FAMILY RESILIENCY, SENSE OF COHERENCE, SOCIAL SUPPORT
AND PSYCHOSOCIAL INTERVENTIONS: REDUCING CAREGIVER BURDEN
AND DETERMINING THE QUALITY OF LIFE IN PERSONS WITH
ALZHEIMER’S DISEASE

by

Havovi B. Shroff

A Dissertation Submitted to the Faculty of
The College of Education
in Partial Fulfillment of the Requirements for the Degree of
Doctor of Philosophy

Florida Atlantic University
Boca Raton, Florida
August 2014
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This dissertation was prepared under the direction of the candidate's dissertation advisor, Dr. Michael Frain, Department of Counselor Education, and has been approved by the members of her supervisory committee. It was submitted to the faculty of the College of Education and was accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

SUPERVISORY COMMITTEE:

Michael Frain, Ph.D.
Dissertation Advisor

Elizabeth Villares, Ph.D.

Greg Brignan, Ph.D.

Paul R. Peluso, Ph.D.
Chair, Department Counselor Education

Valerie J. Bristor, Ph.D.
Dean, College of Education

Deborah L. Floyd, Ed.D.
Interim Dean, Graduate College

07/08/2019

Date
ACKNOWLEDGEMENTS

It is with the deepest gratitude that I would like to thank everyone who has contributed in affording me with the numerous opportunities and efforts required, for completing this dissertation. Firstly, I would like to thank Florida Atlantic University’s Department of Counselor Education for its professional and skilled faculty, especially the Department Chair Dr. Paul Peluso. In particular, I would especially like to thank my dissertation Chairperson, Dr. Michael Frain, who has patiently guided, encouraged and advised me throughout this process. Thank you to my committee members Dr. Elizabeth Villares, and Dr. Greg Brigman who have been a source of support and comfort from the commencement of this journey. I will be forever indebted to these three individuals for assisting and advocating for me every step of the way. I’d like to thank Dr. Maria Ordonez and Glenda Connelly LCSW for lending their invaluable expertise in the area of Alzheimer’s disease and also to Anita Pennathur, Anu Nagar, Bradley Trager and Jaimee Schulson for all their assistance. My special thanks to Dr. Dushyant Uttamsingh, Dr. Asmeeta Punwani, Erica Brown, Dr. and Mrs. Mukesh Wadhwa at Stratford Court and Ms. Preet Sahi at Assisted Living in Florida, for coming through for me when I needed them the most. My heartfelt gratitude to Dr. Holly Katz, Dr. Marcia Mofson, Dr. Richard Reiter and Linda Tepper, LCSW who have kept me focused and committed on this road. This dissertation would not have been possible without the constant encouragement, warmth and caring from the Caregivers of the Thursday morning Alzheimer’s support
group at the Louis and Anne Green Memory and Wellness Center at FAU that I facilitate, and to them I am forever grateful. I am in awe of the strength, courage and resiliency you demonstrate in spite of all the odds. I would especially like to thank all the willing and engaged caregivers who participated in this study and made it all happen.

I would like to thank my wonderful family and friends who have enabled my dream to come to fruition: my husband Burjis for being my truth, my inspiration, my loving, best friend and motivator, and for your faith, patience, understanding and confidence in me that has propelled me to excel; to my sons Dustyn and Kevyn for bringing joy and humor in my life and seeing me through my struggles with technology; to my dad, for your steadfast guidance and love always; and to my soul sister Maya for always being there for me with your prayers, affection and support. And lastly, my heartfelt thank you to my very special and talented mentor, Dr. Debra Ainbinder, for being my role model and beacon on this journey from start to finish. You’ve always been my inspiration and have set the bar by embodying qualities such as unconditional positive regard, empathy, warmth and professionalism that make you such an effective, proficient and dedicated counselor, supervisor, educator and human being… I thank you for giving me the zest to enrich, educate and improve myself every day.
ABSTRACT

Author: Havovi B. Shroff

Title: Family Resiliency, Sense of Coherence, Social Support and Psychosocial Interventions: Reducing Caregiver Burden and Determining the Quality of Life in Persons with Alzheimer’s Disease

Institution: Florida Atlantic University

Dissertation Advisor: Dr. Michael Frain

Degree: Doctor of Philosophy

Year: 2014

Alzheimer's disease (AD) is a progressive, degenerative disorder that attacks the brain's nerve cells, or neurons, resulting in loss of memory, thinking and language skills, and results in behavioral changes and lack of communication. Family members and caregivers of persons with Alzheimer’s disease can assume added responsibilities and stress due to the progressive and degenerative component of this disability and places an added strain on the family system. This study was designed to examine predictors of quality of life of persons living with AD and to examine caregiver burden and predictors of quality of life of persons living with AD. This study hopes to empower the caregivers and test the resiliency model of family stress, sense of coherence and social support while incorporating individual patient and family needs by surveying caregivers involved with
working with patients with AD. Specific aims of the study include validating relationships of the resiliency model while determining the importance of family resiliency, the sense of coherence, social support and the role of psychosocial interventions specifically Validation Communication Intervention (VCI), to reduce caregiver burden and to predict the quality of life in persons with Alzheimer’s disease.
DEDICATION

The following manuscript is dedicated to my parents: My courageous and tireless dad who was by my mum’s side for fifty years and was her sole caregiver. My mum who fought bravely and succumbed valiantly to Parkinson’s disease and who continues to be my inspiration and guidance and whose motivation, strength and light continues to shine on me always.
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CHAPTER I. INTRODUCTION

Alzheimer’s disease (AD) is the leading cause of dementia worldwide. Aging is the major risk factor for AD. Nearly 50% of people over the age of 85 are likely to be affected by AD. As the general population ages, Alzheimer’s disease is becoming a global health and social crisis. Recent statistics indicate that 4.5 million Americans have Alzheimer’s disease and by the year 2050 there will be 32 million people over the age of eighty in the United States and half of these will have Alzheimer’s disease (Petsko, 2012). The numbers are staggering and a better understanding of the disease mechanism is crucial for developing specific and effective interventions (Alzheimer’s Association, 2012). A number of health professionals that include physicians, mental health counselors, social workers and neuropsychologists work daily with persons with AD and it are imperative for these health care workers to be knowledgeable and current about AD research and literature in order to assist the patients and their families.

Statement of the Problem

Alzheimer’s disease is the sixth-leading cause of death in the United States and the only cause of death among the top 10 in the United States that presently cannot be cured. One in eight older Americans have Alzheimer’s disease which adds up to approximately five hundred million Americans who are currently living with Alzheimer’s disease. More than fifteen million Americans provide unpaid care valued at $210 billion for persons with Alzheimer’s and other dementias. Payments for care are estimated to be
$200 billion in the United States in 2012 and will rise exponentially to a trillion dollars by the year 2050 (Alzheimer’s Association, 2012; Petsko, 2012).

Dementia is an umbrella term describing a variety of diseases and conditions that develop when nerve cells in the brain die or no longer function normally. Alzheimer’s disease is the most common type of dementia. The death or malfunction of nerve cells, called neurons, causes changes in one’s memory, behavior and ability to think clearly. In Alzheimer’s disease, these brain changes eventually impair an individual’s ability to carry out such basic bodily functions as walking, grooming, communicating and swallowing. Alzheimer’s disease is ultimately fatal. It is important to note that Alzheimer’s disease is the most common cause of dementia, or loss of intellectual function, among people aged 65 and older. However, Alzheimer’s disease is not a normal part of aging (Alzheimer’s Association, 2012).

It is important that health care professionals including mental health counselors, social workers and psychologists working with families and loved ones who are living with AD, clearly understand the constructs of family resiliency. Having a framework of family resiliency provides theoretical knowledge whereby it allows the mental health counselors to assist the family and caregivers to gain insight into allowing for adjustments and adaptations in times of illness and crisis. Personality changes in the person with AD significantly affect the people around them bringing about a break-down in the quality of communication. Symptoms such as cognitive impairments, psychological and behavioral changes such as agitation, repetition, confusion, aggression, sleep issues, and wandering change the family dynamics drastically. Communicating, eating, dressing and grooming become more challenging as the disease progresses. This
loss of independence and privacy can be an extremely difficult transition for a person with dementia of the Alzheimer’s type (Alzheimer’s Association, 2012). The onset of AD places demands on coping resources, therefore the development of adaptive coping strategies are important to bring about maximum results for well-being and reduce the negative symptoms of the disease. Developing a fighting spirit and coming to terms with the disease, viewing these as a challenge and then responding with acceptance is a positive self-protective strategy (Clare, 2002). Current literature conducted by researchers demonstrates that that families and caregivers that attempt to avoid the situation at hand in order to protect their loved ones respond less positively and cause damage to their own psychological health (Clare, 2002; Clare et al., 2013). Diagnosis of Alzheimer’s disease is made through evaluation of an individual’s mental status and through use of other neurological tests that evaluate memory, language, reasoning and physical condition (Alzheimer’s Association, 2012). Alzheimer’s disease progresses over time, starting with minor changes in cognition and functional ability and ending with severe cognitive compromise and death (Granello & Fleming, 2008). Once an individual is diagnosed with AD, the disease can progress extremely quickly or plateau for many years. The gradual loss of memory, the lack of communication and reasoning capacity results in high levels of stress for those diagnosed with AD and also for the caregivers. Persons living with AD undergo severe physical and psychological changes. These significant changes, can place families and loved ones under duress and adjusting to the disease can be mentally shameful and financially draining (Granello & Fleming, 2008).

During the early stages of AD, patients are aware of the changes they are undergoing. Behaviors often exhibited by individuals with AD include lack of
communication, anger and agitation, hallucinations and paranoia, repetitive actions, screaming and verbal noises, incontinence, problems with bathing, dressing, sleeping, wandering and eating (Granello & Fleming, 2008; Robinson, Spencer, & White, 1989). Individuals with mild cognitive impairments or early stages of AD are able to register these downward spirals in executive functioning and activities of daily living (Centiski, 2004; Martyr & Clare, 2012) by acknowledging some difficulties with memory. Reacting to the changes in memory can vary from minimizing the impact, to focusing directly on a sense of disintegration. Some patients and families explain the changes by normalizing and attributing them to ageing. Experiencing the emotional impact reflects a struggle and a need to protect oneself from emotional pain (Centiski, 2004; Martyr & Clare, 2012). With the recognition of the disease, feelings of dismay and hopelessness are not uncommon. Losses in the domains of control, decision making, and communication and functioning on a daily basis can cause persons with AD to feel less willing to venture out or attempt things that were previously manageable (Centiski, 2004; Martyr & Clare, 2012). Feelings of embarrassment and nervousness in social situations and the fear of becoming a nuisance or burden is a predominant thought. Nonetheless, persons with early stages of AD do tend to adjust to the changes they are undergoing in some way. They indulge in self maintaining strategies, by compensating and appear to be functioning and are able to cover up their disease until further progression. As the disease progresses, the loss of reasoning ability, language, decision-making ability, judgment and the breakdown of communication skills makes navigating day-to-day living impossible without help from others, most often a family member or friend (Centiski, 2004; Martyr & Clare, 2012).
When coping with AD, taking the patient’s needs into consideration and allowing the person with AD to live with personal dignity and value is most challenging (Lyman, 1989; Sorensen, Waldorff, & Waldemar, 2008a; Woods, 2001). Coping has been established as a critical factor between stressful events and physical and psychological adaptation (Tache & Selye, 1985). Furthermore, coping has been defined as a concept that can constantly change in order to manage external and internal demands under conditions that an individual finds taxing and exceeding the resources that he believes he possesses (Folkman, Lazarus, Gruen, & DeLongis, 1986; Sorensen et al., 2008a). As the disease moves through the stages of mild to moderate to severe, several persons living with AD can undergo a continuum of feelings from well-being to anxiety and sorrow. Despair in the person with AD increases, especially in relationship to their spouses and the growing concern for what will happen to their spouse as the disease worsens their own condition (Robinson, 1997; Robinson, Clare, & Evans, 2005; Sorensen et al., 2008a). As the level of functioning declines in a person with AD it becomes more challenging to participate in the activities of daily living. Proactive caregivers strive to develop strategies to cope with the stressors by staying socially involved and active and using a person centered approach for the person with AD appears to alleviate some of the strain for the person with AD as well as the caregiver (Kitwood, 1997; Sorensen, Waldorff, & Waldemar, 2008b).

In order to alleviate caregiver burden, determine a better quality of life and assist with the coping and progression of the disease, researchers are constantly seeking effective psychosocial treatments for Alzheimer’s disease. There is a need to develop psychosocial interventions to help patients and caregivers better manage and cope with
the troublesome symptoms of Alzheimer’s disease. Strategies implemented include cognitive interventions, and functional and communication interventions. However, more research is needed to further develop new and easy to implement interventions and establish their best use. Psychosocial interventions hold great promise for reducing caregiver burden and improving the quality of life and well-being of persons with Alzheimer’s disease (Beck, 1998).

**Theoretical Framework**

Alzheimer’s disease (AD) is the fastest-growing threat to health in the United States. Alzheimer’s disease is not a normal part of aging, although the greatest risk factor is increasing age. The majority of people with Alzheimer’s are 65 and older, however AD is not just a disease of old age. Five percent of people with the disease have early onset Alzheimer’s, which often appears when someone is in their 40s or 50s (Alzheimer’s Association, 2012). At the onset of the disease, families struggle to understand and cope with the diagnosis and prognosis of the disease. The burden of caregiving for a person with AD often falls upon informal caregivers, such as the spouse or other family members. The demanding nature of the disease can take a substantial toll on the family and can place significant strain and stress on the family dynamic. This can be examined by the application of the resiliency model of family stress, adjustment and adaptation (McCubbin, Thompson, Thompson, & Futrell, 1999).

Resilience has been defined by researchers as successful outcomes under adverse conditions (Boss, 1987; McCubbin & McCubbin, 1996). Resiliency is a process that involves complex relationships, accompanied with risks and resources (McCubbin & McCubbin, 1996). Family resilience entails more than just the management and survival
of stressful situations. It involves the potential for personal and relational transformation and growth. The resiliency model of family stress, adjustment and adaptation describes how families adjust to the situation they are faced with, using their internal and external resources in a time of crisis. The resiliency model encompasses social support, appraisal of the situation and the problem solving abilities of the family (McCubbin et al., 1999). The model explains how stressors and strains can cause a family crisis. The factors that determine whether a family has the resources to overcome this adversity depend on their problem solving and coping and adaptation mechanisms.

The adaptation process results in either ‘bonadaptation’ or ‘maladaptation’ (McCubbin & Thompson, 1991; Robinson, 1997). While coping with stressors, some families possess the ability to bounce back from these challenges while producing coping mechanisms (McCubbin & McCubbin, 1993). Bonadaptation or successful adaptation means that the family is stabilizing itself and can achieve a sense of coherence when under a strain. The Sense of Coherence is described as turning a crisis into a challenge that is meaningful and problem solving (Antonovsky, 1988; Antonovsky & Sourani, 1988). On the other hand maladaptation is unsuccessful adaptation whereby the family members are in a chaotic state and family growth and development are at stake (Robinson, 1997). Resiliency involves the capacity to respond to a crisis in a constructive and positive manner. There are many factors that determine if a person, family, or a group will either deteriorate or grow in response to a crisis. It is not only the magnitude of the stressful event that determines how resilient an individual or family is but how they perceive the event, discover and develop new insights and abilities to cope with difficult experiences, and the various resources available to them are factors that determine their
level of resiliency and sense of coherence (Antonovsky, 1998; Patterson, 1988; Walsh, 2003).

The impact of Alzheimer’s disease and the implications thereof on a family has been examined in both pharmacological and psychosocial literature which has resulted in recommendations for medical practitioners and mental health counselors (Brodaty, Green, & Koschera, 2003; Duara et al., 1986). The current literature related to AD suggests that family resiliency, sense of coherence, social support, and the use of psychosocial interventions such as validation communication intervention (VCI) can be beneficial in reducing caregiver burden and can bring about the quality of life for both the care giver and person living with Alzheimer’s disease (Davison, Pennebaker, & Dickerson, 2000; Schneider, Murray, Banerjee, & Mann, 1999; Schultz et al., 2004). According to statistics, medical costs for AD patients is on the rise compared to average Medicare beneficiaries in the United States, related to other diseases (Alzheimer’s Association, 2012). The failure to understand and recognize these costs can result in inappropriate resource disbursements and can result in monetary loss for families who are facing this struggle (Kuo, Zhao, Weir, Kramer, & Ash, 2008). There is a need to assist families and health care professionals in finding suitable and cost-effective psychosocial interventions to bridge this gap and bring about a better quality of life that is beneficial to both the caregiver and the person living with AD.

In focusing on factors that are associated with bringing about a detriment in the quality of life for both the caregiver and the person living with Alzheimer’s disease, current literature documents increases in caregiver burden, distress, and a decrease in mental health and well-being (Sorensen, Duberstein, Gill, & Pinquart, 2006). More
severe behavioral, cognitive, and functional impairments in a person with AD are associated with higher levels of caregiver burden and distress in the family. Distress increases with the break-down in communication and the number of hours of caregiving per week, number of tasks, and declining coping and support resources. Making the treatments and psychosocial interventions easy to implement, cost effective and available, allows clinicians and families to campaign together for monetary reimbursement and researchers to further develop more preventive and easily accessible interventions that are beneficial to both the person with AD and the caregiver (Sorensen et al., 2006).

**Statement of the Purpose**

The purpose of this study is to contribute to knowledge in the field of mental health and to examine psychosocial interventions such as the implementation of validation communication intervention (VCI) to improve the relationship between the caregiver and the patient and bring about positive interpersonal satisfaction in communication. The study will also strive to support previous existing theory on family resiliency and adjustment. The study used a population of caregivers with a loved one with Alzheimer’s disease. In order to effectively support modalities such as the validation method which has been used in previous literature, further studies are needed to measure resiliency factors and therapies that assist in reduce caregiver burden, and improve the communications and relationships in persons with AD and their caregivers (Farina et al., 2002; Feil, 2002; Miller, 1995; Touzinsky, 1998).

This study attempted to bring awareness to the healthcare professionals in the field of mental health by shedding light on the factors that are beneficial to families when dealing with a loved one with AD. By surveying caregivers who care for a person with
AD, this study will highlight the areas of family resiliency, sense of coherence, social support and psychosocial interventions, especially Validation Communication Intervention (VCI) that can result in interpersonal communication satisfaction and may significantly reduce caregiver burden and improve the quality of life for both the caregiver and the person living with Alzheimer’s disease.

**Research Questions and Hypotheses**

The following questions will assist with guiding this study:

1. Does the implementation of a training workshop on Validation Communication Intervention for caregivers increase interpersonal communication satisfaction between the caregiver and the person with Alzheimer’s disease?

   • HO1: The implementation of a training workshop on Validation Communication Intervention will not improve interpersonal communication satisfaction between the caregiver in the experimental group compared to the caregiver in the control group and the person with Alzheimer’s disease as measured by the Interpersonal Communication Satisfaction Inventory and the Alzheimer’s Related Quality of Life Scale.

   • H1: The implementation of a training workshop on Validation Communication Intervention will improve interpersonal communication satisfaction between the caregiver in the experimental group compared to the caregiver in the control group as measured by the Interpersonal Communication Satisfaction Inventory.
2. Does the implementation of a training workshop on Validation Communication Intervention for caregivers reduce caregiver burden for the caregivers in the experimental group?

- HO2: The validation communication training workshop will not reduce caregiver burden for caregivers in the experimental group as compared to the caregivers in the control group as measured by the Caregiver Burden Scale.
- H2: The validation communication training workshop will reduce caregiver burden for caregivers in the experimental group as compared to the caregivers in the control group as measured by the Caregiver Burden Scale.

3. Will there be a relationship between family resiliency and caregiver burden and family resiliency and the attainment of quality of life in persons with Alzheimer’s disease, as measured by the Family Crisis and Oriented Personal Evaluation Scales, Caregiver Burden Scale and the Alzheimer’s Related Quality of Life scale?

- HO3: There will not be a relationship between family resiliency and caregiver burden and family resiliency and the quality of life in persons with Alzheimer’s disease as measured by the Family Crisis and Oriented Personal Evaluation Scales, Caregiver Burden Scale and the Alzheimer’s Related Quality of Life Scale.
- H3: There will be a relationship between family resiliency and caregiver burden and family resiliency and quality of life for persons with
Alzheimer’s disease as measured by the Family Crisis and Oriented Personal Evaluation Scales, Caregiver Burden Scale and the Alzheimer’s Related Quality of Life Scale.

4. Will there be a relationship between sense of coherence and caregiver burden and the sense of coherence and the quality of life for the caregivers and in persons with Alzheimer’s disease?
   - HO4: There will not be a relationship between sense of coherence and caregiver burden and sense of coherence and the quality of life as measured by the Family Coping Coherence Index, Caregiver Burden Scale and the Alzheimer’s Related Quality of Life Scale.
   - H4: There will be a relationship between sense of coherence and caregiver burden and sense of coherence and the quality of life as measured by the Family Coping Coherence Index, Caregiver Burden Scale and the Alzheimer’s Related Quality of Life Scale.

5. Will there be a relationship between social support and caregiver burden and social support and the quality of life for the caregivers and in persons with Alzheimer’s disease?
   - HO5: There will not be a relationship between social support and caregiver burden and social support and the quality of life as measured by the Social Support Index, Caregiver Burden Scale and the Alzheimer’s Related Quality of Life Scale.
   - H5: There will be a relationship between social support and caregiver burden and social support and the quality of life as measured by the Social
Support Index, Caregiver Burden Scale and the Alzheimer’s Related Quality of Life Scale.

6. Does family resiliency, sense of coherence, social support and validation communication intervention predict caregiver burden and the quality of life in caregivers and persons with Alzheimer’s disease?

• Ho6: Family resiliency, sense of coherence, social support and validation communication intervention will not predict caregiver burden and the quality of life in as measured by the Family Crisis and Oriented Personal Evaluation Scales, the Family Coping Coherence Index, the Social Support Index and the Caregiver Burden Scale and the Alzheimer’s disease Related Quality of Life Scale.

• H6: Family resiliency, sense of coherence, social support and validation communication intervention will predict caregiver burden and the quality of life in as measured by the Family Crisis and Oriented Personal Evaluation Scales, the Family Coping Coherence Index, the Social Support Index and the Caregiver Burden Scale and the Alzheimer’s disease Related Quality of Life Scale.

Definitions

Alzheimer’s disease. Alzheimer’s disease (AD) is one form of dementia that gradually gets worse over time. It affects memory, thinking, and behavior. Getting lost or wandering, language and communication problems, loss of interest in things previously enjoyed, flat mood, personality changes and loss of social skills are some of the symptoms of AD (A.D.A.M. Medical Encyclopedia, 2011).
Caregiver. This is referred to someone who is an individual (a spouse, family member or a paid professional) involved in assisting others with activities of daily living and/or medical tasks (Family Caregiver Alliance, 2012).

Caregiver burden. This term is used in reference to a high level of stress that may be experienced by people who are caring for another person with some kind of chronic and sometimes degenerative illness. Caregiver Burden can occur when stressors cause alterations in caregivers’ emotional and physical health and a break-down in communication which can be found when care demands outweigh available resources (Given, 1992).

Dementia. Dementia is a loss of brain function that occurs with certain diseases. It affects memory, thinking, language, judgment, and behavior. Most types of dementia are nonreversible or degenerative. Nonreversible means the changes in the brain that are causing the dementia cannot be stopped or turned back (A.D.A.M. Medical Encyclopedia, 2013).

Family. A family includes one or more people living in the same household who are related by birth, marriage, or adoption. All people in a household who are related are regarded as members of his or her family (United States Census Bureau, 2013).

Interpersonal communication satisfaction. This term is defined as an interpersonal relationship where need gratification, expectation fulfillment, and the producing of appropriate behaviors and reinforcement is perceived (Hecht, 1978b).

Person or loved one living with Alzheimer’s disease. This term includes an individual who has undergone a thorough medical history, a mental status testing, a physical and neurological exam, tests (such as blood tests and brain imaging) to rule out
other causes of dementia-like symptoms and has subsequently been diagnosed with Alzheimer’s disease or a related dementia (Alzheimer’s Association, 2012).

**Psychosocial interventions.** Psychosocial interventions refer to different therapeutic techniques, usually classed as non-pharmacological (not involving medication), that address the psychological aspects of an individual or group and consider the person’s or group’s situation from a societal, familial perspective (Douglas, James, & Ballard, 2004).

**Quality of life (QOL) for a person with AD.** QOL is understood to be both subjective and multidimensional. It is subjective, as it is measured from the patient’s perspective and it is also multidimensional, as its measurement requires the investigation of several areas of the patient’s life, including physical well-being, functional ability, emotional well-being, and social well-being (Cella, 1994).

**Resilience.** Is the capacity to rebound from adversity, crisis and challenges by implementing positive coping and adjustment strategies. Resilience has become an umbrella term to cover many aspects of overcoming adversity and adapting to one’s environment. Resiliency is a family’s perspective about the current challenge, their social support, and their appraisal of the challenge, their optimistic expectancies, and their coping and problem-solving abilities (McCubbin et al., 1999). Resilience has become a popular construct encompassing many different variables including personal characteristics, coping processes, the development of other associated constructs such as hardiness and sense of coherence, and risk and protective factors (L. McCubbin, 2001).
Sense of coherence. This is a construct that refers to the extent to which an individual sees his/her world as comprehensible, manageable and meaningful (Antonovsky & Sourani, 1988).

Social support. This term is defined as an exchange of resources between two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient. (Shumaker & Brownell, 1984).

Validation communication intervention. For the purpose of this study, a communication modality called validation therapy used with persons with dementia, will be referred to as validation communication intervention (VCI) and is synonymous to Validation Therapy. It is the reciprocated communication of respect which communicates that the other’s opinions are acknowledged, respected, heard, and (regardless whether or not the listener actually agrees with the content), they are being treated with genuine respect as a legitimate expression of their feelings, rather than marginalized or dismissed. Usually, it is focused on a particular issue, in this case, interventions that bring satisfaction in interpersonal communication and assist in bringing about the quality of life of persons with Alzheimer’s disease (Feil, 2002).

Summary

Alzheimer’s disease (AD) is a chronic disease without a cure, and the numbers are steadily rising (Alzheimer’s Association, 2012). Healthcare professionals such as physicians and mental health counselors work alongside families and caregivers to help persons with AD adjust to the disease. Due to the degenerative component of the disease, persons with AD steadily go downhill and this may result in stress and burden on both the patient and the caregiver. There is a gap and a need in the current literature to explore
different modalities specifically psychosocial interventions to help alleviate caregiver burden and improve the quality of interpersonal communication, thereby improving quality of life. This study will assess the correlation between family resiliency, sense of coherence and social support as well as indicate the possible benefits of the implementation of validation communication intervention to reduce caregiver burden and bring about positive interpersonal communication satisfaction. By understanding and implementing psychosocial interventions and effective coping strategies, healthcare professionals and mental health counselors can create integrative plans for caregivers and families who have a loved one with AD. This will help to reduce caregiver burden and address the overall quality of life for both the caregiver and the person living with Alzheimer’s disease.
CHAPTER II. REVIEW OF LITERATURE

The global prevalence of dementia is estimated to be as high as 24 million and is predicted to double by 2040 (Reitz, Brayne, & Mayeux, 2011). Dementia is a general term for a decline in mental ability severe enough to interfere with daily life. Alzheimer’s disease (AD) is the most common type of dementia. 5.4 million Americans are living with Alzheimer’s disease and one in eight older Americans has AD. Alzheimer’s disease is the sixth-leading cause of death in the United States and the only cause of death among the top 10 in the United States that cannot be prevented, cured or even slowed (Alzheimer’s Association, 2012). Based on final mortality data from 2000-2008, death rates have declined for most major diseases such as heart disease, breast cancer, prostate cancer, stroke, and HIV/AIDS. However, deaths from Alzheimer’s disease have risen sixty-six percent during the same period. More than 15 million Americans provide unpaid care (caregivers), valued at $210 billion for persons with Alzheimer’s and other dementias and payments for care are estimated to be $200 billion in the United States in 2012 (Alzheimer’s Association, 2012). The Medicare payments for an older person living with Alzheimer’s disease or other dementias are nearly three times higher than for an older person without these conditions and Medicaid payments are 19 times higher. These costs will only continue to soar in the coming years given the projected rapidly escalating prevalence of Alzheimer’s disease as the baby boomers age (Alzheimer’s Association, 2012).
In 2012, the direct costs of caring for those with Alzheimer’s or other dementias to American society totaled an estimated $200 billion, including $140 billion in costs to Medicare and Medicaid. Cost-effective interventions need to be implemented in the treatment of Alzheimer’s disease as the targeted costs currently will soar from $200 billion this year to a projected $1.1 trillion by 2050 (Alzheimer’s Association, 2012).

Alzheimer’s disease (AD) is the common form of dementia and characterized by a progressive decline in cognitive function, which typically begins with deterioration in memory. In 1906, Alois Alzheimer gave a lecture at a congress in Tubingen, Germany on the first case of the disease. In this single case Alzheimer described a 51-year old woman with typical characteristics that are associated with memory disturbances and psychotic symptoms that rapidly progressed until she died four years later. Alzheimer applied chemical stains to brain tissue obtained during the patient’s autopsy and what he found were tiny amyloid plaques and tau tangles (Small & Vorgan, 2011). These are abnormal waxy protein fragments and twisted fibers and are synonymous with the disease. The hallmarks of Alzheimer’s disease are these microscopic deposits that are located in areas of the brain that control memory and other functions such as language, decision making and personality (Blennow, de Leon, & Zetterberg, 2006).

Alzheimer’s disease accounts for 50-60% of all dementia cases. The prevalence of dementia is below 1% in individuals aged 60-64 years, but shows an almost exponential increase with age, so that in persons aged 85 or older, the prevalence is between 24% and 33% in the Western hemisphere (Blennow et al., 2006). Due to the increasing numbers of persons with AD, the disease is a major public health problem which is expected to reach the 81 million mark in 2040, due to anticipated increase in life expectancy (Ferri et
al., 2005). Besides aging, which is the most obvious risk factor for the disease, research studies have suggested several other associations. Some can be linked to a decreased reserve capacity of the brain, including reduced brain size, low educational and occupational attainment, low mental ability in early life and reduced mental and physical activity during late life (Mayeux, 2003; Mortimer, Snowdon, & Makesbery, 2003).

The brain reserve capacity is determined by the number of neurons and the branching, treelike shape or arrangement, of the dendrite of a nerve cell which is referred to as dendritic arborisation (Blennow et al., 2006). Moreover several epidemiological studies have shown that head injury could be an added risk factor (Jellinger, 2004). Whether brain trauma leads to plaque and tangle formation or whether it simply reduces the brain reserve capacity is still unclear. Other risk factors linked to AD are associated with vascular disease, including hypercholesterolemia, hypertension, atherosclerosis, coronary heart disease, smoking, obesity and diabetes (Luchsinger & Mayeux, 2004; Mayeux, 2003). The possibility that an individual will develop AD or a dementia related illness is a reality in older adults. Researchers and scientists have found that the disease’s relentless infiltration in the brain stems from plaque deposits and tau tangles that emerge from deep structures in the temporal lobe of the brain (Small & Vorgan, 2011). These deposits and tau tangles then spread throughout the brain’s outer rim or cortex and attack the cells that control short term memory, while long term memory is preserved.

**Early Detectors of Alzheimer’s disease**

According to researchers there are ten early detectors to AD. These include memory loss that disrupts daily life, challenges in solving problems, difficulty completing familiar tasks, confusion with time and place, trouble understanding visual
and spatial relationships, new problems with speaking, communication and writing, misplacing things and losing the ability to retrace steps, decreased or poor judgment, withdrawal from work or social activities and changes in mood and personality (Alzheimer’s Association, 2012). For instance, a person with AD may recall his friends from high school but is unable to recall what he had for lunch on a given day, or if had lunch at all. As the disease progresses the person living with AD forgets the names of loved ones along with the ability to make sound decisions. Individuals are unable to handle finances, they often get lost, and many may experience behavioral changes. Accompanied with memory loss and cognitive impairments, a person with Alzheimer’s disease may also have personality and communication changes. Sometimes these changes are the first sign of brain degeneration (Small & Vorgan, 2011). Approximately 50% to 80% of persons diagnosed with Alzheimer’s disease have some type of behavioral or psychiatric condition. These may include agitation, psychosis, and/or disinhibition (Lesser & Hughes, 2006).

These behavioral and communication disturbances within a person with AD may cause dysfunction within the family dynamics. With increased public awareness and better diagnostic procedures, persons with AD can be diagnosed in the early stages of the onset of the disease. Most persons with AD reside in the community and require assistance, caregiving and supervision on a daily basis. With the progression of the disease, the person with AD is robbed of his or her independence. Caregiving literature and researchers have demonstrated that being a family caregiver for a person with AD takes a toll on the caregiver. Furthermore, researchers in the field have demonstrated that counseling and psychosocial interventions can have positive effects in alleviating
behavioral disturbances and stress in patients as well as the caregiver (Manepalli, Desai, & Sharma, 2009; Waldorf et al., 2012). Many individuals with mild dementia pay more attention to programs directed to their needs. Therefore there is a vital need to develop and evaluate support programs and interventions that attend to the needs of both the person with AD and the caregiver. The following chapter will outline relevant concepts and findings pertinent to the targeted areas of this study. These will include family resiliency, the implementation of psychosocial interventions such as validation communication intervention (VCI), the role of the sense of coherence, the role of social support, the role of the caregiver, and the prognosis for a better quality of life and interpersonal communication satisfaction both for the caregiver and the person living with Alzheimer’s disease.

**Family Resiliency**

Individuals face serious challenges over the course of their respective lifespans. No one individual or family is problem free. How do we define the process that enables individuals and families to support each other, to cope with illness, to survive trauma, disabilities or loss? Resilience has been defined as the ability to rebound from crisis and overcome these life challenges (Walsh, 2004). Current literature on resiliency has a foundation for researchers to build on the definition and meaning of resilience. The general definition of resilience within developmental psychopathology involves good outcomes based on the interactions between risks and assets (Gilgun, 1996; Masten, Best, & Garmezy, 1990). Individuals can be termed as being resilient when they are put in at risk situations (McCubbin et al., 1999). Resilience can also be viewed as a set of behaviors and internalized capacities and means being able to recover from, to be able to
cope with and overcome adversity (Masten et al., 1990; L. McCubbin, 2001). Cohler (1987) observed that persons who demonstrate resilience are flexible, problem-solvers and possess help-seeking behaviors, rather than having rigid responses to stress and adversity. Resiliency is associated with the ability to adapt to adversity, disability or trauma. Individuals who overcome and recover from adversity will show an understanding of the adaptation processes (Frain et al., 2007). Resilience is defined as the ability to withstand and rebound from disruptive life changes and it is considered to be a success in adaptation (Walsh, 2003; Wilks & Croom, 2008). Resilience involves processes that foster positive adaptation within the context of significant adversity (Luthar, Cicchetti & Becker, 2000). These strengths enable an individual and families to respond successfully to challenges and crisis.

In the 1980’s research in this area focused primarily on individual resiliency (Walsh, 2003). Early family resiliency theories focused primarily on characteristics that pertained to children who functioned competently even when exposed to adversity (Garmezy, 1991; Masten & Coatsworth, 1998; Rutter, 1987). Researchers noted that there was no specific combination of adverse factors, regardless of severity that affected more than half the children that were exposed to adverse situations (Walsh, 2003). Although many children were affected, others overcame these challenges and were able to lead loving and productive lives and raise children of their own. Furthermore, researchers noted that most abused children did not become abusive parents (Rutter, 1987; Walsh, 2004). To account for these differences early studies focused on individual and personal traits for resilience or hardiness that reflected the individual that possessed rugged traits (Luthar & Zeigler, 1991; Walsh, 2004). The recognition and development of
resilience is linked to an individual’s ability to have hope and find assurance amid the
distress in his life (Wilks, 2008). Closely related to individual resiliency is the resiliency
of the family in adjusting to an adverse factor or to a family member’s disability or
illness.

Theories of Family Resilience

Researchers have explored the concept of family resilience that views individual
family members as potential resources for individual resilience that focus on risk and
resilience together as a functional unit (Walsh, 2003, 2004). The basic understanding is
that when adversity persists, the entire family is affected systemically. Key family
processes come into play and enable family members to rally in times of crisis, buffer
stress and alleviate dysfunction within the family dynamics (Walsh, 2003, 2004).

Positive social assets such as IQ, physical attractiveness, social skills, supportive
families and safe neighborhoods are important concepts in resiliency research. These are
termed as the positive counterpart of risk (Wang & Gordon, 1994). Not all persons with
positive assets turn out well compared to persons who come from low socioeconomic
backgrounds or from families that have maladaptive outcomes (Canada, 1995; Jarrett,
1994). Individuals may possess positive assets that could assist them with dealing with
risks, but if they do not use them, these do not function as assets at all. However when
these positive assets are implemented to constructively deal with risks, they are termed as
protective factors. The study of resilience as a research concept is based on certain
premises. The first premise is its ordinary quality, which is a phenomenon that may result
within any person in a stressful situation and it comes from the operation of basic human
adaptive processes (Masten, 2001). A second premise of the study of resilience is the
criterion of risk. Risk is a condition that has to be present when observing resilience (Rickwood, Roberts, Batten, Marshall, & Massie, 2004). A third premise that is linked to the risk factor is the negative correlation of risk with resilience; as risk increases resilience most likely decreases (Hoge, Austin, & Pollack, 2007). The last premise of the study of resilience addresses the protective factor. A protective factor is one that is a positive correlate to resiliency. Coping factors are protective factors and a common example of these would be social supportive relationships (Rutter, 1990).

Researchers have identified strengths that assist at-risk families (Coleman & Ganong, 2002). Furthermore, just as the understanding of child resilience emerged from studies of stress and coping in children, family resilience can be examined from the perspective of family stress and coping theory (Hill, 1958; McCubbin & Patterson, 1983; McCubbin & McCubbin, 1993; Patterson, 1988).

The Family Stress, Coping and Adaptation theory (McCubbin & Patterson, 1983) grounded on Hill’s seminal work, examined family vulnerability and regenerative power, in order to understand how and why some families withstand and recover from stress and crisis when others cannot. The importance of fit and balance to the individual and the family unit is extremely significant. Fit relates to the functional fit between challenges and resources. With many resources directed towards adaptation, families have to weigh the benefits of the options available (McCubbin, Thompson, Thompson, & Fromer, 1998; McCubbin et al., 1999). Building on theory and research on family stress, coping, and adaptation (Hill, 1958; McCubbin & Patterson, 1983), the concept of family resilience is more than just managing stressful conditions or surviving an ordeal. It involves the potential for personal and relational growth that can come from adversity (Boss, 2001).
Many families report that a crisis can in a sense be a like a wake-up call (Walsh, 2003), and weathering a crisis together can make relationships stronger and more loving. Over the years researchers have conducted and implemented a number of theories that address family resiliency. This study will explore seminal research conducted by Hill (1958), the FAAR model developed by Patterson (1988) and the concept of Sense of Coherence (Antonovsky & Sourani, 1988). Additionally this study will examine the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin et al., 1999) as the theoretical framework for this study.

**ABCX Model of Family Stress**

At the family level of analysis, Hill’s pioneering ABCX model of family stress in wartime led to further research developments on family coping and adaptation (Boss, 1987). McCubbin and Patterson (1983) developed a family crisis framework, stating concepts like family vulnerability and growth to understand why some families can withstand and recover from stress and crisis while others cannot. Furthermore, researchers (McCubbin & Patterson, 1983) emphasized the importance of fit and balance in adaptation to achieve a level of functioning that promotes the growth of the individual and the family as a whole. Family resiliency exhibits positive behavioral patterns and functional competencies that families demonstrate under stress. These patterns enhance the family’s ability to recover and restore well-being (M. McCubbin, 2001). Simon, Murphy, and Smith (2005) stated two components of family resiliency: The family’s ability to demonstrate positive responses to adverse and stressful situations and the family’s ability to be resilient and leave a stressful situation feeling strengthened. The initial model applied to families who were undergoing stressful situations was the ABCX
model (Hanson & Lynch, 2004; Hill, 1949). The model defines A as problem solving skills; B is defined as family resources; C is the family’s interpretation of the situation and the ways or modalities used by A, B, and C to interact with each other produces X, which is the adaptation to the stressful event (Hanson & Lynch, 2004).

**The Family Adjustment and Adaptation Response (FAAR) Model**

The Family Adjustment and Adaptation Response model (FAAR), developed by Patterson in 1988, expands upon prior models and focuses on positive outcomes. The FAAR model is an integrated addition to the family stress theory and the ABCX model. It introduces the concept of balance between required of family-to-member and family-to-community fit as a critical factor for adaptation (M. McCubbin, 2001). The FAAR model posits that illness, whether acute or chronic, acts as a stressor for families (Patterson, 1988). The seriousness and chronicity of the illness, influences the intensity of the demand and how much it upsets the family’s balanced state. A family’s response to any identified stressor can best be understood in the context of the multiple demands confronting a family at any point in time. Families seldom manage only one demand at a time. Rather, they are continuously faced with multiple demands, the nature of which change over time as some demands are resolved and new ones emerge and the family often gives priority to some demands over others. In the original ABCX Model, the C factor was the family’s definition of the stressor. This factor has can also be explained as the meaning that is found in the stressor that the family is faced with (Patterson, 1988). Situational meanings include the family’s subjective definitions of their demands, and their capabilities to fulfill these demands. Global meanings on the other hand make up the
family schema for how it views the relationship of family members to each other, and the relationship of the family unit to the larger community.

**Sense of Coherence (SOC)**

The Sense of Coherence (SOC) is an important factor for understanding family resiliency. SOC is considered to be the foundation for a family’s response to stressful situations and the subsequent result in functional competence (McCubbin et al., 1998). The SOC is a construct that refers to the extent to which an individual sees his/her world as being comprehensible, manageable and meaningful (Antonovsky & Sourani, 1988). The SOC is based on an individual’s inner and outer environments, especially how he/she makes meaning of an event. In order to measure the sense of coherence, researchers have conducted studies using family caregivers’ subjective experiences of satisfaction with regards to dementia care, implementing the Family Coping Coherence Index taking into consideration caregiver burden, subjective health and sense of coherence (Andren & Elmstahl, 2005; McCubbin & McCubbin, 1993). Both the ABCX and FAAR models examine why some families recover from a crisis while others suffer negative consequences. Adhering to the ABCX model quite simply explains why some families recover and are resilient while other families remain vulnerable (M. McCubbin, 2001).

**Resiliency Model of Family Stress, Adjustment, and Adaptation**

For the purpose of this study the Resiliency Model of Family Stress, Adjustment and Adaptation will be used as a theoretical framework to explain resiliency as a factor for persons’ with Alzheimer’s disease. The resiliency model of family stress, adjustment and adaptation is a comprehensive model that emphasizes the significant role of the family and the behaviors that contribute to adjusting to stressful life events (McCubbin &
McCubbin, 1988). The premise of the model is to understand what a family does well and then to build on this base to help the family become more effective in problem solving, coping, and adjustment (McCubbin, Thompson, & McCubbin, 1996). Furthermore, the resiliency model of family stress, adjustment and adaptation stresses that an individual’s view and how he sees his family is a significant factor of family resiliency (Frain, Berven, Chan, & Tschopp, 2008). The family’s adaptation to an illness or disability can be brought about by understanding five key factors about the family. These include a family’s uncertainty about the illness, their social support, their appraisal of the illness, their optimistic expectancies, and their coping and problem-solving abilities (Kosciulek, 1994). With the implementation of this theory this study can further examine the effects of illness and disease on the family unit and how it can problem solve and adapt to the given situation.

Some families may do well with a short-term crisis but may buckle if there are persistent hardships or challenges. A continuous piling-up of internal and external stressors can increase vulnerability and extend the risk with in families for subsequent problems (Boss, 2001; McCubbin, 1982; Patterson, 1988). Factors dealing with adversity are effective family processes that involve flexibility and the quality of caring and committed relationships (Walsh, 2003). It is extremely important for parents and caregivers to provide nurturance, protection and guidance through a disruptive period or crisis (Walsh, 2003).

With widespread concern about the challenges within the family, whether it is due to a short or a long term crisis, conceptual models such as the family resilience framework are helpful to guide and strengthen family relationships. Resilience
researchers offer a knowledge base for practice, and has potential implications for building connections between clinicians, research and policy makers (Werner & Johnson, 1999). Another factor in determining the resiliency of an individual undergoing a crisis or a progressive illness such as Alzheimer’s disease is social support.

**Social Support**

“Love thy neighbor as you love yourself” is a term used in the New Testament to describe the first of two commandments cited by Jesus in Matthew 22:35 and Mark 12:28, and is a phrase that we have often heard and used in today’s ever evolving society. This has been the prescription followed by spiritual leaders for many centuries and so when it comes to the importance of addressing health, the adoption of such a principle comes to light. Albrecht and Adelman (1984) defined social support as verbal and non-verbal communication between recipients and providers. This process reduces uncertainty about the situation, the self and the other person and functions to bring about and enhance personal control in life experiences. Furthermore, social support can be defined as the process of interaction in relationships that brings about a sense of belonging and competence and builds self-esteem and coping through actual or perceived physical or psychosocial resources (Gottlieb, 2000). Social support is composed of emotional and instrumental support. It is an interpersonal process characterized by reciprocal exchange of information. It is contextual and can result in improved mental health (Finfgeld-Connett, 2005). Furthermore researchers described patterns of social relationships that were not explained by families or work groups but found a relationship with health (Israel, 1985). Social support served as a protective factor to people’s vulnerability on the effects of stress on health and can also be defined
as an exchange of resources that are intended to enhance well-being (Shumaker & Brownell, 1984). Social support is also associated with how networking helps people cope with stressful events and can enhance psychological well-being.

Social support distinguishes between four types of support namely emotional, instrumental, appraisal and informational support (House, Umberson, & Landis, 1988). Emotional support is associated with sharing life experiences. It involves the provision of empathy, love, trust and caring. Instrumental support involves the provision of tangible aid and services that directly assist a person in need. It is provided by close friends, colleagues and neighbors. Informational support involves the provision of advice, suggestions, and information that a person can use to address problems. Appraisal support involves the provision of information that is useful for self-evaluation purposes: constructive feedback, affirmation and social comparison. Support groups are an excellent source of providing support to caregivers and the person with AD.

Current literature on social support and the attendance in support groups demonstrates that individuals try to change their health behaviors through self-help rather than professionally designed programs (Davison et al., 2000). Support groups, involving low cost, do have a powerful effect on mental and physical health (Davison et al., 2000). Researchers have suggested that how, when and why individuals seek out their support network may be different especially when it comes to chronic and life threatening illness (Rolland, 1984). Individuals will define what they consider to be supportive and seek out the kind of support that closely fits their definition, which brings about the reduction in stress and a significant positive relationship between support and illness (Roberts, 1985; Rolland, 1984).
The Nature of Social Support

According to Cobb (1976), social support is significant as it is also referred to as communicated caring. It is informational in nature and has three components. These are (a) emotional support that leads the individual to believe that he/she is cared for and loved, (b) esteem support leads the individual to believe that he/she is valued and esteemed and (c) network support leads the individual to believe that he/she has a resource of network communication and mutual obligation (Cobb, 1976).

Yet another form of support is instrumental in nature and involves counseling. This helps to guide individuals to better coping and adaptation skills and enables maximum participation and autonomy. Active support or mothering is what mothers do for their infants and nurses when caring for their patients. When carried out in excess it can lead to dependency. Material support of goods and services according to Cobb (1976) is important as it focuses on the provision of goods and services that enables the individual to feel empowered and is therefore a crucial component of social support.

Social support is a commonly reported resource when coping with stress and adverse circumstance (Cohen & Wills, 1985; Sinha & Watson, 2007). Social support has been linked to a sense of belonging (Powers, Cramer, & Grubka, 2007) along with positive outcomes of psychological health. Social support and perceived social support is also linked to a decrease in depression and an increase in self-esteem and psychological well-being (Chappell & Reid, 2002; Rozario, Chadiha, Proctor, & Morrow-Howell, 2008). Social support is a function of the community, in that it is equally important in its contributions to the functioning of an individual and also to the family. Social support as explained by the resiliency theory (McCubbin & McCubbin, 1988) plays an important
role in a broader sense, in that the more resilient families utilize social support systems more effectively.

Chronic disease and illness represent long-term problems in managing the patient and the family as a whole. The result is an increased amount of work and burden on the family. With this increased burden the family dynamics shift and change over time. Caring for a chronically ill and elderly family member is a stressful experience. Previous researchers suggest five caregiving domains, these being emotional support, direct service provision, mediation with formal organizations and providers, financial help, and sharing a household (Walsh, 2004).

Family members, counselors and physicians who are involved in providing care for someone with Alzheimer’s disease (AD) face significant challenges accompanied with stress, breakdown of the protective resilience factor and significant interpersonal communication issues. Social support when examined with AD patients was found to function as a protective resilience factor among AD caregivers (Beuscher & Grando, 2009b; Wilks & Croom, 2008). Stress negatively influenced variations in resilience while social support positively influenced resilience and caregivers with high family support had elevated resilience (Beuscher & Grando, 2009a; Wilks & Croom, 2008). Support for AD caregivers was also manifested in the form of support that was informational, emotional and tangible (Stone, 2013). Stress when not taken care of, can exacerbate into serious illness and cause discomfort for the caregiver. This is referred to as Caregiver Burden.
Caregiver Burden

Family caregivers of people with dementia of the Alzheimer’s type are often called the invisible second patient (Brodaty & Donkin, 2009) and are critical to the quality of life of the persons living with AD. Family caregivers may be motivated to provide care for several reasons. It could be a sense of love or reciprocity, spiritual fulfillment, a sense of duty, guilt, social pressures or in rare situations, even greed (Brodaty & Donkin, 2009). The progressive deterioration of the person with AD often necessitates increasing reliance upon the caregiver. Therefore caregivers who are motivated by a sense of guilt, duty or social and cultural norms may suffer from greater psychological stress as they resent their role compared to the more positive caregivers. Caregivers who experience more social support and see their role as being positive in their relationship with the person they are caring for, demonstrate less stress and burden accompanied with better physical and psychological health (Brodaty & Donkin, 2009; Erder et al., 2012). Stress and burden are the most common problems for those who care for someone with Alzheimer’s disease. Caregiving, especially full-time caregiving requires tremendous physical effort, and can lead to chronic physical and emotional strains. These stressors are further increased depending on the length of time the caregiver spends with the person with AD, the availability of social support systems, the relationship of the caregiver to the patient and also how the caregiver perceives the demands on his own capacity within the caregiving environment (Donaldson & Burns, 1999; Erder et al., 2012; Takai et al., 2009).

Caring for someone with Alzheimer’s involves constant vigilance and activity. Almost 50% of persons living with AD have some type of behavioral or psychiatric
disturbance such as agitation. Agitation can be described as a restlessness, irritability or resistance (Lesser & Hughes, 2006). Psychosis and the lack of inhibition can also be found in persons with AD. Psychosis is recognized as a disturbance in the perception of object reality, while the lack of inhibition can present itself as hyperactivity, aggression and socially intrusive behaviors. Such conditions are extremely difficult for the caregiver’s to manage and results in caregiver burden and sometimes patient abuse and institutionalization (Lesser & Hughes, 2006). Higher levels of caregiver burden also correspond to higher levels of depressive symptoms; spiritual loss, fear, and the inability to cope subsequently lower the quality of life (Callaby, 2007; Takai et al., 2009). Female caregivers of persons with dementia suffer from higher rates of stress, distress, anxiety and depression (Mahoney, Regan, Katona, & Livingston, 2005).

AD may affect families in different ways. Those with the disease report being misunderstood because of the myths and misconceptions others have about the disease. Stigma is yet another source of stress and can lead to caregiver burden (Werner, Mittelman, Goldstein, & Heinik, 2011). Researchers point to pervasive stigma not only in the United States but also globally (Chang & Horrocks, 2006; Werner & Heinik, 2008). Family stigma was primarily experienced by AD caregivers covering three dimensions. These included the intrapersonal, interpersonal and social aspects of stigma by association and go hand-in-hand with the stigma related to the severity of the disease. The appearance of the person with AD and the supposed danger associated with it (Werner et al., 2011) elicits public emotional reactions such as distancing, fear, pity and shame (Corrigan, 2000; Werner, Goldstein, & Buckbinder, 2010).
The effects of being an Alzheimer’s caregiver are generally negative with high rates of burden and social isolation, physical and psychological ill-health and financial hardships (George & Gwyther, 1986). Therefore providing resources, introducing and implementing non-pharmacological and psychosocial interventions to alleviate their burden and stress is needed, to further improve the quality of life for both the caregiver and the person living with AD.

**Alzheimer’s Disease and Caregiver Resources**

Caring for a family member with Alzheimer’s disease (AD), poses significant challenges and caregivers report acute stress, the use of psychotropic medications and rate their physical health as being significantly poorer than their peers (Dunkin & Anderson-Hanley, 1998). Current literature demonstrates that husband’s whose spouses have AD have demonstrated emotions such as anger, worry, guilt, distress and isolation (Samuelsson, Annerstedt, Elmstahl, Samuelsson, & Grafstorm, 2001).

In response to the emotional and physical burdens that are associated with caregiving for an individual with AD, the number of support groups has increased over time (Glosser & Wexler, 1985). Alzheimer support groups vary widely in format and content. In a meta-analysis, comparing caregivers in support groups in 23 studies, the results showed that the AD caregivers were worse off regarding their global health and well-being (Vitaliano, Zhang, & Scanlon, 2003). Furthermore, psychological and spiritual crisis affected the AD caregiver also termed as the other victims of dementia. These individuals are faced with stressors on a daily basis that may lead to caregiver burden (Schneider et al., 1999). Pavot and Diener (1993), while focusing on the Alzheimer’s caregiver, revealed a grieving process that had a negative effect on the psychological
well-being of the caregiver but it also had adverse effects on the caregivers personally. This grieving process acts as a block for the caregiver to set goals and plans for a personally meaningful future (Potgieter, Heyns, & Lens, 2011).

Financial constraints and pressures may lead to further caregiver burden. Compared to the average per person, Medicare payments for an older person with Alzheimer’s or other dementias are nearly 3 times higher (Alzheimer’s Association, 2012) and Medicaid payments are 19 times higher. The care costs of Alzheimer’s and other dementias will continue to soar from $200 billion in 2012 to a projected $1.1 trillion (in today’s dollars) by 2050. This dramatic rise includes a 500 percent increase in combined Medicare and Medicaid spending (Alzheimer’s Association, 2012).

Caring for a person with Alzheimer’s or another dementia is often very difficult, and many family and other unpaid caregivers experience high levels of emotional stress and depression as a result. Sixty percent of family caregivers of people with Alzheimer’s disease and other dementias are women. Most caregivers are aged 55 or older (56%). Over half are the primary breadwinners of the household (55%), and nearly half are employed full or part time (44%). Twenty-six percent of family caregivers have children less than 18 years of age living with them. These caregivers are sometimes referred to as the “sandwich generation” because they simultaneously provide care for two generations (Alzheimer’s Association, 2012).

Caring for a person with Alzheimer’s or another dementia poses special challenges. Although memory loss is the best-known symptom, these diseases also cause loss of judgment, orientation and the ability to understand and communicate effectively. Personality and behavior are affected as well. Individuals require increasing levels of
supervision and personal care, and many caregivers experience high levels of stress and negative effects on their health, employment, income and financial security. Family members caring for their loved ones often suffer from caregiver burden. This has been defined as the experience of enduring stress and frustration (Butcher, Holkup, & Buckwalter, 2001; Etters & Harrison, 2007). Caregiver burden is often associated with poor outcomes for caregivers such as depression, anxiety and poor quality of life (Etters & Harrison, 2007; Schulz et al., 2004). The close relationship between the caregiver and the impaired person is a relationship involving shared communication, emotions, experiences and memories. This may particularly place caregivers at risk for psychological and physical illness (Alzheimer’s Association, 2012).

**Resources for Enhancing Alzheimer’s Caregiver Health (REACH)**

Established in 1995, Resources for Enhancing Alzheimer’s Caregiver Health (REACH) is a research program sponsored by the National Institute on Aging and the National Institute on Nursing Research (Gitlin, 2003; Schultz et al., 2004). The primary purpose of REACH is to conduct social and behavioral research on interventions designed to promote and enhance family caregiving for Alzheimer’s disease. REACH strives to test the effectiveness of interventions and to evaluate the pooled effect of these interventions (Schultz et al., 2004). In research conducted, REACH findings demonstrated that certain subgroups of caregivers especially female caregivers, demonstrated lower levels of caregiver burden compared to their male counterparts (Etters & Harrison, 2007). Interventions have been developed and evaluated that assist AD caregivers. These interventions may include (a) Individual Information and Support Strategies; (b) Group Support and Family Systems Therapy; (c) Psycho-educational and
Skill-based Training Approaches; (d) Home-Based Environmental Interventions and (e) Enhanced Technology Support Systems (Schultz et al., 2004).

Stressors faced by the caregivers equate with quality of life predictors for the caregivers of persons with AD. Current literature has focused on stressors that contributed to the quality of life. These included caregiving demands, role change and responsibility, lifestyle interference, patient personality, caregiver characteristics, coping methods and social support (Lim & Zebrack, 2004). Determining the factors that lead to the prevention of stress and caregiver burnout and subsequently the quality of life for a person living with Alzheimer’s disease is also important.

In order to alleviate stress, build better modalities of communications, providing education, defining caregiver expectations, discussing day to day activities, explaining treatment plans and teaching families how to interact with their loved ones will help the caregiver to understand and face the uncertainty of the disease with less apprehension (Stone, 2013). Researchers working with AD caregivers are of the opinion that providing care for a person with Alzheimer’s disease takes patience and care. In order to provide the best possible care for a loved one with Alzheimer’s disease the caregiver needs to make his/her own health a priority. Taking one day at a time, getting enough rest, talking to family members and friends, maintaining a sense of humor and having a back-up plan in case something unexpected happens to the caregiver himself are just a few strategies that can be helpful to families who are dealing with this disease. Psychosocial interventions have been used to facilitate communication and reduce negative behavioral symptoms in persons with Alzheimer’s disease, in order to alleviate caregiver burden.
Psychosocial Interventions

Historically there have been several attempts made to introduce psychosocial interventions to support dementia and Alzheimer’s disease caregivers. Researchers recognize that pharmacological treatments such as neuroleptic or other sedation medication has been used for persons with dementia and Alzheimer’s disease, despite modest evidence of efficacy from clinical trials where high placebo response rates are frequently seen (Ballard & O’Brien, 1999; Douglas et al., 2004). Psychosocial interventions have often been used as a second-line approach and are quickly gaining favor due to minimal side-effects and the reported benefits by caregivers and families (Douglas et al., 2004). Studies conducted to assess psychosocial interventions particularly related to dementia and AD literature have demonstrated that problem solving and behavior management models appear to be most suited to assist caregivers with AD patients. Also links between chronic illness and family relationships have led to the implementation of psychosocial interventions targeted at the caregiver. Positive relationship effects and reduction of caregiver burden was found with the implementation of psychosocial interventions compared to usual medical care control groups (Martire, Lustig, Schulz, Miller, & Helgeson, 2004; Pusey & Richards, 2001).

Caregivers of persons with Alzheimer’s disease are faced with complicated cognition problems along with a number of other issues such as agitation, communication, eating and grooming deficits and mood and personality changes and disorders. A number of psychosocial interventions are currently available to clinicians and caregivers and are implemented and taught tailored to the individual requirements of the person with AD. Traditionally behavioral therapy has been used to suppress
challenging behaviors and replacing these with positive programming methodologies (La Vigna & Donnellan, 1986; Moniz-Cook et al., 1998). Behavioral interventions focus on the ABC formula namely the assessment of antecedents, behaviors and consequences to identify interpersonal relationships (Douglas et al., 2004). Reality therapy is widely used as a management strategy for persons with dementia and AD. It aims to help people with memory loss and disorientation by reminding them of facts about themselves and their family and environment. This intervention has been found to increase people’s verbal orientation in comparison to untreated control groups (Bleathman & Morton, 1992). Reminiscence therapy involves in helping a person with cognition deficits to relive past positive experiences that are personally significant. Cognition based therapies that include activities such as art and music provide stimulation and pleasure (Spector, Orrell, Davies, & Woods, 2001). Other alternative therapies such as aromatherapy and interpersonal therapy have also been used with persons with dementia and AD but there is a fundamental weakness within the literature that requires addressing.

Currently, there is little concern paid to process issues and details outlining the mechanism of change with the interventions used. If these interventions were conducted with detailed communication strategies, interpersonal relationship styles, feedback mechanisms, clinician, staff and caregiver training manuals these interventions would be more acceptable and evidenced based (Douglas et al., 2004). Validation therapy was developed as an antidote to the perceived lack of efficacy of reality therapy (Douglas et al., 2004). There have been relatively few empirical studies assessing the efficacy of validation therapy as introduced by Feil (1967); however, some studies (Canon, 1995;
Hitch, 1994) noted that validation therapy can promote relationship contentment and communication satisfaction between the caregiver and the person with AD.

**Validation Communication Intervention (VCI)**

Counseling services offered to caregivers vary greatly. Counseling may include traditional psychotherapy, individual problem solving and coping skills. Counseling whether conducted in a group, family or individual format typically strives to relieve caregiver stress, depression and anxiety and can improve family functioning and bring about interpersonal communication satisfaction. Many studies have examined the effectiveness of counseling services to reduce caregiver burden and improve interpersonal communication (Bourgeois, Schulz, & Burgio, 1996; Hecht, 1978b; Whittier, Coon, & Aaker, 2004). Education and training programs strive to assist caregivers by teaching specific problem solving and coping techniques (Snow, 2011; Toseland, Smith, & McCallion, 2001; Whittier et al., 2004). Problem-solving and behavior management interventions have been found to demonstrate the greatest effectiveness (Gallagher-Thompson et al., 2000; Terri, Logsdon, Uomoto, Zarit, & Vitaliano, 1992). Studies focusing on an individual’s motivation, knowledge, and skills in conversing with another in a given situation are expected to predict both participants’ satisfaction with self, other, and bring about interpersonal communication satisfaction (Spitzberg & Hecht, 2006).

The modality of Validation Therapy (VT) was developed by Naomi Feil between 1963 and 1980, for older people with cognitive impairments. This approach has subsequently been applied in work with people who have a dementia diagnosis, most specifically to persons with Alzheimer’s disease (AD). According to researchers,
Validation Therapy is a method for communicating both verbally and non-verbally in order to reduce problems with behavior and for improving relationships and interactions and also improving overall psychosocial well-being and can be used in group settings, with persons with dementia (Toseland et al., 1997).

Validation therapy classifies individuals with cognitive impairment as having one of four stages in a continuum of dementia (Feil, 2002). The premise is that older individuals with Alzheimer’s disease feel that they have to resolve unfinished business in order to face death peacefully. Keeping this in mind there are four stages of Resolution. These stages are Mal-orientation, Time Confusion, Repetitive Motion and Vegetation. In the mal-orientation stage persons with AD will maintain socially prescribed behaviors. They may display tightening of facial muscles and rigid body stance, with shallow breathing accompanied with an item like a purse or object clutched in their hands (Canon, 1995). Persons in the Time Confusion stage lose communication skills, social skills and no longer conform to dress or social rules and often are isolated and ignored. Speech becomes garbled and persons with AD loose muscle control and develop an unfocused stare (Canon, 1995). Repetition motion is the third stage, which is characterized by movement and sounds that are repetitive. The person with AD is unaware of his/her surroundings, bodily functions and movements. In the final stage, which is Vegetation, the person with AD shuts out the world and there is barely any physical movement. The person rarely expresses any feelings and does not recognize his/her family or spouse (Canon, 1995). Through the course of the different stages individuals with AD will digress through a downward slide and demonstrate a decrease in their language, speech,
orientation, communication, memory, bodily functions, personal care and overall emotional, psychological and behavioral breakdown (Feil, 2002).

Validation therapy (VT) is a psychosocial treatment that can be implemented with persons with Alzheimer’s disease. The work of Feil (2002) suggests an interpretative scheme of the patient’s behavior, with the purpose of helping the caregivers, bring meaning to the confused persons. VT has as its focus the emotional and psychological consequences of short-term memory loss (Morton & Bleathman, 1991). The disorientation observed in many patients is a defense mechanism and the redefinition of the behavior of confused persons confers to the caregivers a therapeutic role: in validating the emotions of the person with AD, they can help him/her to solve the residual life tasks (Depontea & Missanb, 2006). The validation approach means accepting the feelings of the person living with AD; to acknowledge their reminiscences, losses, and the human needs that underlie their behaviors, without trying to insert or force new insights (Feil, 2002). Validating includes, reflecting a person’s feelings, helping them to express unmet human needs, restoring well established social roles, which help to motivate expression of social behaviors, facilitating feelings of wellbeing and stimulating interaction with others (Bleathman & Morton, 1996). Validation therapy recognizes the emotional needs of persons living with AD and provides a therapeutic technique for responding to them. VT can be used in one-on-one conversations as well as for group work. The therapist focuses on ‘validating’ rather than on correcting factual errors so that a meaningful conversation can take place (Bleathman & Morton, 1992; Morton & Bleathman, 1991).
The validation process allows the caregiver and clinician or group facilitator to understand the person with AD. It provides a therapeutic technique for responding to patients who occasionally will refer to their parents in the present tense as if they were still alive. Persons with AD often make requests of persons who are in authority. Jones and Miesen (2006) suggest that these constant requests can be interpreted as a cry of distress or a need for security. By acknowledging the emotions that the experience of the disease creates, VT provides a therapeutic framework in which the multiple losses experienced by patient are acknowledged. VT also provides caregivers with techniques to communicate with people whose speech is confused and/or dysphasic. Two-word statements of emotion, e.g. ‘you’re frustrated’ or ‘you’re sad’ allow the person with AD has his/her feelings acknowledged (Feil, 2002).

For the purpose of this study the Validation Communication Intervention (VCI) that will be used to assess interpersonal relationship communication satisfaction between the caregiver and the person with Alzheimer’s disease is synonymous to validation therapy. VCI is based on the general principle of validation which is the acceptance of the reality and personal truth of another’s experience, and incorporates a range of specific techniques (Neal & Briggs, 2003). The Validation Communication Intervention (VCI) allows the caregiver and clinician or group facilitator to understand the person with AD. Validation Communication Intervention (VCI) training provided to caregivers can provide caregiver satisfaction in communication between the caregiver and the person with AD. Additionally modalities such as this one, can improve the quality of the relationship between the caregiver and the person with AD (Canon, 1995). The experience of the disease is potentially dehumanizing and the recognition that everyone is
an individual is important. It is important to be aware of what is happening when someone has changes in cognition and abilities. It is therefore pertinent to appreciate the role that caregivers have in offering support, care, guidance, or at least recognition that the person with AD is doing the best they he/she can. Furthermore, in order to get something different to happen, it is the caregivers who have make changes. Once the caregivers begin to see things differently, then they can decide to learn more and commit ourselves to developing new knowledge and skills that will make a difference (Snow, 2011). The manner in which the caregiver responds and interacts is of significance and directly related to the mental well-being of the person with AD. Validation Communication Intervention (VCI) is based on an attitude of respect and empathy and aims to restore self-worth and dignity. VCI is essentially a compassionate approach to the care of persons with Alzheimer’s disease and uses counseling techniques such as Client Centered therapy (Rogers, 1942). Using empathic understanding to step into the client’s shoes’ requires caregivers and clinicians to focus on the experience of dementia in order to bring about interpersonal communication satisfaction. Listed below is an example of how Validation Communication Intervention (VCI) can be implemented when working with a person with Alzheimer’s disease.

Case Study using Validation Communication Intervention

Jack is a 75-year old man diagnosed with dementia of the Alzheimer’s type. He lost his wife a few years ago and has since been living with his son Matt. Jack refuses to sleep in his bed and complains and blames everyone and everything constantly. He is aggressive and belligerent and his son Matt is considering placing him in a facility. Matt finds assistance with a therapist who is trained to communicate with persons with AD
using Validation Communication Intervention. On meeting Jack for the first time the therapist, Lina witnesses Jack pacing around in his room and he is shouting at his son Matt.

Jack: I told you the air-conditioning is broken. Can’t you see I’m sweating all over?

Matt: I told you dad the A/C is fine.

Jack: Are you calling me a liar? No one believes me.

Matt: I do believe you. Shall we step out for a bite to eat?

Jack: Don’t ignore me Matt. Your air conditioning is broken and you don’t want to fix it.

The problem is that Jack is aware that he is suffering from incontinence and is trying to control his anxiety due to his fear of what else might happen to him in the future. Lina, the therapist, is introduced to Jack and she volunteers to help with the situation.

Lina: Matt I thought you said you had fixed the air-conditioning.

Matt: I thought I did.

Lina: Matt you did a pretty lousy job. Could there perhaps be another problem or a blockage somewhere?

Matt: Dad do you have any ideas as to what might have happened with the air conditioning?

Jack: I don’t know. If I could fix it I would. Do you think I like getting wet and smelly? Your mother would not stand for this if she were here.

Matt: What does it smell like?
Jack: It reminds me of the hospital with all those sick people and the smell of urine.

Lina: Matt do you have some air freshener? Let’s try and get this smell out of here shall we?

Lina: Matt do you have some after shave or cologne that we could give Jack? Would like that Jack?

Jack: Yes anything to get rid of this smell. Son, you really need to fix this house, it’s falling apart.

From Jack’s speech it is apparent that he is talking about the house but is making reference to his own body falling apart. By validating what Jack is saying, Lina is forging an open line of communication, which helps to reduce the aggression and anger and replaces these emotions with acceptance. The implementation of validation communication intervention (VCI) can ease the distress between the caregiver and the person with Alzheimer’s disease and can improve the quality of interpersonal communication that can result in an improvement in the quality of life for both the caregiver and the person with Alzheimer’s disease.

With the intervention of modalities such as Validation Communication Intervention (VCI) in Alzheimer’s facilities across the United States, and in homes with families of patients with AD, we can gain comfort knowing that our loved ones are receiving a modality that allows patients to regain their dignity, control their behavior and promote a significant improvement in communication whereby improving the quality of life (Bayer, 2002; Boron, 2002). With psychosocial interventions, health care professionals and family members can successfully engage the patient with attentive
listening, and can allow the forming of relationships based on genuine care and honesty facilitating a better quality of life for both the caregivers and the persons with AD (Boron, 2002; Goodwin, 2002).

The need for non-pharmacological and psychosocial solutions that address the emotional damage that is caused by dementia of the Alzheimer’s type will continue to challenge caregivers and clinicians. However with the implementation of psychosocial modalities such as validation communication intervention there is hope and assurance that other non-pharmacological interventions will continue to develop to make further advances in the humanistic care and assist with the improvement of interpersonal relationships, the reduction of behavioral symptoms and the attainment of an improved quality of life of persons living with Alzheimer’s disease.

**Quality of Life in Persons with Alzheimer’s Disease**

Persons diagnosed with Alzheimer’s disease (AD), suffer from cognitive and memory deficits. With the progression of the disease the person is robbed of his/her independence and self-esteem. This can lead to depression, anxiety, and loneliness (Beuscher & Grando, 2009b). Understanding how people with AD cope is critical in enhancing their adaptive abilities and ultimately improving their quality of life. AD affects an individual’s thought process and memory and puts added strain on the ability to draw on coping skills and resources that are so vital in improving the quality of life (Bahro, Silber, & Sunderland, 1995).

Serious illness affects the lives of individuals and the rest of the family members (Anderson, 1993; Campbell, 1986). The onset of a serious illness brings with it demands, stressors and hardships that interact with the normal dynamics experienced by families
(Anderson, 1993; McCubbin & Thompson, 1991). These stressors increase the family’s vulnerability, lead to adaptation issues and may create health problems with other members of the family (Boss, Caron, Horbal, & Mortimer, 1990; Reiss & Klein, 1987; Rolland, 1990). Not all families experience a crisis due to illness. Some in fact may exhibit growth as an outcome of the experience of going through an illness (Boss, 1987; McCubbin & Thompson, 1991). The family’s ability to adapt determines the family’s vulnerability or resiliency to stressors (McCubbin & Thompson, 1991). The quality of family life is important to the resilience of the family when confronted with stress and health is cited as one of the important factors that determine the quality of life for families with a family member coping with a serious illness (McCubbin & Thompson, 1991).

The care of a person with Alzheimer’s disease and promoting a good life means offering a place of safety, which involves the preservation of self-dignity, encouraging a sense of belonging and communication, offering relief and promoting a sense of power and control (Zingmark, Sandman, & Norberg, 2002). The salient factor associated with the quality of life for AD patients as reported by their caregivers, was overall good health of the patient. This leads to independence from the patient, freedom and general sense of well-being for the caregiver (Vellone, Piras, Talucci, & Cohen, 2007).

Quality of Life (QOL) is a topic that has been widely discussed and investigated. The World Health Organization defines QOL as the perceptions of individuals and their perceptions of their position in life within the context of the culture and value systems within which they live and in relation to their goals, expectations, standards and concerns (Machado et al., 2009). Researchers have argued that measuring quality of life is just as
important as measuring disease severity, disease progression, symptom response, cognition, behavioral disturbance and activities of daily living when assessing the impact of disease and intervention in dementia. The subjective nature of quality of life provides healthcare professionals with the opportunity of incorporating the value systems of patients and their caregivers into their assessments. QOL outcomes for the caregiver and the person with AD are closely linked (Dooley & Hinojosa, 2004). However there are as yet no validated methods of assessing the quality of life of both patients with dementia and their caregivers at the same time. In dementia QOL encompasses the integration of cognitive functioning, daily life activities, social interaction and psychological well-being (Machado et al., 2009).

The importance of assessing the quality of life in persons with Alzheimer’s disease is a significant factor. The sheer number of people affected and the impact that the disease has upon the clients and their families is a major health concern in our society. Merchant and Hope (2004) support the notion that QOL is conceptualized as a property of the individual and assessing the quality of life, using a person centered approach to dementia care, is difficult yet necessary and can be successful. Positive affect and decreased caregiver burden makes for improved quality of life (Dooley & Hinojosa, 2004) and future research is needed to identify interventions that will assist in implementing strategies that will enhance the quality of life for both the caregiver and the person with Alzheimer’s disease.

This study hopes to find significant evidence to support correlations between family resiliency, sense of coherence, social support and psychosocial interventions that will in turn result in interpersonal communication satisfaction and further determine and
enhance the quality of life for both the caregiver and the person with Alzheimer’s disease.
CHAPTER III. METHODOLOGY

Persons diagnosed with Alzheimer’s disease (AD) experience cognitive impairments and memory deficits. Additionally with the progression of the disease the individual may also undergo mood and personality changes, which may result in the break-down of communication. The caregiver of a person with AD is confronted with stress and may suffer from caregiver burden. This study explored how the implementation of a psychosocial intervention, that will be referred to as Validation Communication Intervention (VCI) for the purpose of this study, will effect interpersonal communication and bring about satisfaction in the relationship between the caregiver and the person with Alzheimer’s disease and also enhance the quality of life in persons with Alzheimer’s disease and their caregivers. This study identified the effectiveness of therapeutic and psychosocial strategies for counselors, other health-care professionals, caregivers and educators working with persons who have Alzheimer’s disease.

Research is needed and can be beneficial for mental health counselors and healthcare professionals working with this population to assess the success of non-pharmacological interventions. Psychosocial interventions and caregiving strategies can improve interpersonal communication satisfaction and reduce caregiver burden while assisting in the process of adjustment and adaptation. This can result in the better quality of life for the person living with Alzheimer’s disease and the caregiver. This chapter includes specific topics such as participants, research design, dependent variables,
independent variables, instrumentation, procedures, data collection, delimitations, limitations and data analysis in this current study.

**Participants**

The target population for this quasi-experimental study was adult caregivers who were the spouse, family member or paid professional, taking care of a person who had a documented Alzheimer’s disease diagnosis. Participants were invited on a voluntary basis to participate in this study via an initial email and a monthly newsletter notification sent out by administrators of a local memory and wellness center located on the campus of a southeastern public university. Subsequently two additional reminder emails and one additional newsletter notification was sent out with information on the study. Additionally, residents and caregivers at two other assisted living facilities were contacted via a newsletter informing them of the study in the South Florida area. A convenience sample was drawn from a list of caregivers who responded to the emails and newsletters. A table of random numbers was used to locate the sampling pool and subjects were assigned to either the experimental or intervention group, or the control or comparison group (Heppner & Heppner, 2004). Due to the site protocols, the Memory and Wellness Center at a south eastern University was designated as the site where the participants for the experimental group would be drawn from and the two additional assisted living facilities were assigned as the sites for the pool from where the participants of the control group were drawn from. Caregivers from the Memory and Wellness Center differed from the caregivers at the assisted living facilities in that the persons with AD that they were taking care of were all day-care patients at the Center. The caregivers at the assisted living facilities were responsible for taking care of their
loved ones who were in-patients at the respective facilities. Each participant was assigned a number code to help ensure that personal identifiers would not be revealed during the analysis and write-up of findings and there was no compensation given for participating in this study. Once it was determined which subjects would be in the experimental group, the investigator informed the caregivers of the designated dates for the study and the upcoming training workshop and training sessions in Validation Communication Intervention (VCI). The participants in the control group were informed of the pretest and posttest dates. For the purpose of this study all participants were 18 years of age or older and they were all caregivers (spouse, relative, or professional) to a person with Alzheimer’s disease. The participants in the experimental group attended the 120 minute training workshop with seven additional 30 minute training sessions where they were taught two new techniques every week. For the purpose of this study and in order to be considered an active participant, a total of two absences from training sessions were allowed. Participant prior knowledge of the training modality namely Validation Communication Intervention (VCI), determined a caregiver’s participation in this study. In order to become active participants in this study the caregivers could not be familiar with VCI and this was determined by responding to a simple Yes/No question, such as, “Are you familiar with Validation Communication Intervention?” Subjects with prior knowledge and use of validation training could participate in the workshop but were not included in the study. Participants were asked to complete a survey with 139 items along with a demographics questionnaire that included (a) Gender; (b) Age of caregiver; (c) Age of person with AD; (d) Race; (e) Duration that you have been the caregiver; (f) Relationship to the person with AD; (g) Religious or spiritual preference; (h) Have you
ever been exposed to Validation Therapy or Validation Communication Intervention; (i) What is your annual household income; (j) How many persons including yourself live in the household. The survey took 45-50 minutes to complete.

**Research Plan**

This present study is intended to accomplish the following objectives: (a) To examine the factors of resiliency, sense of coherence and social support and how these impact caregiver burden and the quality of life of persons with Alzheimer’s disease (AD); (b) To assess the efficacy of Validation Communication Intervention (VCI) to measure interpersonal relationship communication satisfaction between the caregiver and the person with AD and (c) To propose future treatment recommendations for persons with AD and their caregivers.

This study employed an experimental design with two groups and explored differences between two groups. Subjects in the experimental group received the Validation Communication Intervention (VCI) training workshop while subjects in the Control or the Usual Care (UC) group continued to attend their regularly scheduled Alzheimer’s support groups at a local memory and wellness facility or assisted living facility. VCI training was given to the subjects in the experimental group after the participants voluntarily agreed to participate in the study and signed the required consent documents that were handed out by voluntary facilitators who work at the facilities. Both groups ran concurrently for the 8-week time period. In order to limit cross-talk and maintain fidelity between participants in the two groups, confidentiality was requested. A pre-test was administered a week prior to the start of the study to both groups. The Validation Communication Intervention (VCI) workshop commenced the following week.
and was given to the subjects in the experimental group. This 120-minute workshop outlined the details of the intervention. Subsequently the investigator followed up with weekly 30 minute sessions for seven weeks of VCI, training the caregivers on two additional helping techniques every week. Subjects in the experimental group were asked to record their loved one’s behavior, mood, relationship and communication quality, in a journal, on a weekly basis for the duration of the eight weeks, from start to termination of the study. The journal was provided by the investigator and was used as a measure of fidelity. Simultaneously, the caregivers in the control group continued to attend their usual care (UC) AD support groups at their respective assisted living facilities. Outcome measurements were performed for the experimental group with a pre-test at the beginning of the intervention at week #1, followed by a post-test at the termination of the intervention at week #8 (Villareal-Reyna, Salzar-Gonzalez, Cruz-Quevedo, Carrillo-Cervantes, & Champion, 2012). The investigator was supervised by the site Directors for the duration of the entire study, ensuring that ethical and quality codes were preserved and maintained.

The majority of existing literature on Validation Therapy is narrative or anecdotal and this makes the estimation of an effect size difficult (Bleathman & Morton, 1992, 1996; Feil, 2002). The number of participants needed for this study was determined by comparing past post hoc effect sizes at .50 (Canon, 1995). Canon’s study (1995) assessed the quality of interpersonal relationship satisfaction in caregivers and persons with Alzheimer’s disease and calculated post hoc effect sizes at .50. As noted in Lipsey (1990), effect size is problematic especially when there is a dearth of prior experimental research. Effect sizes in social science as a whole are generally low; however anecdotal
evidence indicates that validation interventions have a pronounced effect on communication, and especially on the quality of the relationship between the caregiver and the person with AD (Canon, 1995). In the study by Canon (1995), the overall sample size was 58 subjects, with 36 subjects for the experimental group and 22 subjects for the comparison group. Canon stated that the power of the study was .50 (Canon, 1995).

It can be argued that while investigating the beneficial effects of a treatment intervention a relatively high level of Type I error is acceptable. Demonstrably effective treatments for many practical problems are rare; however, potentially beneficial interventions such as VCI should not be easily dismissed (Canon, 1995). According to Lipsey (1990), in this context a Type II error can represent practical loss. This is the situation concerning psychosocial interventions for Alzheimer’s disease caregivers (Canon, 1995). Based on G Power analysis (Faul, Erdfelder, Lang, & Buchner, 2007) for a-priori t-test means with differences between two independent means or groups to determine sample size, power was estimated at .80 to attain large effect size. For the purpose of this study the number of participants needed for each group to attain adequate power was a sample size of 84 participants (N=84) with 42 participants in the experimental group and 42 participants in the comparison/control group (Heppner & Heppner, 2004).

**Dependent and Independent Variables**

This study examined the following dependent variables: Caregiver Burden for the caregiver and Quality of Life in the person living with AD. Caregiver burden can be defined as distress in response to caregiver experiences (burden), exposure to stress, which may result in functional impairment in activities of daily living, vulnerability on
the part of the caregiver that may result in caregiver health problems, anger, and anxiety, and the underutilization of resources that may result in decrease in coping skills, a bleak outlook on life, and lack of social supports. Researchers have shown that caregivers with high vulnerability and low resources had higher burden scores (Vitaliano, Russo, Young, Maiuro, & Roland 1991).

Caregivers and persons with Alzheimer’s disease defined quality of life as a product of their health, social supports, and personalities and through their training caregivers can directly influence quality of life (Kane, 2003). Quality of Life is seldom explored in evaluations of therapeutic and psychosocial interventions in Alzheimer’s disease. Researchers have determined that participation in a cognitive and functional rehabilitation program does improve quality of life (QOL) among Alzheimer’s disease (AD) patients (Machado et al., 2009).

This study examined the following independent variables; family resiliency which includes, family coping and problem solving skills, personal resources and family support, along with appraisal of the challenge that is faced by families with persons with Alzheimer’s disease. Sense of Coherence was also examined. Additionally a psychosocial intervention specifically, Validation Communication Intervention (VCI) was examined to determine its efficacy in determining the improvement in interpersonal communication satisfaction in caregivers and persons with AD. Furthermore, caregiver burden was assessed along with the related quality of life of the person with Alzheimer’s disease.

**Instrumentation**

Baseline demographic information was obtained after informed consent was completed. Data on the following socio-demographic variables of the caregiver was also
collected: (a) Age; (b) Race/Ethnicity; (c) Gender; (d) Duration of Alzheimer’s disease (e) Length of time as caregiver and (f) Income. Additionally, six standardized measures were used for this study. These measures included the Family Crisis Oriented Personal Evaluation Scales (F-COPES), Family Coping Coherence Index (FCCI), Social Support Index (SSI), Hecht’s Interpersonal Communication Satisfaction Inventory (ICSI), Caregiver Burden Scale (CBS), and the Alzheimer’s disease Related Quality of Life Scale (ADRQL).

**Family Crisis Oriented Personal Evaluation Scales (F-COPES)**

The F-COPES (McCubbin & Thompson, 1991) was used in this study to assess the coping and problem solving ability as perceived by the caregiver of a person living with Alzheimer’s disease. For the purpose of this study, coping and problem solving can be explained as the way stressors are defined by the family and how they adopt successful strategies to resolve adverse events.

The F-COPES (McCubbin & Thompson, 1991) has been used in literature pertaining to family resiliency and adaptation as an application of stress and coping model for runaway youths, families with young children, in Xhosa families, and with determining stress among Japanese-American and Caucasian-American family caregivers of frail elders (Chun, 2010; McLaughlin, 2002; Walters, 2009). It has also been used by researchers that examined several coping strategies used by caregivers of Alzheimer’s disease patients and the relationship of those strategies to the caregivers’ subjective sense of burden (Pratt, Schmall, Wright, & Cleland 1985). The F-COPES comprises of 30 items based on a 5-point Likert-type scale that ranks family behaviors and their frequency from 1=Strongly Disagree to 5= Strongly Agree. The F-COPES is comprised of five
subscales that assess a family’s ability to seek and acquire social support, reframing, which is the ability to redefine the family’s current stressful situation and make it more manageable, seeking spiritual support, mobilizing the family to accept help, and passive appraisal, which is the ability to accept problematic issues. The F-COPES consists of questions such as, “When we face problems or difficulties in our family, we respond by sharing our difficulties with relatives or knowing that we have the power to solve major problems.” The F-COPES has been studied with several respondents and seminal norms were as follows: Total score (Mean= 93.3, SD=13.62). Scores for the subscales and total are derived by summing up all item scores. The F-COPES has very good internal consistency and reliability with Cronbach Alpha of .86 (McCubbin & Thompson, 1991). Individual subscale alphas range from .63 to .83. The F-COPES also has good stability with a four-week test-retest correlation of .81. Individual subscales have test-retest correlations that range from .61 to .95 (McCubbin & Thompson, 1991).

**Family Coping Coherence Index (FCCI)**

The Family Coping Coherence Index (Antonovosky, 1998) is a 4-item instrument item and was used in this study to measure Antonovosky’s concept of a sense of coherence in families when faced with life changes and stressors. The Family Coping Coherence Index emerged from F-COPES to focus on family coherence as a coping mechanism. This instrument has been used in studies to determine the sense of coherence and strengths perspective in older persons and also when determining caregiver experiences of satisfaction with regards to dementia (Andren & Elmstahl, 2005; Lewis, 1997). The four items on the instrument ask questions such as, “When we face problems or difficulties in our family we cope by accepting stressful events as a fact of life.”
Additional questions on the FCCI are related to acceptance of the stressful event, the ability to accept unexpected difficulties and define the problem in a positive manner and having faith in God. The questions are rated on a 5-point Likert-type scale ranging from 0=Strongly Disagree to 4= Strongly Agree. The FCCI has been studied with a number of samples including native Hawaiian families and families of youth in residential treatment facilities. The overall mean in the original sample was M=16.0, with a SD=2.0. The FCCI can be easily scored by summing up the individual item scores. The FCCI has a fair internal consistency and reliability with a reported Cronbach alpha of .71. It also has good stability with a reported test-retest correlation of .83.

**Social Support Index (SSI)**

The Social Support Index (McCubbin, Patterson, & Glynn, 1996) is a 17-item instrument and was used in this study. The SSI has been designed to measure social support that families can find within the community. Social support is an important factor and is a vital buffer against family crisis that enables family resiliency in a time of distress. This measure allows the investigator to examine the extent of community based social support as an important component of family resiliency. Questions such as, “If I had an emergency, even people I do not know in this community would be willing to help,” are included on the SSI. The SSI has been widely used in Europe and in the United States including with families of different ethnic backgrounds such as Asian, Native Hawaiian, Caucasian, African American and mixed races (McCubbin, Patterson et al., 1996). The SSI has been used to measure social support and perceived stress and coping when a spouse has been diagnosed with lung cancer (Kim, Duberstein, Sörensen, & Larson, 2005). It has also been used to measure social support and internal system
resources and well-being of caregiving families and also to measure family resources and social support in remarried family households (Fink, 1995; Henry & Lovelace, 1995; Tak & McCubbin, 2002). The 17 items on the instrument on a 5-point Likert-type scale range from 1= Strongly Disagree, to 5= Strongly Agree. The SSI has been studied with numerous families including rural bank employees to mid-western farm families. The means on the SSI ranges from (M=35.8, SD=7.9) for 720 rural bank employees to (M=46.6, SD=8.2) for 423 mid-western farm families. The SSI has been used by researchers to explain strains and well-being in families providing care to an elderly parent (Fink, 1995). The influences of family resources and demands on the well-being of caregiving families and the strains they experienced have been examined (Fink, 1995). The score for the SSI is derived by summing the individual items. The SSI has good internal consistency with a Cronbach alpha of .82. It also has good stability with a test-retest correlation of .83. With ethnic and minority families the SSI was negatively correlated to family distress and positively correlated to family well-being (McCubbin, Patterson et al., 1996).

**Interpersonal Communication Satisfaction Inventory (ICSI)**

The ICSI was developed (Hecht, 1978a, 2004) and tested as a measure of interpersonal communication satisfaction. The ICSI was used in this study to measure interpersonal communication satisfaction between the caregiver and the person with Alzheimer’s disease. During the developmental process of the instrument for the first stage, Likert-style items were constructed from two types of questionnaires, face-to-face interviews, and previous empirical and theoretical work in the satisfaction field. During the second stage, items were tested by applying them to ideally satisfying and
dissatisfying conversations. The third stage consisted of further item analyses and factor analysis. The ICSI is a 19-item, seven-point semantic differential scale that asks participants to indicate their level of satisfaction with a particular communication episode. The middle of the scale, 4 represents ‘undecided or neutral’, then moving out from the center, ‘slight’ agreement or disagreement, then ‘moderate’, then ‘strong’ agreement or disagreement. The statements are ranked on a continuum from 1= Strongly Disagree to 7= Strongly Agree. Total score is acquired by adding up the scores on all 19 items (Hecht, 1978a). Statements on the instrument include, “I would like to have another conversation/communication like this one” or “I did not enjoy the conversation/communication.” Hecht reported split half reliability coefficients for the 19 item inventory of .97 for the actual conversation of the treatment group in the seminal sample (Hecht, 1978a). Convergent validity was established by correlating the Communication Satisfaction Inventory with the Faces Scale (Kunin, 1955). The correlations were high and statistically significant providing evidence of concurrent validity (Hecht, 1978a). This instrument has been used in a study to assess the quality of interpersonal satisfaction exploring sibling communication satisfaction over the life cycle (Bass, Gartner, & Hovious, 2004). The ICSI has been used when implementing validation therapy to determine the quality of the interpersonal relationship between the caregiver and the person with AD (Canon, 1995). This study demonstrated higher scores in communication satisfaction for the subjects that took the training compared to the caregivers who did not on Hecht’s interpersonal communication satisfaction inventory. This scale has also been used to assess patterns, characteristics and styles of interpersonal
communication in men and women related to marital, parent-child and group therapy communication (Bienvenu, 2006).

**Caregiver Burden Scale (CBS)**

The CBS is a 29-item scale and was used in this study. The CBS has been designed to measure feelings of burden experienced by caregivers of elderly persons with dementia (Zarit, Reever, & Bach-Peterson, 1980). The CBS has been used to assess caregiver burden in family members caring for patients receiving chemotherapy and for caregivers of persons with Alzheimer’s disease. It has also been used in a randomized psycho-educational intervention for caregivers of persons with dementia (Carey, Oberst, McCubbin, & Hughes, 1991; Ostwald, Hepburn, Caron, Burns, & Mantell, 1999; Pratt et al., 1985). The CBS provides a systematic assessment of caregiver perceptions of this burden. Statements on the instrument reflect how people feel when taking care of another. The statements are ranked as 0=Never, to 4= Nearly Always. Statements such as, “I feel stressed between trying to give to my spouse as well as to other family responsibilities, job,” are part of the CBS. The CBS initially studied 29 elderly people with dementia and 29 caregivers. The mean score for the caregivers was (M=30.8, SD=13.3). The CBS is scored on a 5-point scale where items are summed to get the total score. Therefore higher scores on the CBS mean higher stress and caregiver burden. The CBS has adequate internal consistency reliability and good test-retest reliability (.88). There was a significant negative correlation between the CBS and the frequency of family visits (.48). Which meant that the lower the burden on the CBS, the higher number of visits by the caregiver. This is a form of concurrent validity (Zarit et al., 1980).
Alzheimer’s Disease Related Quality of Life (ADRQL)

The ADRQL instrument was developed (Kasper, Black, Shore, & Rabins, 2009; Rabins, Kasper, Kleinman, Black, & Patrick, 1999) and was used in this study to assess the quality of life in persons with Alzheimer’s disease. The ADRQL is a 40-item instrument (Black, Rabins & Kasper, 2009) designed to assess quality of life by interviewing Alzheimer’s patients and/or their caregivers or informants. The caregiver respondents were asked to ‘agree’ or ‘disagree’ whether the items described the subject in the last 2 weeks. The instrument was validated by 96% of the participants in the seminal study, who were able to respond to the questions, such as “he/she smiles or laughs when around other people” appropriately. The 40 items on the scale describe behaviors associated with 5 domains of importance to health related quality of life in persons with AD. The number of items in each domain varies from 4 to 12 and both positive and negative behaviors are reflected in the items. Mean of the original sample was (M= 73.8, SD= 15.5). The five sub-sections are as follows: Those relating to being around other people or social interaction (Mean=77.2, SD=20.2), person’s identity and relationships or awareness of self (Mean=62.7, SD=25.3), types of behavior or feelings and mood (Mean=76.9, SD=19.2), usual activities or enjoyment of activities (Mean=65.3, SD=28.7) and behavior in person’s own environment or response to surroundings (Mean=79.8, SD=17.6). Each ADRQL item has a numeric value. The score is computed by summing up the values assigned to each item response and dividing the total by the maximum value of the overall scale or individual domains. The resultant quotient is then multiplied by 100 to obtain a percentage score from 0-100. A higher percentage score reflects a higher health related quality of life. This instrument has been used in a study to measure
the caregivers’ quality of life and this was correlated to the quality of life of the patients they cared for (Thomas et al., 2005).

**Descriptive Information**

Basic information pertaining to the family was collected to provide descriptive information about the family unit so as to make the study generalizable. Questions asked in the demographics survey included gender and age of the caregiver, the age of the person with Alzheimer’s disease, the duration in years that the individual has been a caregiver, the relationship of the caregiver to the person with Alzheimer’s disease, the religious or spiritual preference of the caregiver, the number of persons living in the household and household income.

Recent literature on caregivers and families includes descriptive information such as that which was collected in the present study (Greenwood, Habibi, Mackenzie, Drennan, & Easton, 2013; Lorig et al., 2012).

**Data Collection Procedures**

This study used a convenience sample. Caregivers taking care of a person with a diagnosis of Alzheimer’s disease were approached through a newsletter that was distributed via email followed up with a notification of the upcoming study in a monthly newsletter that was distributed to patients and caregivers who attended a local Memory and Wellness Center and Alzheimer’s treatment day care center as well as two assisted living facilities in the south Florida area. The email and newsletter notification included a brief description of the purpose of the study, its benefits and contact information of the researcher. The newsletter is listed in Appendix A, followed by the consent form in
Appendix B and the complete survey that was completed by the caregivers in Appendix C.

Following approval from the Institutional Review Board (IRB) at Florida Atlantic University (Appendix D), the caregivers of persons with Alzheimer’s disease were contacted. After gaining consent of participation, the willing participant was informed by phone or email about the dates of the study. The participants in the experimental group were informed of the location and time of the upcoming study and were invited to participate in an eight week workshop called the Validation Communication Intervention (VCI) Workshop. This workshop started on October 10, 2013. Subsequently due to attrition in the experimental group and in order to attain sufficient participants in the experimental group an additional eight week VCI workshop commenced on November 18, 2013. Participants in the control group continued with their daily activities.

Participants in both experimental and control groups completed the pre-test questionnaires prior to the commencement of the eight week workshop. The 139 item survey took approximately 45-50 minutes to complete. Participants in the experimental group received psycho-educational information on Alzheimer’s disease and fourteen stress relieving and communicating interventions which were taught to them over the course of the eight week VCI intervention workshop (Appendix E). Each week the participants in this group were asked to implement the techniques that were taught to them as part of the workshop and then implement the same while communicating with their loved one. Additionally the caregivers were asked to evaluate their loved ones’ in the areas of behavior, mood, communication and relationship by simply completing a YES/NO fidelity journal that was provided by the researcher (Appendix F). Upon the
completion of eight weeks participants in both groups were given a post test and asked to complete the survey once again.

Results of the survey were promised to all participants by contacting the researcher (Havovi Shroff). The outcomes of the study, recommendations for the Validation Communication Intervention Workshop and directions for future research will be submitted to the administrators of all the sites that participated in the study. Participants were also made aware of the data accessibility once the study is complete.

Surveys were examined and scored by hand at the time of submission. There were no missing items in the data as the researcher made sure that every survey was completed by the caregivers upon submission. Out of the original 95 surveys completed, 12 subjects from the experimental group could not be included in the study for a number of reasons. These included death on the part of caregiver’s spouses (N=5), scheduling conflicts (N=4), length and difficulty understanding the questionnaire (N=2), death of caregiver (N=1). This brought the final number of subjects in the study to 83. (Experimental Group N=35, Control Group N=48).

**Data Analysis**

For the present study, multiple regression/correlation analysis (MRC) was used to examine family resiliency, sense of coherence, social support, validation communication intervention, caregiver burden and the quality of life. Multiple regression analysis answers questions about relationships and studies connected to illness and disability (Hoyt, Leierer, & Milington, 2006). For the purpose of this study caregiver burden and the quality of life for persons with Alzheimer’s disease served as the dependent variables
while the independent variables were family resiliency, sense of coherence, social support and interpersonal communication satisfaction.

Specific research questions were examined and tested through a combination of bivariate linear correlations and multiple regression analysis. T-tests were conducted to measure change scores between the experimental and the control groups, using the CBS and the ADRQL scale. T-tests were also conducted to measure change score means (posttest minus pretest) between the experimental and the control group to determine the differences in change in the CBS and in the ADRQL. A correlation analysis was conducted to determine the relationship between family resiliency, sense of coherence, social support, interpersonal communication satisfaction, caregiver burden and the quality of life by implementing the F-COPES, the FCCI, the SSI, the ICSI, the CBS and the ADRQL scale. Furthermore, stepwise regression analysis was conducted to predict the quality of life and measure the relationship between quality of life and caregiver burden by implementing the F-COPES, the FCCI, the SSI, the ICSI, the CBS and the ADRQL scale.

Demographic variables were used to provide descriptive information of the sample. Information collected from this portion of the survey was summed up and averages of the sample are provided in the results.

**Limitations of the Study**

Sample size was a major limitation in the study (N=83 due to the intervention having small effect sizes as found by the instruments. Additionally, participants had to be caregivers (spouse, child, relative or a paid professional) to a person with Alzheimer’s disease and they had to have the ability to answer and complete a lengthy questionnaire.
pertaining to the person with Alzheimer’s disease and themselves. Participants could not have prior knowledge of Validation Communication Intervention (VCI). Subjects were approached and recruited from only three sites in the local area and most of the respondents were female (85.5%) and Caucasian (89%). This excluded data from other ethnic populations due to lack of awareness of the study.

Caregiver level of functioning was not assessed prior to the study and this was problematic. Yet another limitation to the study may have been the different stages and progression of the disease of the person with AD. These were not accounted for and maybe attributed to the degree of variance in the level of caregiver burden on the part of the caregivers. Additionally, caregiver bias in responses about their loved one as well as their own responses to statements on the questionnaires was not accounted for. As the investigator also facilitates caregiver support groups at one of the sites, investigator bias in implementation of the intervention was not accounted for. Furthermore, the Hawthorne Effect may have been another limitation to the study. The awareness on the part of the subjects in the experimental group specifically, and having the knowledge that they would be in constant contact with the researcher for the duration of the study (from start to termination of the intervention), may have resulted in biases on the part of the participants in the experimental group.

**Summary**

Multiple regression analysis was used to assess overall relationships between each of the concepts examined in the study (family resiliency, sense of coherence, social support, validation communication intervention, caregiver burden and quality of life) as well as to measure underlying relationships between the scales representative of the
family resiliency model, the family coping index, the social support index, the caregiver burden scale and the Alzheimer’s disease related quality of life scale. The 139 item instrument consisted of items that provided detailed implications into family relationships, resiliency, and sense of coherence, social support resources, caregiver burden, psychosocial interventions such as validation communication intervention and the quality of life for persons living with Alzheimer’s disease. The following chapter concentrates on results collected from the survey and a detailed description of statistical analyses performed.
CHAPTER IV. RESULTS

The study design attempted to answer research questions pertaining to predictive relationships between family resiliency, sense of coherence, social support, interpersonal communication satisfaction, caregiver burden and the quality of life of the person with Alzheimer’s disease (AD). A convenience sample of volunteer caregivers of persons with AD, were asked to complete a 139-item questionnaire comprised of 6 standardized instruments and demographic questions. This chapter provides information on the descriptive data for the total sample, descriptive information for the responses to each of the six standardized instruments, reliability testing of the instruments, and the results of the hypothesis testing.

Descriptive Data for the Sample Population

Data collection began on October 10, 2013 and continued on till February 22, 2014. Approximately 200 surveys were mailed or personally hand delivered by the researcher at the three different site locations approved by the institutional review board (IRB) at Florida Atlantic University. A total of 83 participants completed the survey and were assigned to either the experimental or control group. Both groups of participants were caregivers of persons with Alzheimer’s disease. The data received was reviewed for discrepancies and no significant discrepancies were observed pertaining to either descriptive information or quantitative results.
Basic information related to the family was collected to provide descriptive information as to the generalizability of the study. Specific questions asked included gender of caregiver, age of caregiver, age of person with Alzheimer’s disease, race of the caregiver, duration of caregiving in years, relationship of the caregiver to the person with Alzheimer’s disease, exposure to Validation therapy, household income and number of persons in the household.

For the gender of the caregiver, results of the study showed that the number of female caregivers outnumbered the male caregivers. Female caregivers comprised of 85.5% and the male caregivers comprised of 14.5% of the total population. For the population sampled in this study, the mean age of caregivers was 62.38 and standard deviation was 18.21. The mean age of the person with Alzheimer’s disease was 84.78 and the standard deviation was 7.78. Caregiver participants were also asked to identify the number of years they had been caregivers. Responses to this question ranged from 1 to 15 years and the mean duration of years was 3.96 and the standard deviation was 3.18. Caregiver participants were also questioned about their race. Participant response results were White (89%), Black (9%), Asian/Pacific Highlander (1%) and Multiracial (1%). Participants were asked to identify their relationship to the person with Alzheimer’s disease. Answer choices included wife (41%), husband (13.3%) and other (45.7%) which could be a relative or a professional caregiver. Caregiver participants were asked to identify their household income. Response choices included less than 100,000 (88.7%), and 100,000-300,000(13.3%).
Descriptive Information for Responses on Standardized Instruments

Each of the instruments was hand scored according to directions provided in the respective scoring manuals as described in Chapter 3. The PASW statistic package (2013) was used for all analyses. The following section will describe the results of the individual responses on the six standardized instruments (FCOPES, FCCI, SSI, ICSI, CBS, ADRQL) that comprised the questionnaire.

The F-COPES measures family coping and problem solving skills in the areas of: acquiring social support, seeking spiritual support, reframing, mobilizing the family and passive appraisal. The F-COPES was scored by adding all of the items with items 12, 17, 26 and 28 being reverse scored. Overall scores range from 30 indicate low family coping and problem solving to 150 indicate high family coping and problem solving. Scores of above 107 indicate family strength and resiliency, while below 81 reflect family weakness. For the population sampled in this study (N=83), mean pretest scores on the F-COPES for the experimental group was 103.34 and the standard deviation was 10.18. The mean posttest scores for the experimental group on the F-COPES were 102.28 and the standard deviation was 9.86. The mean pretest scores on the F-COPES for the control group were 102.72 and the standard deviation was 10.53 and mean posttest scores for the control group on the F-COPES were 101.79 and the standard deviation was 10.08. Scores indicated medium family strength and resiliency, although the respondents in the experimental group scored slightly higher than the control group.

The FCCI was used as a measure of the family’s understanding and making meaning of the adverse situations they are faced with. There are 4 items scaled from 0-4 with total scores ranging from 0-16. Higher scores indicate better adjustment to the
adverse situations. For the population sampled in this study (N=83), mean pretest scores for the experimental group on the FCCI were 11.97 and the standard deviation was 2.89. Mean posttest scores for the experimental group on the FCCI were 12.14 and the standard deviation was 3.0. The mean pretest scores for the control group on the FCCI were 13.75 and the standard deviation was 1.93. Mean posttest scores for the control group on the FCCI were 13.69 and the standard deviation was 1.98. Overall scores on the FCCI ranged from 11.97 to 13.75, which indicated medium sense of coherence for respondents in this study.

The SSI was used to measure the caregiver’s understanding of social support related to community, family and social relationships and how the caregiver utilizes these to gain social support from himself/herself. There are 17 items scaled from 1-5, with total scores ranging from 0-85. Items 7, 9, 10, 13, 14, and 17 are reverse scored. Higher scores indicate better social support. For the population sampled in this study (N=83), mean pretest scores for the experimental group on the SSI was 61.77 and the standard deviation was 7.98. Mean posttest scores for the experimental group on the SSI were 60.74 and the standard deviation was 5.80. The mean pretest scores for the control group on the SSI were 62.43 and the standard deviation was 7.58. Mean posttest scores for the control group on the SSI were 62.37 and the standard deviation was 7.13. Overall scores for the SSI in this study appeared to be in the mid-range indicating a medium level of social support for the respondents in this study.

The CBS was used to measure the caregiver’s understanding of caregiver burden by assessing his/her feelings while taking care of a person with Alzheimer’s disease. There are 29 items, with total scores ranging from 0-116. Items 14, 16, 20 and 29 are
reverse scored. Higher scores on the CBS represent higher caregiver burden, while lower scores represent lower caregiver burden. For the population sampled in this study (N=83), mean pretest scores on the CBS for the experimental group was 49.14 and the standard deviation was 20.06. Mean posttest scores on the CBS for the experimental group were 52.00 and the standard deviation was 18.29. The mean pretest scores on the CBS for the control group were 33.50 and the standard deviation was 17.26. Mean posttest scores on the CBS for the control group was 36.02 and the standard deviation was 15.52. Overall scores for the sample population for caregiver burden were low. However, respondents in the control group demonstrated less caregiver burden than respondents in the experimental group. This could be because the caregivers in the experimental group were responsible for taking care persons with AD where the progression of the disease was more severe and could subsequently account for more caregiver burden.

The ICSI was used to measure the degree of interpersonal communication satisfaction with the person with Alzheimer’s disease. There are 19 items with total scores from 1-133. Items 2, 5, 6, 11, 12, 17, 18, and 19 are reverse scored. Higher scores indicate better interpersonal communication satisfaction between the caregiver and the person with Alzheimer’s disease. For the population sampled in this study (N=83), mean pretest scores on the ICSI for the experimental group was 65.77 and the standard deviation was 17.21. Mean posttest scores on the ICSI for the experimental group were 65.94 and the standard deviation was 17.69. The mean pretest scores on the ICSI for the control group were 80.43 and the standard deviation was 20.23. Mean posttest scores on the ICSI for the control group was 78.37 and the standard deviation was 17.55. Overall
scores on the ICSI were in the low range demonstrating low interpersonal communication satisfaction between the caregiver and the person with Alzheimer’s disease.

The ADRQL was used to measure the quality of life in a person with Alzheimer’s disease in five domains, namely social interaction (SI) which is comprised of 12 items; Awareness of Self (AS) which is comprised of 8 items; Feelings and Mood (FM) which comprises of 12 items; Enjoyment of Activities (EA) which comprises of 4 items; and Response to Surroundings (RS) which is comprised of 4 items. The ADRQL is scored based on scale values that are assigned to each item. A higher score reflects a higher quality of life. For the population sampled in this study (N=83), mean pretest scores on the ADRQL was 69.96 and the standard deviation was 18.75. Mean posttest scores on the ADRQL were 67.65 and the standard deviation was 18.93. Sample population scores were in the mid-range indicating medium quality of life.

The total results of the central tendency measures presented in Table 1 indicate a wide range of responses on the survey used in the questionnaire. The mean scores are representative of the sample’s total average scores.
Table 1

*Central Tendency Measures for F-COPES, FCCI, SSI, ICSI, CBS, and ADRQL*

<table>
<thead>
<tr>
<th>Measures</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
<th>Actual Range</th>
<th>Possible Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>F-COPES</td>
<td>83</td>
<td>103.0</td>
<td>10.3</td>
<td>75-135</td>
<td>30-150</td>
</tr>
<tr>
<td>FCCI</td>
<td>83</td>
<td>13.0</td>
<td>2.5</td>
<td>3-16</td>
<td>0-16</td>
</tr>
<tr>
<td>SSI</td>
<td>83</td>
<td>63.3</td>
<td>7.8</td>
<td>44-83</td>
<td>17-85</td>
</tr>
<tr>
<td>ICSI</td>
<td>83</td>
<td>74.3</td>
<td>20.3</td>
<td>37-122</td>
<td>1-133</td>
</tr>
<tr>
<td>CBS</td>
<td>83</td>
<td>40.0</td>
<td>20.0</td>
<td>24-100</td>
<td>0-116</td>
</tr>
<tr>
<td>ADRQL</td>
<td>83</td>
<td>70.0</td>
<td>18.7</td>
<td>8-85</td>
<td>0-100</td>
</tr>
</tbody>
</table>

*Notes.* F-COPES=Family Crisis Oriented Evaluation Scale, FCCI=Family Coping Coherence Index, SSI=Social Support Index, ICSI=Interpersonal Communication Satisfaction Inventory, CBS=Caregiver Burden Scale, ADRQL=Alzheimer’s Disease Related Quality of Life Scale, N=total number of participants, SD=Standard deviation.

Reliability Testing

Reliability of the six instruments that comprised the study’s questionnaire was tested using Cronbach’s alpha coefficient as an estimate of internal consistency. Table 2 reflects the alpha coefficients for this study that ranged from .63 to .93 suggesting sufficient reliability. Results of reliability testing indicated Cronbach’s Alpha for F-COPES and FCCI were satisfactory (.63 and .69, respectively). Cronbach’s Alpha for CBS, ICSI and ADRQL were very good (.93, .89, .88) The Cronbach’s Alpha for SSI was good (.74).
Table 2

*Cronbach’s Alpha Coefficient for Instruments in the Study*

<table>
<thead>
<tr>
<th>Measures</th>
<th>$\alpha$</th>
<th>Items in Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>F-COPES</td>
<td>.63</td>
<td>30</td>
</tr>
<tr>
<td>FCCI</td>
<td>.69</td>
<td>4</td>
</tr>
<tr>
<td>SSI</td>
<td>.74</td>
<td>17</td>
</tr>
<tr>
<td>ICSI</td>
<td>.89</td>
<td>29</td>
</tr>
<tr>
<td>CBS</td>
<td>.93</td>
<td>19</td>
</tr>
<tr>
<td>ADRQL</td>
<td>.88</td>
<td>40</td>
</tr>
</tbody>
</table>

*Notes.* F-COPES=Family Crisis Oriented Evaluation Scale, FCCI=Family Coping Coherence Index, SSI=Social Support Index, ICSI=Interpersonal Communication Satisfaction Inventory, CBS=Caregiver Burden Scale, ADRQL=Alzheimer’s Disease Related Quality of Life Scale, $\alpha =$ Cronbach’s Alpha.

Based on Cronbach’s Alpha (Internal consistency), 0.9-> excellent, 0.7 -0.9 Good, 0.6 -0.7 Acceptable, 0.5 - 0.6 Poor, $\alpha < 0.5$ Unacceptable. Cronbach’s Alpha performed with F-COPES, the overall reliability for the normative sample was found to be .87 (McCubbin & McCubbin, 1988). In this study the alpha was .63. The FCCI shows correlations with the F-COPES and other instruments measuring the family’s ability to manage stressful life events and changes at .71 for the normative sample (McCubbin & McCubbin, 1988). In this study the FCCI tested with an alpha of .69. The SSI has good internal reliability testing at with an alpha across several samples of .82 (McCubbin, Patterson et al., 1996). For this study the SSI was .74. The CBS was initially studied with 29 people with dementia and their 29 caregivers. No data on reliability was reported.
(Zarit et al., 1980). However for this study reliability testing was at .93. The ICSI reported reliability coefficients of .93 (Hecht, 1978a) while alphas for this study were at .89. The ADRQL exhibits good item-internal consistency (67.5%) and .86 for total scores (Kasper et al., 2009). For this study the Cronbach’s Alpha was .88.

**Results of Hypothesis Testing**

This study employed six alternative (and null) hypotheses. In order to answer research questions and test the proposed hypotheses, a combination of multiple regression correlation analyses were performed. MRC is commonly used throughout mental health counseling research, specifically for research related to dementia and Alzheimer’s disease, as it addresses a wide range of questions (Jones & Miesen, 2004). MRC most often is used to test causal hypotheses and when special attention is needed for theory testing (Hoyt, Imel, & Chan, 2008). Hypotheses in this study were designed to support the framework of the Resiliency Model of Family Stress, Adjustment and Adaptation whereby families with high levels of resiliency adjust to adverse events, specifically in this study the adjustment to Alzheimer’s disease. The study also explored the independent variables that included the family’s sense of coherence and how they made meaning of the adverse situation, the family’s social support, and the degree of interpersonal communication satisfaction between the caregiver and the person with Alzheimer’s disease. This section answers the study’s specific research questions and provides information to accept or reject the null hypotheses.

The first research question pertained to the implementation of a training workshop on Validation Communication Intervention (VCI) and the relationship of the interpersonal communication satisfaction inventory (ICSI) on the caregivers in the
experimental group compared to the caregivers in the control group. The alternative hypothesis is phrased as, “the implementation of a training workshop on VCI will improve interpersonal communication satisfaction between the caregivers in the experimental group compared to the caregivers in the control group.” To test this hypothesis, an independent sample T-test was conducted to compare average response scores between the participants in the experimental and the control group. Results suggest that there was no significant difference between the experimental group and the control group. Therefore we failed to reject the null hypothesis.

The second research question pertained to the implementation of a training workshop on VCI and the relationship of the caregiver burden scale on the caregivers in the experimental group compared to the caregivers in the control group. The alternative hypothesis is phrased as, “the implementation of a training workshop on VCI will reduce caregiver burden between the caregivers in the experimental group compared to the caregivers in the control group.” To test this hypothesis, an independent samples T-test was conducted to compare average response scores between the participants in the experimental group and the control group. Results suggest that there was no significant difference between the experimental group and the control group therefore we failed to reject the null hypothesis.

Furthermore, an additional independent sample T-test was conducted to compare average response scores between the participants in the experimental group and the control group to examine the effects of Validation Communication Intervention and the quality of life in the person with Alzheimer’s disease. Results suggest that effect size was
.17. We failed to reject the null hypothesis. The results of the analyses for research questions 1 and 2 are found in Table 3.

Table 3

*T-Tests for F-COPES, FCCI, SSI, CBS, ICSI, and ADRQL*

<table>
<thead>
<tr>
<th>Measures</th>
<th>Experimental (N=35)</th>
<th>Control (N=48)</th>
<th>t</th>
<th>df</th>
<th>p</th>
<th>d</th>
</tr>
</thead>
<tbody>
<tr>
<td>F-Copes</td>
<td>-1.12 (6.67)</td>
<td>-.94 (3.83)</td>
<td>.1</td>
<td>50.65</td>
<td>.92</td>
<td>.02</td>
</tr>
<tr>
<td>FCCI</td>
<td>.14 (1.44)</td>
<td>-.06 (1.02)</td>
<td>-.79</td>
<td>55.52</td>
<td>.43</td>
<td>.18</td>
</tr>
<tr>
<td>SSI</td>
<td>-1.03 (5.60)</td>
<td>-2.06 (4.2)</td>
<td>-.96</td>
<td>81</td>
<td>.36</td>
<td>.21</td>
</tr>
<tr>
<td>CBS</td>
<td>2.86 (8.7)</td>
<td>2.52 (6.95)</td>
<td>-.2</td>
<td>81</td>
<td>.85</td>
<td>.04</td>
</tr>
<tr>
<td>ICSI</td>
<td>.17 (12.35)</td>
<td>-2.06 (6.92)</td>
<td>-1.05</td>
<td>49.47</td>
<td>.34</td>
<td>.22</td>
</tr>
<tr>
<td>ADRQL</td>
<td>-3.49 (14.9)</td>
<td>-1.45 (6.67)</td>
<td>.76</td>
<td>43.97</td>
<td>.45</td>
<td>.17</td>
</tr>
</tbody>
</table>

Notes. F-COPES=Family Crisis Oriented Evaluation Scale, FCCI=Family Coping Coherence Index, SSI=Social Support Index, ICSI=Interpersonal Communication Satisfaction Inventory, CBS=Caregiver Burden Scale, ADRQL=Alzheimer’s Disease Related Quality of Life Scale, N=number of participants, df=degrees of freedom, d=Cohen’s d effect sizes.

The third research question pertained to the relationship between the independent variable of family resiliency as measured by the F-COPES and the dependent variables of caregiver burden (CBS) and quality of life (ADRQL). The alternative hypothesis was phrased as “there will be a positive relationship between family resiliency and caregiver burden and the attainment of quality of life with persons with Alzheimer’s disease.” To
test this hypothesis a correlation analysis was first conducted using the F-COPES and the CBS, followed with a second correlation analysis with the F-COPES and the ADRQL. The results suggested that there was no correlation between F-COPES and CBS and F-COPES and ADRQL.

The fourth research question pertained to the relationship between the independent variable of sense of coherence as measured by the FCCI and the dependent variables of caregiver burden (CBS) and quality of life (ADRQL). The alternative hypothesis was phrased as “there will be a positive relationship between sense of coherence and caregiver burden and the attainment of quality of life with persons with Alzheimer’s disease”. To test this hypothesis a correlation analysis was conducted using the FCCI and the CBS, followed by a second correlation analysis with the FCCI and the ADRQL. The results suggest that there was a negative correlation between FCCI and CBS (If sense of coherence scores are high, then caregiver burden scores are low). There was no correlation between FCCI and ADRQL.

The fifth research question pertained to the relationship between the independent variable of sense of coherence as measured by the SSI and the dependent variables of caregiver burden (CBS) and quality of life (ADRQL). The alternative hypothesis was phrased as “there will be a positive relationship between social support and caregiver burden and the attainment of quality of life with persons with Alzheimer’s disease”. To test this hypothesis a correlation analysis was conducted using the SSI with the CBS followed by a second correlation analysis with the SSI and the ADRQL. The results suggest that there was a correlation between SSI and CBS (If social support scores are
higher, caregiver burden scores are lower). There was no correlation between SSI and ADRQL.

Furthermore, additional correlational analyses were conducted to assess the relationship between caregiver burden (CBS) and the quality of life. A negative correlation was found between CBS and ADRQL (If caregiver burden scores are low then the quality of life scores are high). Subsequently another correlational analysis was conducted to assess the relationship between validation communication intervention (ICSI) and the quality of life. A positive relationship was found between ICSI and ADRQL (when interpersonal communication scores are high, the quality of life scores are high). Additionally, a negative relationship was found between FCCI and CBS (when sense of coherence scores are high, caregiver burden scores are low). The results of the analyses for research questions 3, 4, and 5 are shown in Table 4.

Table 4

*Correlation Table for F-COPES, FCCI, SSI, ICSI, CBS, and ADRQL*

<table>
<thead>
<tr>
<th>Measures</th>
<th>F-COPES</th>
<th>FCCI</th>
<th>SSI</th>
<th>ICSI</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADRQL</td>
<td>.00</td>
<td>-.10</td>
<td>.12</td>
<td>.48**</td>
</tr>
<tr>
<td>CBS</td>
<td>.13</td>
<td>-.37**</td>
<td>-.27*</td>
<td>-.52**</td>
</tr>
</tbody>
</table>

*Notes.* F-COPES=Family Crisis Oriented Evaluation Scale, FCCI=Family Coping Coherence Index, SSI=Social Support Index, ICSI=Interpersonal Communication Satisfaction Inventory, CBS=Caregiver Burden Scale, ADRQL=Alzheimer’s Disease Related Quality of Life Scale. *p < .05, ** p < .01.

The goal of multiple regression is to enable a researcher to assess the relationship between a dependent (predicted) variable and several independent (predictor) variables.
The end result of multiple regressions is the development of a regression equation (line of best fit) between the dependent variable and several independent variables (Brace, Kemp, & Snelgar, 2009). Standard multiple regression is used to address a couple of questions: a) what is the size of the overall relationship between CBS (the predicted variable) and the independent (predictor) variables of F-COPES, FCCI, SSI, and ICSI and ADRQL (predicted variable) and the independent variables of F-COPES, FCCI, SSI, and ICSI, b) how much does each independent (predictor) variable uniquely contributed to that relationship? In a standard multiple regression all predictor variables are entered into the regression equation at once. For this study the researcher decided to implement a multiple regression to answer the question as to what would be the best combination of independent (predictor) variables to predict the dependent (predicted) variable.

For the final research question, two multiple regression analyses were performed as demonstrated in Tables 5 and 6. The first multiple regression (Table 5) examined family resiliency, sense of coherence, social support and interpersonal communication satisfaction (F-COPES, FCCI, SSI, ICSI) as predictors of Caregiver Burden (CBS). Results of the regression indicated that the four predictors explained 37.8% of the variance or adjusted R square was .346, F (4, 78) = 11.87, p<.001).

The second multiple regression (Table 6) examined family resiliency, sense of coherence, social support and interpersonal communication satisfaction (F-COPES, FCCI, SSI, ICSI) as predictors of Alzheimer’s disease related quality of life (ADRQL). The results of the regression indicated that the four predictors explained 18.9% of the variance (R square=.179, F (4, 78) =5.06, p<.001). The alternative hypothesis for the sixth question was phrased as, “family resiliency, sense of coherence, social support and
interpersonal communication satisfaction will predict caregiver burden and the quality of life”. Results of the multiple regression analyses indicated that F-COPES, FCCI, SSI and ICSI were significant predictors for CBS and ADRQL.

Table 5

*Multiple Regression Analyses Predicting CBS*

<table>
<thead>
<tr>
<th>Predictor Variable</th>
<th>$R$</th>
<th>$R^2$</th>
<th>Adjusted $R^2$</th>
<th>$F$</th>
<th>$df$</th>
<th>$p$</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>F-Copes</td>
<td>.615</td>
<td>.378</td>
<td>.346</td>
<td>11.87</td>
<td>4, 78</td>
<td>.001</td>
<td>[-.05, .65]</td>
</tr>
<tr>
<td>FCCI</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>[-3.17, -.37]</td>
</tr>
<tr>
<td>SSI</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>[-1.13, -.16]</td>
</tr>
<tr>
<td>ICSI</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>[-.54, -.21]</td>
</tr>
</tbody>
</table>

*Notes.* CBS= Caregiver Burden Scale, F-COPES= Family Crisis Oriented Personal Evaluation Scale, FCCI=Family Coping Coherence Index, and SSI=Social Support Index. df = degrees of freedom, CI = confidence intervals.

Table 6

*Multiple Regression Analyses Predicting ADRQL*

<table>
<thead>
<tr>
<th>Predictor Variable</th>
<th>$R$</th>
<th>$R^2$</th>
<th>Adjusted $R^2$</th>
<th>$F$</th>
<th>$df$</th>
<th>$p$</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>F-Copes</td>
<td>.435</td>
<td>.189</td>
<td>.179</td>
<td>5.03</td>
<td>4, 78</td>
<td>.001</td>
<td>[-.36, .45]</td>
</tr>
<tr>
<td>FCCI</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>[-.25, .70]</td>
</tr>
<tr>
<td>SSI</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>[-.37, .76]</td>
</tr>
<tr>
<td>ICSI</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>[.22, .60]</td>
</tr>
</tbody>
</table>

*Notes.* ADRQL=Alzheimer’s Disease Related Quality of Life Scale. F-COPES=Family Crisis Oriented Evaluation Scale, FCCI=Family Coping Coherence Index, SSI=Social Support Index, ICSI=Interpersonal Communication Satisfaction Inventory. df = degrees of freedom, CI = confidence intervals.
Summary

In this chapter, descriptive statistics of the sample population (N=83) and the results of the study’s hypothesis testing were provided. Out of the 83 caregiver participants in the study, 85.5% were female (N=71) and 14.5% were male caregivers (N=12). The respondents in the sample were predominantly Caucasian at 89.2% and 8.4% were Black. About 3% of the sample was Pacific/Highlander or Multiracial. It is noteworthy that current literature demonstrates that older African-Americans and Hispanics are more likely than older white Americans to have AD or other dementias. Current estimates are that African-Americans are about 2 times more likely, and Hispanics about 1.5 times more likely, than their white counterparts to have these conditions (Alzheimer’s Association, 2012). However the higher rates of Caucasian participants in this study could be attributed to method and location of collection of data as discussed by Guo and Musso (2007) that suggest that Caucasian populations are over represented.

Significant correlations were found between the family’s sense of coherence (FCCI) and caregiver burden (CBS and also between social support (SSI) and caregiver burden scores (CBS). Furthermore, caregiver burden (CBS) was significantly correlated to the quality of life with the person with Alzheimer’s disease (ADRQL) and the validation communication intervention (ICSI) was significantly correlated to the quality of life (ADRQL) in a person with Alzheimer’s disease.

This study found an effect size of .20 which resulted in a post hoc power of .23. In order to have sufficient power of .80 for this study at an effect of .20, there would have needed to have been 310 subjects in each group to find statistical significance. However,
the practical significant findings of a small effect size, being sample size free show the 
effects of the intervention.

The overall results of this study found a significant improvement in the areas of 
behavior, mood, communication and relationship in the participants involved in the 
Validation Communication Intervention Workshop, in the experimental group. Responses 
received from the caregiver participants by way of their weekly fidelity journals were 
analyzed by converting the nominal variables to scale scores. The mean for each group 
(experimental and control) was then calculated. The caregiver response average mean in 
the experimental group who received the VCI training workshop were compared with 
caregiver participants in the control who did not receive the training workshop. More 
research using a valid instrument to measure these variables would further validate the 
success of such a workshop. The fidelity journal data as reported by the caregivers in 
both the experimental and control groups for the areas of Behavior, Mood, Relationship 
and communication have been shown using Bar Graphs in Figures 1, 2, 3, and 4.
Figure 1. Behavior bar graph for week 1 to week 8. Notes. Control group (n=48) and experimental (n=35).
Figure 2. Mood bar graph for week 1 to week 8. Notes. Control group (n=48) and experimental (n=35).
Figure 3. Relationship bar graph for week 1 to week 8. Notes. Control group (n=48) and experimental (n=35).
Figure 4. Communication bar graph for week 1 to week 8. Notes. Control group \((n=48)\) and experimental \((n=35)\).
CHAPTER V. DISCUSSION

The purpose of this study was to contribute to mental health literature, more specifically to literature pertaining to families with family members with Alzheimer’s disease and the underlying relationships that involved family resiliency, sense of coherence, social support, and interpersonal communication satisfaction that determined the reduction of caregiver burden and improving the quality of life for persons with Alzheimer’s disease (AD). The study attempted to allocate the factors of family coping, problem solving, social support and improving interpersonal communication through the application of the Resiliency Model of Family Stress Adjustment and Adaptation in predicting caregiver burden and quality of life in persons with Alzheimer’s disease. A review of the resiliency model has proven to be successful in predicting how healthy families respond when faced with adverse situations. For the purpose of this study, the adverse situation was Alzheimer’s disease and family resiliency, sense of coherence social support and interpersonal communication satisfaction were used to assess caregiver burden and quality of life.

Family stress, adjustment, adaptation and coping were surveyed to analyze caregiver burden and the quality of life in persons with Alzheimer’s disease. The use of stress process models as organizing frameworks have often been implemented in research to demonstrate the predictors of caregiver burden (Pinquart & Sörensen, 2003; Yee & Schulz, 2000). The use of intervention workshops for caregivers has often been examined to support the caregiver and explore caregiver burden for those individuals working with
cognitively impaired adults (Lorig et al., 2012). Additionally, current research pertaining to quality of life has explored caregivers estimation of patients’ quality of life (QOL) with Alzheimer’s disease as well as assessed quality of life of community-residing persons with dementia, based on self-rated and caregiver-rated measures (Black et al., 2012).

Through email and newsletter notifications of the study at a local memory and wellness center and two other assisted living facilities in south eastern Florida, a community based sample of caregivers of persons with Alzheimer’s disease participated in this study and completed the 139 item survey.

By compiling six standardized instruments, two of which are designed specifically for populations with dementia and Alzheimer’s disease, the survey provided answers pertaining to the relationship between caregiver burden and the quality of life for persons with Alzheimer’s disease (dependent variables) and the independent variables of family resiliency, sense of coherence, social support and interpersonal communication intervention. The survey was distributed and scored by hand in the south Florida region.

**Contributions**

The present study contributes to professional literature as it supports prior investigations of similar subject matter while exploring and elaborating previous studies. This section describes an overview of the main contributions of the study.

The Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1996) was implemented to incorporate family resiliency measures, which have been well researched and supported throughout counseling literature and provide a sound theoretical base. This model has been utilized throughout researched literature as a
useful conceptual approach for counselors working with families in transition or faced with adverse situations (Frain et al., 2007). This study shed light on the significance of the instruments taken from this model and the importance of addressing family resiliency factors when families are under duress and face a crisis in this case Alzheimer’s disease. The scales used in the survey comprised of family resiliency scores, problem solving and coping scores, social support scores, interpersonal communication scores and scores related to a family’s sense of coherence. All of these variables were explored to assess their effect on the predictor variables of caregiver burden and quality of life in persons with Alzheimer’s disease. All of these contributor variables demonstrated smaller variance and significance in this study than other studies that have implemented components of family resiliency factors (Frain et al., 2007; Gonzales, Chronister, Linville, & Knoble, 2012). However, scores of participants in the experimental group that were part of the Validation Communication Intervention Workshop demonstrated higher interpersonal communication satisfaction and sense of coherence and lower caregiver burden as compared to the caregiver participants in the control group, which proves that the results pose their own unique set of contributions.

**Implications**

Implications generated from prior and current literature and future studies are an excellent resource pool for counselors and healthcare professionals working with persons with Alzheimer’s disease (AD). These have been discussed in Chapter 2 and were further highlighted through the completion of this study. Researchers work to suggest that psychosocial interventions, stress relieving interventions and support groups assist when working with caregivers and persons with Alzheimer’s disease (Brodaty et al., 2003;
Hornillos & Crespo, 2011; Lewis et al., 2009). The results of this study suggest that emphasis should be placed on the caregiver’s needs and caregiver burden needs to be alleviated in order to better protect and preserve the quality of life of the person with Alzheimer’s disease. Family resiliency factors along with the family’s sense of coherence and social support can also contribute to improving interpersonal communication between the caregiver and the person with AD, whereby reducing caregiver burden and improving the quality of life of the person with AD.

Counseling Implications

Family support along with the implementation of psychosocial interventions such as Validation Communication Intervention can be beneficial to both the caregiver and the person with AD. Healthcare professionals and mental health and rehabilitation counselors can become aware of and learn and promote counseling interventions such as the one used in this study (VCI) to better assist the caregiver with the stress that comes with the progression of the disease. Research has demonstrated that caregiver interventions are not a one size fits all and that the intervention has to be tailored to suit the needs of the caregiver. Sorensen, Pinquart, and Duberstein (2002) conducted a meta-analysis of the effectiveness of caregiver interventions where they discussed several different forms of caregiver interventions. These were divided into respite, supportive, psycho-educational, multi-component or psychotherapy based interventions. Effectiveness of these interventions was assessed by computing effect sizes as the difference between the post treatment measure between the experimental and the control groups divided by the pooled standard deviation (Glass, McGraw, & Smith, 1981; Hedges, 1981). Results for
this study demonstrated effect sizes at .02, .18, .21, .04, .22 and .17 for F-COPES, FCCI, SSI, CBS, ICSI and ADRQL, respectively.

Most consistent effectiveness has been found with psycho-educational and supportive interventions (Kosberg & Cairl, 1986) over a total of eight sessions (Sorensen et al., 2002). The Validation Communication Intervention workshop that the caregiver participants were involved in lasted for a total of eight weeks (i.e. 8 sessions) and focused on psycho-educational information regarding Alzheimer’s disease, family resiliency, and supportive interventions such as community support groups and interpersonal modalities to implement while communicating with the person with AD that relieved stress and caregiver burden. The fidelity graphs for the four areas of behavior, mood, communication and relationship showed a significant improvement in interpersonal communication satisfaction over the eight week intervention workshop. Behavior of the person with Alzheimer’s disease improved significantly after week 4 of the Validation Communication Intervention as reported by caregivers in the experimental group. Mood of the person with Alzheimer’s disease improved significantly after week 3 of the Validation Communication Intervention as reported by caregivers in the experimental group. Communication between the caregiver and the person with Alzheimer’s disease improved significantly after week 3 of the Validation Communication Intervention as reported by caregivers in the experimental group. Relationship between the caregiver and the person with Alzheimer’s disease improved significantly after week 5 of the Validation Communication Intervention as reported by caregivers in the experimental group.
Research demonstrates that psychosocial interventions are successful in alleviating caregiver burden with multi-component approaches such as the one used in this study. Validation Communication Intervention addresses psychosocial information, stress relieving strategies, support and respite that help alleviate caregiver burden which results in the improvement of quality of life for the person with Alzheimer’s disease. Having knowledge as a counselor of different interventions to assist the caregiver would be beneficial in the treatment and care of the caregiver client.

As a counselor it is important that one is aware of innate features attached to what makes a family resilient and at-risk families can be treated preventatively (Sperry, 2009). Counseling interventions that foster family resiliency focus on shared hope, family coherence, support and new collaborative measures to bring about family strengthening are vital for counselor to be aware of (Walsh, 2006). A counselor can allow the family to reframe and make meaning when faced with a challenging situation and can target the family’s vulnerability and improve family functioning (Hanson & Lynch, 2004).

Family members are the primary source of care and support for persons with Alzheimer’s disease. One of the most self-sacrificing and compassionate things a person can do is care for a loved one who has been diagnosed with AD. Identifying a family’s state of distress and the ways the family members accept, cope and adjust to an illness is information that can assist the counselor in the therapeutic setting. Caregiving is an experience that most people are not prepared for and the caregiver becomes the hidden victim of the disease (Lewis et al., 2009). Mental health counselors can be prepared and become aware of the psychological, social and economic impacts of being an Alzheimer’s disease caregiver. This is extremely important in order to assist the family in
dealing with and coping with this progressive illness. By facilitating access to programs and services that have provided success rates for caregivers for persons with Alzheimer’s disease, such as the one used in this study, the quality of life of the person with Alzheimer’s disease can be enhanced while reducing caregiver burden by access to training workshops such as Validation Communication Intervention.

**Limitations**

While contributing to knowledge pertaining to caregivers and persons with Alzheimer’s disease, this study had some limitations decreasing its generalizability and statistical relevance.

The study was comprised of predominantly female subjects and approximately 89% of these were Caucasian. This limits the scope as the population was skewed and not inclusive of families from various cultural backgrounds. Additionally, in order to participate in the study, the respondent had to be a caregiver of a person with Alzheimer’s disease at the three sites contacted for the purpose of this study. This suggests that many families who lack awareness or the ability to be actively involved in community resources such as Alzheimer’s disease support groups were excluded from this sample.

A significant factor that was not assessed in this study was the stages and progression of the disease. For example when the disease started and the severity of the disease was not evaluated in this model. Persons with Alzheimer’s disease were at different stages of the disease therefore caregiver stress and burden was also varied. Responses to the CBS and ADRQL may have been biased on the part of the caregiver and therefore results may have been skewed.
The structure and length of the survey posed to be a major barrier. The survey had 139 items, which was a deterrent to many completing the survey. Several respondents inquired to the length and time required for the completion of the survey. Four respondents in the experimental group started the VCI workshop but chose to drop out due to the length of the survey. Furthermore, the average age of the caregiver in the study was 62 years. This could have been a limitation as the survey required concentration and adequate reading skills as well as adequate time to allocate to a research-related undertaking.

Another limitation of the study was the number of absences allowed on the part of the caregiver in the experimental group. As per the requirements of the study the caregiver participant of the experimental group was allowed only two absences in order to be considered a viable study participant. Data provided by two caregiver participants in the experimental group could not be included in the data analysis as they had more than two absences from attendance in the training workshop.

Attrition was a significant limitation to the study. Research has found that 500,000 people die from Alzheimer’s disease each year, more than five times the number reported by the CDC (Lake, 2014). That makes Alzheimer’s disease the third leading cause of death in the United States after heart disease and cancer. Currently the CDC ranks Alzheimer’s disease sixth as a cause of mortality where AD was the reported cause of 84,000 deaths on death certificates (Lake, 2014). By 2050 the number of people with Alzheimer’s disease will triple and costs for Alzheimer’s care will reach a trillion dollars. For this study data collected from five caregivers in the experimental group could not be included in the study as their spouses passed away during the duration of the study.
Additionally, one of the caregiver respondents in the experimental group passed away and therefore his responses could not be included in the data analysis. Furthermore, the Hawthorne effect was a major consideration in this study, especially in the case of the participants in the experimental group. The term Hawthorne effect refers back to a series of experiments on managing factory workers carried out around 1924 in the Hawthorne works of the Western Electric Company in Chicago. The term generally refers to the experiment’s biased results based upon the awareness of participants that they are the subject of an intervention (Olson, Verley, Santos, & Salas, 1994). In this study, the participants in the experimental group received more attention from the researcher in the form of imparting the information provided in the workshop. Additionally the participants were in constant contact with the researcher for the total duration (8 weeks) of the workshop and were at liberty to ask questions, and consult with other participants and share their concerns with the researcher. On the other hand participants in the control group met with the researcher on only two occasions (Pretest and posttest administration). This may have resulted in bias responses from participants in the experimental group.

Conclusion

Research shows that some clients report positive changes had occurred in relation to their presenting problem between the time when they were called for the initial appointment and when they came for their first session, hence pretreatment change (Guterman, 1998). In this study, participants in the experimental group that were exposed to the Validation Communication Intervention reported to “feeling better” and “less stressed” about themselves after hearing that they were going to be part of the
treatment/experimental group. Some caregivers reported that, “we wish we had heard about this intervention a few years ago.” Qualitative relationships were demonstrated in the form of written feedback from the participants in the experimental group post intervention. Statements like, “The information provided in the workshop about Alzheimer’s disease was most helpful,” “The stress relieving tips helped me when I was feeling down,” “Learning how to ground myself and learning deep diaphragmatic breathing has been wonderful,” “I wish I knew about the validation intervention when my husband was diagnosed many years ago,” “I just learned that I could communicate with my husband after all,” “Being part of the workshop made me feel better because I was with friends,” and “This workshop has to be made available to other caregivers and staff working with patients with Alzheimer’s disease.” Due to the quantitative design of the current study these statements were not factored into the data analysis but could be examined and used for future qualitative or mixed design research. Family resiliency factors that include, family coping and problem solving along with social support, sense of coherence and interpersonal communication have proven to be stress reducing when families are faced with adverse events. In the case of this study the adverse event that caregivers had to overcome was the caregiving responsibilities of a person with Alzheimer’s disease. This study found that making meaning of the adverse event, utilizing community and personal support resources and involving oneself in caregiver’s supportive training workshops contributed to the reduction of caregiver burden and the improvement in the quality of life of the person with Alzheimer’s disease.

Further research to identify exactly what psychosocial intervention is most effective for this population and exploring an instrument to effectively measure this, may
prove useful in assisting caregivers and families and in answering widely represented questions about caregiving for a person with Alzheimer’s disease. Focus should be placed on the stages of the disease while enhancing characteristics and interventions that are related to stronger, resilient family coping factors and how caregivers respond to adverse events such as caring for a person with Alzheimer’s disease. Mental health professionals can help at-risk families by identifying training workshops, coping and communication strategies that will help reduce caregiver burden and improve the quality of life for a person with Alzheimer’s disease.
Dear Caregiver,

We are conducting a training workshop as part of a research study to increase our understanding of an intervention that can improve the quality of interpersonal communication and the quality of life for both you the caregiver and your loved one who has been diagnosed with dementia of the Alzheimer’s type. As a caregiver you are in an ideal position to give us valuable first-hand information from your own perspective.

The training workshop will be conducted on Thursday November 21, 2013 at the Louis and Anne Green Memory and Wellness Center, and will last for a total of 120 minutes. Additionally you will be asked to attend seven more 30 minute sessions in order to learn more about the intervention. These sessions will be conducted 30 minutes prior to the start of the support group that you would normally attend at the Center. If you are unable to attend any support group and require a time that is convenient to you, kindly indicate the same below. The duration of the study will be a total of eight weeks from start to finish.

You will be asked to complete a questionnaire at the beginning and at the end of the study. Your responses to the questions will be kept confidential. Each participant will be assigned a number code to help ensure that personal identifiers are not revealed during
the analysis and write up of findings. There is no compensation for participating in this study. However, your participation will be an extremely valuable addition to our research and findings thereof could lead to greater public understanding of Alzheimer’s disease and the communication intervention that will enable caregivers such as yourself to improve communication skills with your loved one and will bring awareness to facilitators, counselors and healthcare personnel in the field.

If you are interested in being a part of this study, kindly return this letter by filling out the details at the bottom.

For further questions: Contact Jaimee at 561-297-0103 or Hovi at 561-703-1878

Thank you very much for your time.

Hovi Shroff LMHC
Principal Investigator

Additional times for 7 weekly sessions: Kindly indicate exact times that work for you.

Monday AM/PM      Tuesday AM/PM      Wednesday AM/PM      Thursday AM/PM

CAREGIVER NAME:     YES/NO:
APPENDIX B

CONSENT FORM

ADULT CONSENT FORM

1) **Title of Research Study:** FAMILY RESILIENCY, SENSE OF COHERENCE, SOCIAL SUPPORT, AND PSYCHOSOCIAL INTERVENTIONS: REDUCING CAREGIVER BURDEN AND DETERMINING THE QUALITY OF LIFE IN PERSONS WITH ALZHEIMER’S DISEASE.

2) **Investigator(s):** Michael Frain, Ph.D. & Havovi B. Shroff LMHC

3) **Purpose:** The purpose of this research study is to investigate a communication intervention designed to improve the effects of family resiliency, sense of coherence, social support and psychosocial interventions, especially that of Validation Communication Intervention (VCI). With the implementation of this protocol namely, Validation Communication Intervention caregivers, counselors and educators can utilize a modality that can assist in improving the quality of interpersonal communication, whereby reducing caregiver burden and determining the quality of life in persons with Alzheimer’s disease.

4) **Procedures:**
   - You will participate in a research study for a total time of eight weeks.
   - You will participate in a Validation Communication Intervention training workshop. You will be asked to complete six evaluation instruments. These will include a family resiliency and coping questionnaire, a sense of coherence index, a social support index, an interpersonal communication inventory, a caregiver burden scale and an Alzheimer’s disease related quality of life scale. Additionally, a demographic/information questionnaire will also be completed by you.
   - You will attend one, mandatory 120 minute training workshop on Validation Communication Intervention.
   - Following this training workshop, you will be given 30-35 minutes to complete the required questionnaires stated above.
   - Subsequently you will attend 30 minute training sessions for the next seven weeks.
   - In order to be included in the study, you will have to attend a minimum of 5 out of the 7, thirty minute sessions.
   - You will also be asked to complete journal entries for the 8-week duration of the study. The journal will be provided by the investigator/workshop facilitator.
   - This journal will be used to record the behavior, mood, relationship and communication quality between the caregiver and the person with AD.
• You will have to complete the questionnaires provided at the termination of the study, at the 8 week mark.
• The date for the workshop and sessions will be scheduled upon advisement of the Clinical Director of the facility that you attend.
• The training workshop and the entire duration of the study will be held on dates that have been pre-determined and given to you in advance.
• No monetary compensation will be provided. You can choose to participate if you want to and may withdraw at any time with no penalties.

5) **Risks:** We understand that due to the sensitive nature of this study, you may experience some stress when completing the questions asked about your relationship with the person with Alzheimer’s disease, family resiliency, sense of coherence, social support and quality of life. Some fatigue or frustration with the questions is possible and you may take a break at any time or stop the process altogether if you so wish. Furthermore, if you wish to withdraw from the study kindly inform your group facilitator of your decision. Additionally, some individuals may experience some self-consciousness related to knowing that your data will be included in the analysis; though your name will not be associated with the data. At times your participation may result in some emotional discomfort as a result of focusing on memory changes and emotional problems your loved one is experiencing, and as a result of stressors experienced by you. If you continue to experience stress due to your participation in this study, on-site licensed mental health professionals are available for consultation.

6) **Benefits:** Although no benefits can be promised from participation in this study, it is hoped that the Validation Communication Intervention will facilitate an improvement in the quality of the patient/caregiver relationship, improve interpersonal relationships and can result in the reduction of caregiver burden and enhancement of quality of life in the person with AD. Additionally it is hoped that the study will further our knowledge of best practices in care and communication for persons with Alzheimer’s disease and their caregivers.

7) **Data Collection & Storage:**
Any information collected about you will be kept confidential and secure and only the people working with the study will see your data, unless required by law. The data will be kept for 5 years in a locked cabinet and/or password-protected computer in the investigator’s office. After 5 years, paper copies will be destroyed by shredding and electronic data will be deleted. We may publish and present what we learn from this study. If we do, we will not let anyone know your name/identity unless you give us permission.

8) **Contact Information:**
For questions or problems regarding your rights as a research subject, you can contact the Florida Atlantic University Division of Research at (561) 297-0777. For other questions about the study, you should call the principal investigator Michael Frain at (561) 297-3626 or doctoral student, Havovi B. Shroff at (561) 703-1878
9) **Consent Statement:**
I have read or had read to me the preceding information describing this study. All my questions have been answered to my satisfaction. I am 18 years of age or older and freely consent to participate. I understand that I am free to withdraw from the study at any time without penalty. I have received a copy of this consent form.

Signature of Subject: _______________________________ Date: ____________

Printed name of Subject: First Name ______________ Last Name ____________

Signature of Investigator: _______________________________ Date: ____________
Appendix C

Family Resiliency, Sense of Coherence, Social Support, Caregiver Burden, Interpersonal Communication Satisfaction, and Alzheimer’s Disease Related Quality of Life Questionnaire

Part 1

FAMILY CRISIS ORIENTED PERSONAL EVALUATION SCALES (F-COPES)

First read the list of response choices one at a time. Second decide how well each statement describes your attitude and behavior in response to problems or difficulties. If the statement describes your response very well, the circle the number 5 indicating that you STRONGLY AGREE; if the statement does not describe your response at all, then circle the number 1 indicating that you STRONGLY DISAGREE; if the statement describes your response to some degree, then select a number 2, 3, or 4 to indicate how much you agree or disagree with the statement about your response.

WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY, WE RESPOND BY:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Sharing our difficulties with relatives</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. Seeking encouragement and support from friends</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. Knowing we have the power to solve major problems</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. Seeking information and advice from persons in other families who faced the same or similar symptoms</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. Seeking advice from relatives</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. Seeking assistance from community agencies and programs designed to help families in our situation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. Knowing that we have the strength within our own family to solve our problems</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. Receiving gifts and favors from neighbors (e.g. food, taking in the mail, etc.)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. Seeking information and advice from the family doctor</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
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<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>10. Asking neighbors for favors and assistance</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Facing the problems “head-on” and trying to get the situations right away</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Watching television</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Showing that we are strong</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Attending church services</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Accepting stressful events as a fact of life</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Sharing concerns with close friends</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Knowing that luck plays a big part in how well we are able to solve family problems</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. Exercising with friends to stay fit and reduce tension</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. Accepting that difficulties occur unexpectedly</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. Doing things with relatives (get-togethers, dinners, etc.)</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. Seeking professional counseling and help for family difficulties</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. Believing we can handle our own problems</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. Participating in church activities</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24. Defining the family problem in a more positive way so that we do not become too discouraged</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25. Asking relatives how they feel about problems we face</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26. Feeling that no matter what we do to prepare, we will have difficulty handling problems</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>27. Seeking advice from a minister</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>28. Believing if we wait long enough, the problem will go away</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>29. Sharing problems with neighbors</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30. Having faith in God</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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Part 2

FAMILY COPING COHERENCE INDEX (FCCI)

Decide to what degree you either agree or disagree with each statement about your family.
0 = Strongly Disagree, 1 = Disagree, 2 = Neutral, 3 = Agree, 4 = Strongly Agree

When we face problems/difficulties in our family we cope by:

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Accepting stressful events as a fact of life</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Accepting that difficulties occur unexpectedly</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Defining the family problem in a positive way so that we do not become too discouraged</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Having faith in God</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

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Part 3

SOCIAL SUPPORT INDEX (SSI)

Read the statements below and decide for your family whether you: (1) Strongly disagree; (2) Disagree; are (3) Neutral; (4) Agree; or (5) Strongly agree and circle that number.

Please indicate how much you agree or disagree with each of the following statements about your community and family:

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. If I had an emergency, even people I do not know in this community would be willing to help</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. I feel good about myself when I sacrifice and give time and energy to members of my family</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. The things I do for members of my family and they do for me make me feel part of this very important group</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. People here know they can get help from the community if they are in trouble</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. I have friends who let me know they value who I am and what I can do</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. People can depend on each other in this community</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. Members of my family seldom listen to my problems or concerns; I usually feel criticized</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. My friends in this community are part of my everyday activities</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. There are times when family members do things that make other members unhappy</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. I need to be very careful of how much I do for my friends because they take advantage of me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. Living in this community gives me a secure feeling</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. The members of my family make an effort to show their love and affections for me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. There is a feeling in this community that people should not get too friendly with each other</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. This is not a very good community to bring children up in</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. I feel secure that I am as important to my friends as they are to me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
16. I have some very close friends outside the family who I know really care for me and love me

17. Member(s) of my family do not seem to understand me; I feel taken for granted

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Part 4

CAREGIVER’S BURDEN SCALE (CBS)

The following is a list of statements which reflect how people sometimes feel when taking care of another person. In the space to the left of each statement, please indicate how often you feel that way using the following scale.

0 = Never
1 = Rarely
2 = Sometimes
3 = Quite frequently
4 = Nearly always

1. Feel resentful of other relatives who could do but do not do things for my spouse.

2. I feel that my spouse makes requests which I perceive to be over and above what he/she needs.

3. Because of my involvement with my spouse, I don’t have enough time for myself.

4. I feel stressed between trying to give to my spouse as well as to other family responsibilities, job, etc.

5. I feel embarrassed over my spouse’s behavior.

6. I feel guilty about my interactions with my spouse.

7. I feel that I don’t do as much for my spouse as I could or should.

8. I feel angry about my interactions with my spouse.

9. I feel that in the past, I haven’t done as much for my spouse as I could have or should have.

10. I feel nervous or depressed about my interactions with my spouse.

11. I feel that my spouse currently affects my relationships with other family members and friends in a negative way.

12. I feel resentful about my interactions with my spouse.

13. I am afraid of what the future holds for my spouse.


15. It’s painful to watch my spouse age.

16. I feel useful in my interactions with my spouse.

17. I feel my spouse is dependent.

18. I feel strained in my interactions with my spouse.

19. I feel that my health has suffered because of my involvement with my spouse.

20. I feel that I am contributing to the well-being of my spouse.

21. I feel that the present situation with my spouse doesn’t allow me as much privacy as I like.
22. I feel that my social life has suffered because of my involvement with my spouse.

23. I wish that my spouse and I had a better relationship.

24. I feel that my spouse doesn’t appreciate what I do for him/her as much as I would like.

25. I feel uncomfortable when I have friends over.

26. I feel that my spouse tries to manipulate me.

27. I feel that my spouse seems to expect me to take care of him/her as if I were the only one he/she could depend on.

28. I feel that I don’t have enough money to support my spouse in addition to the rest of our expenses.

29. I feel that I would like to be able to provide more money to support my spouse than I am able to now.

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Part 5

INTERPERSONAL COMMUNICATION SATISFACTION INVENTORY

Please indicate the degree to which you agree or disagree that each statement describes communication with the person with Alzheimer’s disease. The 4 or middle position on the scale represents “undecided” or “neutral”, then moving out from the center, “slight” agreement or disagreement, then “moderate” then “strong” agreement or disagreement. For example, if you strongly agree with the following statement you would circle 7;

The other person (in this survey refers to the person with AD) moved around a lot.

7= Strongly Agree, 6=Moderately Agree, 5= Slightly Agree, 4=Neutral, 3= Slightly Disagree, 2= Moderately Disagree, 1=Strongly Disagree

1. The other person let me know that I was communicating effectively.____
2. Nothing was accomplished.____
3. I would like to have another conversation like this one.____
4. The other person genuinely wanted to get to know me.____
5. I was very dissatisfied with the conversation/communication.____
6. I had something new to improve communication.____
7. I felt that during the conversation I was able to present myself as I wanted the other person to view me.____
8. The other person showed that he/she understood what I said.____
9. I was very satisfied with the conversation.____
10. The person expressed a lot of interest in what I had to say.____
11. I did NOT enjoy the conversation.____
12. The other person did NOT provide support for what he/she was saying.____
13. I felt I could communicate about anything with the other person.____
14. We each got to communicate what we wanted.____
15. I felt that we could laugh easily together.____
16. The conversation/communication flowed smoothly.____
17. The other person changed the topic when his/her feelings were brought into the conversation.____
18. The other person frequently said things which added little to the conversation/communication.____
19. We talked/communicated about something I was NOT interested in.____

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Part 6

ALZHEIMER’S DISEASE RELATED QUALITY OF LIFE (ADRQL)

A. Those statements are about relating to and being around other people. After each statement, please answer “Agree” if the statement describes the person with Alzheimer’s disease in the last 2 weeks or answer “Disagree” if it does not.

<table>
<thead>
<tr>
<th></th>
<th>AGREE</th>
<th>DISAGREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1. He/She smiles or laughs when around other people</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A2. He/She does not pay attention to the presence of others</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A3. He/She will stay around other people</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A4. He/She seeks contact with others by greeting people or joining in conversations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A5. He/She talks with people</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A6. He/She touches or allows touching such as handshakes, hugs, kisses, pats</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A7. He/She can be comforted or reassured by others</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A8. He/She reacts with pleasure to pets or small children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A9. He/She smiles or laughs or is cheerful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A10. He/She shows delight</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A11. He/She shows a sense of humor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A12. He/She sits quietly and appears to enjoy the activity of others even though he/she is not active participating</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

B. These statements are about a person’s special identity and important relationships. After each statement, please answer “Agree” if the statement describes the person with Alzheimer’s disease in the last 2 weeks or answer “Disagree” if it does not.

<table>
<thead>
<tr>
<th></th>
<th>AGREE</th>
<th>DISAGREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>B1. He/She talks about or still does things related to his/her previous work or daily activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>B2. He/She is aware of his/her place in the family such as being a husband/wife, parent, or grandparent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>B3. He/She makes or indicates choices in routine daily activities such as what to wear, what to eat, or where to sit</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
B4. He/She shows interest in events, places or habits from his/her past such as old friends, former residences, church or prayer.................................................................

B5. He/She does not respond to his/her own name................

B6. He/She does not express beliefs or attitudes that he/she always had.................................................................

B7. He/She talks with people on the telephone..................

B8. He/She gets enjoyment from or is calmed by his/her possessions or belongings.............................................

C. These statements are about different types of behavior in the last 2 weeks. After each statement, please answer “Agree” if the statement describes the person with Alzheimer’s disease in the last 2 weeks or answer “Disagree” if it does not.

AGREE      DISAGREE

C1. He/She squeezes, twists, or wrings his/her hands.............

C2. He/She throws, hits, kicks, or bangs objects....................

C3. He/She calls out or yells or curses or makes accusations...

C4. He/She locks or barricades himself/herself in his/her room/house/apartment..........................................................

C5. He/She is irritable or easily angered...............................

C6. He/She cries, wails, or frowns........................................

C7. He/She is restless and wound up, or repeats actions such as rocking, pacing, banging against walls..............................

C8. He/She resists help in different ways such as with dressing, eating or bathing, or by refusing to move..........................

C9. He/She appears to be content or satisfied..........................

C10. He/She becomes upset or angry when approached by another person.................................................................

C11. He/She pushes, grabs, or hits people..............................

C12. He/She is upset or unsettled in his/her living environment.................................................................

D. These statements are about usual activities in the last 2 weeks. After each statement, please answer “Agree” if the statement describes the person with Alzheimer’s disease in the last 2 weeks or answer “Disagree” if it does not.

AGREE      DISAGREE
D1. He/She enjoys doing activities alone such as listening to music or watching TV ......................

D2. He/She does not take part in activities he/she used to enjoy, even when encouraged to take part ..................

D3. He/She shows no signs of pleasure or enjoyment when taking part in leisure activities or recreation ..................

D4. He/She dozes off or does nothing most of the time ....

E. These statements are about behavior in a person’s living environment in the last 2 weeks. After each statement, please answer “Agree” if the statement describes the person with Alzheimer’s disease in the last 2 weeks or answer “Disagree” if it does not.

AGREE       DISAGREE

E1. He/She talks about feeling unsafe or says his/her belongings are not safe .................................

E2. He/She is upset or unsettled when in places other than where he/she lives ......................................

E3. He/She talks about wanting to leave or go home ........

E4. He/She says he/she wants to die ...........................
Part 7

DEMOGRAPHIC/INFORMATION QUESTIONNAIRE

Please answer all of the questions as accurately as possible.

(1) Gender: (please circle) Male or Female

(2) Age of caregiver: (in years): _________

(3) Age of person with Alzheimer’s disease: (in years) ____________

(4) Race: (please circle):
   (a) Black
   (b) White
   (c) Asian/Pacific Islander
   (d) Latino (a)
   (e) Multiracial
   (f) Other: (please specify): _________________________

(5) Duration that you have been a caregiver to your loved one with Alzheimer’s disease: (in years) ________________

(6) Relationship of you the caregiver to your loved one with Alzheimer’s disease:____________________________

(7) Religious or spiritual preference of the caregiver (please specify):____________________________________

(8) Have you ever been exposed to Validation Therapy and/ or Validation Communication Intervention? (please circle):
   (a) Yes
   (b) No

(9) If you answered YES to the above question, do you wish to continue to participate in the training workshop however, you will not be a part of the study. (Please circle):
   (a) Yes
   (b) No

(10) What is your household income?
    (a) Less than 100,000
    (b) 100,000-300,000
    (c) Over 300,000

(11) How many persons live in your household, including yourself?
    ____________
Appendix D

IRB Approval

Florida Atlantic University

DATE: September 30, 2013
TO: Michael Frain, PhD
FROM: Florida Atlantic University Social, Behavioral and Educational Research IRB
IRBNET ID #: 463564-2
PROTOCOL TITLE: [463564-2] FAMILY RESILIENCY, SENSE OF COHERENCE, SOCIAL SUPPORT AND PSYCHOSOCIAL INTERVENTIONS: REDUCING CAREGIVER BURDEN AND DETERMINING THE QUALITY OF LIFE IN PERSONS WITH ALZHEIMER’S DISEASE
PROJECT TYPE: New Project
ACTION: APPROVED
APPROVAL DATE: September 30, 2013
EXPIRATION DATE: September 29, 2014
REVIEW TYPE: Expedited Review
REVIEW CATEGORY: Expedited review category # B7

Thank you for your submission of Response/Follow-Up materials for this research study. The Florida Atlantic University Social, Behavioral and Educational Research IRB has APPROVED your New Project. This approval is based on an appropriate risk/benefit ratio and a study design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

• This study is approved for a maximum of 120 subjects.
• It is important that you use the approved, stamped consent documents or procedures included with this letter.
• **Please note that any revision to previously approved materials or procedures, including modifications to numbers of subjects, must be approved by the IRB before it is initiated. Please use the amendment form to request IRB approval of a proposed revision.
• All SERIOUS and UNEXPECTED adverse events must be reported to this office. Please use the appropriate adverse event forms for this procedure. All regulatory and sponsor reporting requirements should also be followed, if applicable.
• Please report all NON-COMPLIANCE issues or COMPLAINTS regarding this study to this office.
• Please note that all research records must be retained for a minimum of three years.
• **This approval is valid for one year. A Continuing Review form will be required prior to the expiration date if this project will continue beyond one year.

If you have any questions or comments about this correspondence, please contact Elisa Gaucher at:

- 1 -
Institutional Review Board
Research Integrity/Division of Research
Florida Atlantic University
Bldg. 80, Rm. 106
Boca Raton, FL 33431
Phone: 561-297-0777

* Please include your protocol number and title in all correspondence with this office.

This letter has been electronically signed in accordance with all applicable regulations,
and a copy is retained within our records.
## Appendix E

### Validation Communication Intervention

**Training Workshop**

**SESSIONS 1-8**

<table>
<thead>
<tr>
<th></th>
<th>WK # 1</th>
<th>WK # 2</th>
<th>WK # 3</th>
<th>WK # 4</th>
<th>WK # 5</th>
<th>WK # 6</th>
<th>WK # 7</th>
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<tr>
<td></td>
<td>120 minutes</td>
<td>30 MINS</td>
<td>30 MINS</td>
<td>30 MINS</td>
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<td>30 MINS</td>
<td>30 MINS</td>
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<td>Follow up Journal Collection</td>
<td>Follow up Journal Collection</td>
<td>Follow up Journal Collection</td>
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<td>Follow up Journal Collection</td>
<td>Follow up Journal Collection</td>
<td>Follow up Journal Collection</td>
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<tr>
<td>Alzheimer’s disease facts and figures</td>
<td>Psycho Education/Stigma Building Trust</td>
<td>Adjusting to the disease</td>
<td>Imagining the opposite</td>
<td>Seeking Support Family</td>
<td>Maintaining Close Eye Contact</td>
<td>Seeking support Community</td>
<td>Re-phrasing</td>
<td>Support groups Linking the client Behavior with the Unmet Need</td>
</tr>
<tr>
<td>Caregiver Coping Strategies</td>
<td>Validation Communication Intervention (VCI) Centering/Music</td>
<td>Exploration of the past</td>
<td>Touch</td>
<td>Utilize a clear loving tone of voice’ Rolling with the Alphabet soup</td>
<td>Implementing of Polarity</td>
<td>Implement Ambiguity</td>
<td>Mirroring</td>
<td>Termination of the study Questions &amp; Feedback</td>
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</tbody>
</table>

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Appendix F

Caregivers Weekly Journal Entries based on VCI Training

Instructions: As the caregiver, you are asked to record your loved ones behavior, mood, relationship, and communication quality on a weekly basis for the next 8 weeks. Kindly circle “YES”, if you have found a significant improvement with the implementation of VCI. If there have been no significant improvements in the areas listed, kindly circle “NO.”

<table>
<thead>
<tr>
<th></th>
<th>Week 1</th>
<th>Week 2</th>
<th>Week 3</th>
<th>Week 4</th>
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<th>Week 7</th>
<th>Week 8</th>
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<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
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<tr>
<td>Mood</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
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<tr>
<td>Relationship</td>
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<td>Y / N</td>
<td>Y / N</td>
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<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
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<tr>
<td>Communication</td>
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<td>Y / N</td>
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<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
<td>Y / N</td>
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REFERENCES


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