Female _____
- Male _____

Age: (Mark X by selected response)

- 21 to 30 years _____
- 31 to 40 years _____
- 41 to 50 years _____
- 51 to 60 years _____
- Over 60 years _____

Are you: (Mark X by selected response)

- American Indian or Alaska Native _____
- Asian (Chinese, Japanese) or Pacific Islander _____
- Black (African American, Caribbean) _____

Appendix K (continued)

Caregiver Demographic Questionnaire

- Hispanic (Latin-American, Mexican) _____
- Non-Hispanic White (Caucasian) _____
- Other (please specify) _____

Highest level of education completed: (Mark X by selected response)

- Some high school or less _____
- High school graduate/GED _____
- Some college _____
- College graduate _____
- Some post-graduate work _____
- Post-graduate degree _____

How long have you provided care for an individual with Alzheimer's disease? (Mark X by selected response)

- less than 1 year _____
- 1 to 2 years _____
- 3 to 4 years _____
- 5 to 8 years _____
- 9 to 10 years _____
- Over 10 years _____

Appendix K (continued)

Caregiver Demographic Questionnaire

Family caregivers, when was your family member with Alzheimer's disease placed in a nursing home? (Mark X by selected response)

- Less than 6 months ago _____
- 6 months to 1 year ago _____
- 1 plus year to 2 years ago _____
- 2 plus years to 3 years ago _____
- 3 plus years to 4 years ago _____
- 4 plus years to 5 years ago _____
- 5 plus years to 6 years ago _____
- Other (please specify) _____

Appendix L

List of Community and Governmental Agencies

1. Alzheimer's Association
24-hour helpline 800-272-3900 (toll free)
Web site: www.alz.org
2. Aging Commission of the Mid-South
Area Agency on Aging and Disability
901-222-4111
Web site: www.agingcommission.org
3. National Institute on Aging
800-438-4380
Web site: www.nia.nih.gov
4. Department of Health and Human Services
Eldercare Locator
800-677-1116
Web site: www.eldercare.gov
5. Tennessee Commission on Aging and Disability
615-741-2056
Web site: www.state.tn.us/comaging
6. Tennessee Department of Human Services
615-313-4700
Web site: www.tn.gov/humanserv
7. Shelby County Health Department
901-222-9000
Web site: www.shelbycountyttn.gov

Appendix L (continued)

List of Community and Governmental Agencies

8. City of Memphis Senior Centers

- Frayser-Raleigh Senior Center
3985 Egypt Central, 38128

Telephone: 901-893-9100

M-F (8:00 am-4:00 pm), Saturday Dance (6:00 pm-10:00 pm)
- J. K. Lewis Senior Center
1188 N. Parkway, 38105

Telephone: 901-636-4255

M-F (8:00 am-4:00 pm), Saturday Dance (6:00 pm-10:00 pm)
- Orange Mound Senior Center
2572 Park Avenue, 38114

Telephone: 901-636-6622

M-F (8:00 am-4:00 pm), Saturday Dance (6:00 pm-10:00 pm)
- McWherter Senior Center
1355 Estate Drive, 38119

Telephone: 901-761-2462

M-F (8:00 am-4:00 pm), Saturday Dance (6:00 pm-10:00 pm)
- Ruth Tate Senior Center
1620 Marjorie Street,

Telephone: 901-774-2000

M-F (8:00 am-4:00 pm), Saturday Dance (6:00 pm-10:00 pm)

Appendix M

Risk Priority Inventory

Caregiver: _____

Interventionist/Group Leader Initials: ___ ___ ___

RISK APPRAISAL

Please answer the following questions about your caregiving situations.

SAFETY

1. Can (CR) get to dangerous objects (e.g., gun, knife or other sharp objects)?
 - 1.1 If yes, is it a gun?
2. Does (CR) drive?
3. Do you ever leave (CR) alone or unsupervised in the home?
4. Does (CR) try to leave the home and wander outside?
5. Are there any safety concerns with (CR) smoking?

HEALTH/PHYSICAL WELL-BEING

6. In the past month, have you lost or gained weight with out meaning to?
7. In the past 6 months, have you missed any scheduled doctor's appointments?
8. Have you cut back on your physical activities, like exercise and walking, because of caregiving?
9. In the past month, has it been hard to eat health or well-balanced meals on a regular basis?
10. How often do you get a good night's sleep?
11. Please rate your current health compared to what it was this time last year.
12. In general would you say your health is:

Appendix M (continued)

Risk Priority Inventory

Caregiver: _____

Interventionist/Group Leader Initials: ___ ___ ___

SOCIAL SUPPORT

13. If you were unable to care for (CR) or yourself, do you have someone who would take over?
14. Overall, how satisfied have you been in the past month with the help you have received from family members, friends, or neighbors?

CAREGIVER FRUSTRATIONS AND VIGILANCE

15. How often in the past six months, have you felt like screaming or yelling at (CR) because of the way he/she behaved?
16. How often in the past month, have you had to keep from hitting or slapping (CR) because of the way he/she behaved?
17. Within the past month, have you at any time...
 - 17.1 Felt overwhelmed?
 - 17.2 Felt like you needed to cry?
 - 17.3 Been frustrated as a result of your caregiving?
 - 17.4 Felt cut off from your family/friends?
 - 17.5 Felt lonely?
18. On a scale of 1 to 10, with 1 being “not stressed” to 10 being “extremely stressed”, please rate your current level of stress.
19. About how many hours a day do you feel the need to “be there” or “on duty” to care for (CR)? [**24 hours acceptable**]
20. About how many hours a day do you estimate that you are actually doing things for (CR)? [**subtract sleeping & activity hours from 24 if CG has difficulty**]

Appendix M

Risk Priority Inventory

Caregiver: _____

Interventionist/Group Leader Initials: ___ __

CAREGIVER WELL-BEING
(Zarit Burden Inventory)

Never Rarely Sometimes Quite Nearly
Frequently Always

21. DO YOU FEEL that because of the time you spend with your relative that you don't have enough time for yourself?					
22. DO YOU FEEL stressed between caring for your relative and trying to meet other responsibilities (work/family)?					
23. DO YOU FEEL strained when you are around your relative?					
24. DO YOU FEEL uncertain about what to do about your relative?					

Add columns: _____ + _____ + _____ + _____ + _____

Total: _____

(cumulative total of all columns)

A score of 8 or higher reflects high burden and high risks.

CAREGIVER MOOD (PHQ-4)

Over the last 2 weeks, how often have you been bothered by any of the following problems? **Not at all** **Several days** **More than half the days** **Nearly every day**

25. Feeling nervous, anxious or on edge				
26. Not being able to stop or control worrying				
27. Little interest or pleasure in doing things				
28. Feeling down, depressed, or hopeless				

Add columns: _____ + _____ + _____

Total: _____

(cumulative total of all columns)

*A total score of 8 or higher is an Alert

Developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues, with an educational grant from Pfizer Inc. No permission required to reproduce or distribute.

Appendix M (continued)

Risk Priority Inventory

Caregiver: _____

Interventionist/Group Leader Initials: ___ ___ ___

BEHAVIORAL PROBLEMS

The following is a list of problems patients sometimes have. Please indicate if (CR) has had any of these problems during the last month.

If CG answers yes: the ask- Did it bother or concern you?	Has it occurred?		Bother or Concern
1. Sleeping during the day and keeping you up at night	No	Yes	
2. Showing little interest in daily activity	No	Yes	
3. Having problems with bathing or refusing to bathe	No	Yes	
4. Arguing, irritability, and/or complaining	No	Yes	
5. Aggressive to others verbally	No	Yes	
6. Trouble remembering recent events (e.g., items in newspaper/ TV)	No	Yes	
7. Trouble remembering significant past events	No	Yes	
8. Losing or misplacing things	No	Yes	
9. Starting, but not finishing, things	No	Yes	
10. Difficulty concentrating on a task	No	Yes	
11. Expressing feelings of sadness or appearing sad or depressed	No	Yes	
12. appearing anxious or worried	No	Yes	
13. Crying and tearfulness	No	Yes	
14. Having problems with dressing or refusing to get dressed	No	Yes	
15. Refusing to eat or eating too much	No	Yes	
16. Falling or tripping	No	Yes	
17. Believing someone is stealing from them	No	Yes	
18. Seeing people or things that are not there	No	Yes	
19. Accidents of bowel or bladder	No	Yes	
20. Waking you or other family members up at night	No	Yes	
21. Losing weight	No	Yes	
22. Asking the same question over and over	No	Yes	
23. Inappropriate sexual behavior	No	Yes	
24. Following you everywhere or getting upset if you leave the room	No	Yes	
25. Getting upset when friends or family visit	No	Yes	

Appendix N

REACH Caregiver Notebook Section 1 Behavioral Issues

Table of Contents	Page
Activities	1
Bathing	9
Combativeness	17
Communicating with a Person with Dementia	23
Confusion	31
Dental Care	37
Depression	43
Dressing	47
Driving	51
Early-stage Dementia	57
Eating	63
Environment	71
Feelings	77
Grief	83
Hallucinations and Delusions	89
Holidays	93
Hospitalization	97
Incontinence	101
Medications	109
Nutrition	115
Repeated Questions	119
Safety	125
Sexuality	131
Shadowing	135
Sleeping	139
Sundowning	145
Telling the Patient and Others	151
Traveling	155
Visiting	161
Wandering	165

Appendix O

REACH Caregiver Notebook Section 2 Caregiving Issues

Table of Contents	Page
Adult Day Care	173
Asking for Help	177
Communicating with Health Care Providers	183
Depression	189
Early-Stage Dementia	193
Feelings	199
Financial and Legal Issues	205
Getting Help	211
Grief	217
Healthy Lifestyle	223
Holidays	229
Lifting and Moving	233
Making new Friends	239
Positive Thinking	243
Problem Solving	249
Sexuality	253
Stress Management	257
Visiting	267

Appendix P

Data Analysis Table

Question/Topic	Responses	Categories
<i>Problems or concerns related to family caregiving</i>		
Persistent or Recurrent Challenges	feeling that something was happening over again just at a different point in my wife's condition (Participant 03/FG2/ p.12)	- emotional and mental health - repeated issues or problems
Persistent or Recurrent Challenges	that kind of pressure... made being there hard to deal with and manage (Participant 07/FG3/ p.36)	- emotional and mental health - stress and coping - repeated issues or problems
Persistent or Recurrent Challenges	accepting that it's something that had to be done, I mean, for everybody's sake (Participant 09/FG4/ p.59)	- transition and adjustment - role and responsibility - stress and coping
Persistent or Recurrent Challenges	not being in as charge and responsible for everything... that's what changed the minute we stepped into the nursing home (Participant 06/FG3/ p.32)	- transition and adjustment - role and responsibility - stress and coping
Persistent or Recurrent Challenges	it took me some time getting used to it (Participant 05/FG2/ p.14)	- transition and adjustment - nursing home regimen - stress and coping
Persistent or Recurrent Challenges	timed it not to stay too long and interfere with his nursing care (Participant 10/FG4/ p.57)	- nursing home regimen - unpaid caregiver schedule - stress and coping
Persistent or Recurrent Challenges	something else with the Alzheimer's and the nursing home show up and you just have to change (Participant 08/FG3/ p.38)	- emotional and mental health - stress and coping - change and adaptation - repeated issues or problems
Persistent or Recurrent Challenges	you have to get used to having somebody else in the process (Participant 04/FG2/ p.20-21).	- transition and adjustment - emotional and mental health - stress and coping
Persistent or Recurrent Challenges	concern about whether this was the right choice or the right time... feelings got strained (Participant 07/FG3/ p.26)	- transition and adjustment - emotional and mental health - stress and coping - planning and support

Appendix P

Data Analysis Table

Question/Topic	Responses	Categories
<i>Problems or concerns related to paid caregiving</i>		
Persistent or Recurrent Challenges	... I was on that side of it, of the you know wishing I had some help that I didn't have you know... understood where they were coming from (Participant 02/FG1/ p.4)	<ul style="list-style-type: none"> - transition and adjustment - planning and support - role and responsibility
Persistent or Recurrent Challenges	confused and distressed looking, at least at first anyway... getting used to it and learning their way around in the nursing home (Participant 01/FG1/ p.5)	<ul style="list-style-type: none"> - transition and adjustment - stress and coping - change and adaptation
Persistent or Recurrent Challenges	there's only so one much person can do and if I got a heavy case load, then it's just not possible to get everything done for everybody (Participant 01/FG1/ p.3)	<ul style="list-style-type: none"> - nursing home regimen - stress and coping - planning and support - role and responsibility - repeated issues or problems
Persistent or Recurrent Challenges	something wrong with them or they wouldn't be in there to start with... it takes time to assist all of them... in addition to all the other assignments (Participant 02/FG1/ p.3)	<ul style="list-style-type: none"> - emotional and mental health - nursing home regimen - stress and coping - planning and support - role and responsibility
Persistent or Recurrent Challenges	they just want you right there when they hit the call button... that caused a ongoing issue between them and the staff (Participant 01/FG1/ p.4)	<ul style="list-style-type: none"> - nursing home regimen - stress and coping - planning and support - role and responsibility - nursing home interaction
Persistent or Recurrent Challenges	not really asking for help at first... but after a while they start to come around... ask for more and more assistance (Participant 02/FG1/ p.4)	<ul style="list-style-type: none"> - planning and support - nursing home interaction - role and responsibility
Persistent or Recurrent Challenges	some of the residents with dementia might be fine one minute and going off the next (Participant 01/FG1/ p.5)	<ul style="list-style-type: none"> - emotional and mental health - stress and coping - repeated issues or problems

Appendix P

Data Analysis Table

Question/Topic	Responses	Categories
<i>Experiences with unpaid caregiver role/responsibility</i>		
Support and Resources	as far as some formal class work on how to live with Alzheimer's, I didn't get any of that (Participant 03/FG2/ p.47)	- planning and support - community interaction
Support and Resources	I was always uneasy about the Alzheimer's and everything else (Participant 07/FG3/ p.38-39).	- planning and support - stress and coping - transition and adjustment
Support and Resources	some of it was a lot harder to deal with than the other parts (Participant 09/FG4/ p.40).	- planning and support - stress and coping - change and adaptation
Support and Resources	took up time I could use on something else... and all that mattered to them was whether we were eligible or not (Participant 04/FG2/ p.42)	- planning and support - nursing home interaction - community interaction - stress and coping
Support and Resources	recognizing I couldn't deal with it like I did before at home (Participant 08/FG3/ p.33)	- change and adaptation - planning and support - nursing home interaction - role and responsibility
Support and Resources	to let him know that we were all there and hadn't just put him in there and forgot about him (Participant 09/FG4/ p.23)	- role and responsibility - stress and coping - emotional and mental health - nursing home interaction
Support and Resources	I tried to be ready for whatever came up and it did most of the time (Participant 10/FG4/ p.40)	- stress and coping - planning and support - role and responsibility - nursing home interaction
Support and Resources	getting them to understand that I wasn't a demanding type of person or hard to deal with... just doing what I needed to do (Participant 07/FG3/ p.32)	- stress and coping - planning and support - role and responsibility - nursing home interaction - change and adaptation
Support and Resources	didn't want to bother them and really didn't know how to describe it to them anyway (Participant 03/FG2/ p.44)	- stress and coping - planning and support - community interaction - change and adaptation
Support and Resources	not everybody in the family was on the same page with the decision (Participant 07/FG3/ p.25-26)	- stress and coping - planning and support - community interaction - change and adaptation

Appendix P

Data Analysis Table

Question/Topic	Responses	Categories
<i>Experiences with paid caregiver role/responsibility</i>		
Support and Resources	it seems like about money it's more about money... so and so working... if someone don't show up... there's only so much you can do and then that's not good care (Participant 01/FG1/ p.2)	<ul style="list-style-type: none"> - stress and coping - planning and support - nursing home interaction - role and responsibility
Support and Resources	in addition to all the other assignments.... one or two and at the most three with Alzheimer's was hard to work with (Participant 02/FG1/ p.3)	<ul style="list-style-type: none"> - stress and coping - planning and support - nursing home interaction - role and responsibility
Support and Resources	then they expect you to drop what doing already and come straight to their room (Participant 01/FG1/ p.4)	<ul style="list-style-type: none"> - planning and support - nursing home interaction - role and responsibility - stress and coping
Support and Resources	feeling their family member wasn't being active or involved enough in the nursing home (Participant 01/FG1/ p.1)	<ul style="list-style-type: none"> - nursing home interaction - planning and support - nursing home regimen - stress and coping
Support and Resources	sometimes they get frustrated and go off on us because we're right there (Participant 01/FG1/ p.5)	<ul style="list-style-type: none"> - nursing home interaction - stress and coping - emotional and mental health
Support and Resources	if it helps them then it helps us too, because then they won't be so stressed out (Participant 01/FG1/ p.9).	<ul style="list-style-type: none"> - nursing home interaction - planning and support - stress and coping - emotional and mental health
Support and Resources	the director and supervisors and the nursing home staff... if everybody sees the benefit (Participant 02/FG1/ p.9)	<ul style="list-style-type: none"> - nursing home interaction - planning and support
Support and Resources	good about keeping up with training we had to get for the State Inspection... and the health fairs and all but that's just one side of it... I had all my assigned rooms and like I said, there is just so much you can do (Participant 01/FG1, p.2).	<ul style="list-style-type: none"> - nursing home interaction - planning and support - role and responsibility - information and training

Appendix P

Data Analysis Table

Question/Topic	Responses	Categories
<i>Knowledge /Needs in nursing home unpaid caregiver</i>		
Usefulness of Information	explain what's happening with his dementia and how I can stay on top of it... I needed (Participant 07/FG3/ p.44)	- planning and support - transition and adjustment - nursing home interaction
Usefulness of Information	walk me through the process and give me advice (Participant 10/FG4/ p.52)	- planning and support - transition and adjustment - nursing home interaction
Usefulness of Information	the pamphlets... some of them were a problem understanding sometimes, you know, just reading, or trying to read it, and then trying to understand how to use it in my situation (Participant 03/FG1, p.53)	- planning and support - information and training - transition and adjustment - nursing home interaction
Usefulness of Information	any kind of information that help me with all the stress from being in there caused, I'm all for that (Participant 09/FG4, p.52)	- stress and coping - planning and support - information and training - transition and adjustment - emotional and mental health
Usefulness of Information	it's not like its stagnant or something when her Alzheimer's got worse that made me more stressed out too (Participant 06/FG3/ p.27)	- stress and coping - planning and support - information and training - transition and adjustment - emotional and mental health
Usefulness of Information	kind of different and the same, you know... that pressure wasn't much different than it was at our house (Participant 04/FG2/ p.30)	- stress and coping - information and training - role and responsibility - planning and support
Usefulness of Information	who had time to take on learning something else? (Participant 06/FG3/ p.61)	- information and training - stress and coping - planning and support
Usefulness of Information	hard trying to digest all of that and still take care of things happening everyday (Participant 05/FG2/ p.48)	- information and training - stress and coping - planning and support - change and adaptation
Usefulness of Information	more involvement and everybody talking to each other... from the top down (Participant 10/FG4/ p.52)	- planning and support - nursing home interaction - information and training

Appendix P

Data Analysis Table

Question/Topic	Responses	Categories
<i>Knowledge /Needs in nursing home paid caregiver</i>		
Usefulness of Information	not like some in-depth information about dementia, if that's what you mean, not at admissions, anyway (Participant 02/FG1/ p.6)	<ul style="list-style-type: none"> - information and training - planning and support - change and adaptation - nursing home regimen
Usefulness of Information	bulletins and brochures on dementia and diabetes and high blood pressure from the nurses and case managers on the station... you know, instructions and directions and things like that (Participant 01/FG1/ p.6).	<ul style="list-style-type: none"> - information and training - planning and support - change and adaptation - nursing home regimen - nursing home interaction
Usefulness of Information	not given at a choice of times during the day or else can't be taken at their own pace somewhere, then that might be a barrier to some of them (Participant 01/FG1/ p.8)	<ul style="list-style-type: none"> - nursing home regimen - unpaid caregiver schedule - planning and support - change and adaptation
Usefulness of Information	something that covers handling what they are dealing with at the end of it, you know, at the end stage of the Alzheimer's ... how it affects the person with it and the people in their family... how to deal with the behaviors and problems and their own issues too (Participant 01/FG1/ p.7)	<ul style="list-style-type: none"> - planning and support - change and adaptation - stress and coping - information and training
Usefulness of Information	a resource room or a space for the family members to go and get whatever it is they need to help them cope with their situation... one way of doing it (Participant 02/FG1/ p.8)	<ul style="list-style-type: none"> - planning and support - stress and coping - information and training - nursing home interaction
Usefulness of Information	if there isn't a good effort of promoting and making it accessible and reasonable, and really at no cost at all if possible, they probably won't be willing to take part in it (Participant 02/FG1/ p.9)	<ul style="list-style-type: none"> - planning and support - stress and coping - information and training - nursing home interaction - change and adaptation

Appendix P

Data Analysis Table

Question/Topic	Responses	Categories
<i>Contact, dialogue, training unpaid caregiver</i>		
Interaction with Providers and Management	nurses helped with questions or anything like that... I didn't see the managers on the floor as much as I would have liked to (Participant 05/FG2/ p.42)	<ul style="list-style-type: none"> - information and training - nursing home interaction - planning and support - stress and coping
Interaction with Providers and Management	somebody in charge there available, more available, to talk to about what I might need to help with my dad's health condition and dementia (Participant 07/FG3/ p.45).	<ul style="list-style-type: none"> - information and training - nursing home interaction - planning and support - stress and coping
Interaction with Providers and Management	the nursing home had information about it and the social worker gave us some too and kind of helped with questions and like that... I still learned most of it just by going through it and trying different ways of doing things (Participant 10/FG4/ p.58).	<ul style="list-style-type: none"> - information and training - nursing home interaction - planning and support - change and adaptation - role and responsibility
Interaction with Providers and Management	support from the nursing home staff, top to bottom, would be encouragement(Participant 08/FG3/ p.65)	<ul style="list-style-type: none"> - information and training - nursing home interaction - planning and support
Interaction with Providers and Management	is management and the other people there showing support for the program?... that's what I would need to consider too (Participant 09/FG4/ p.66)	<ul style="list-style-type: none"> - information and training - nursing home interaction - planning and support - change and adaptation
Interaction with Providers and Management	I got the basic program on being in the nursing home... the social worker and the aides and other staff got me up to speed on (Participant 03/FG2/ p.48)	<ul style="list-style-type: none"> - information and training - nursing home interaction - planning and support
Interaction with Providers and Management	it was hard on everybody in the nursing home to deal with his dementia.... plan the schedules and the daily routines and programs and things like that and include me in the decisions (Participant 05/FG2/ p.37)	<ul style="list-style-type: none"> - stress and coping - nursing home regimen - nursing home interaction - planning and support - information and training - unpaid caregiver schedule

Appendix P

Data Analysis Table

Question/Topic	Responses	Categories
<i>Contact, dialogue, training paid caregiver</i>		
Interaction with Providers and Management	it's not like it's easy to get into a good nursing home to begin with... some of them are a little intimidated by the nursing home, you can tell... they don't really get involved with the managers like some of them do (Participant 01/FG1/ p.10-11)	<ul style="list-style-type: none"> - nursing home interaction - planning and support - information and training - nursing home regimen
Interaction with Providers and Management	and something like orientation but the information and training would be available year round, you know... just extend the hours so they can reach who they need to when they're in there visiting... that way the managers can see how many residents we have to cover now too (Participant 02/FG1/ p.8-9).	<ul style="list-style-type: none"> - nursing home interaction - planning and support - information and training - nursing home regimen - unpaid caregiver schedule
Interaction with Providers and Management	there's only so much time you have to get everything done everyday... you know with everything required by the State and the inspectors... and family members got tight schedules too, so when they visit they already got things on their mind that need to be taken care of before they leave, too (Participant 02/FG1/ p.8).	<ul style="list-style-type: none"> - nursing home interaction - planning and support - information and training - nursing home regimen - unpaid caregiver schedule - stress and coping
Interaction with Providers and Management	the nursing home just has to see the benefits and offer the training program or it probably won't happen. So the staffing level would probably be the biggest barrier for me too (Participant 01/FG1/ p.9)	<ul style="list-style-type: none"> - information and training - nursing home regimen - planning and support - nursing home interaction

Appendix P

Data Analysis Table

Question/Topic	Responses	Categories
<i>Contact, dialogue, training paid caregiver</i>		
Interaction with Providers and Management	I don't see any one program doing all the stuff everyone of them needs... it needs different kinds of information and training for whatever issues the family members have in the nursing home... if they could put all the information family members need in it and save them some time and be easy to take advantage of, then that might be worth the time invested (Participant 02/FG1/ p.7).	<ul style="list-style-type: none"> - information and training - planning and support - nursing home regimen - unpaid caregiver schedule - stress and coping