

**A Study on the Effects of a Specifically Designed Workbook
on the Burden of Care, Problem Solving Abilities, and Depression Levels of Home
Caregivers of Persons with Alzheimer's Disease or Dementia**

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**Dissertation Submitted to the Faculty of
Holos University Graduate Seminary
in partial fulfillment of the requirements
For the degree of**

**Doctor of Theology
in
Spiritual Healing**

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The work reported in this dissertation is original and carried out by me solely, except for the acknowledged direction and assistance gratefully received from colleagues and mentors.

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DEDICATION

My heartfelt appreciation and thanks to the Chair of my research committee, Dr. Ann Nunley, for her enduring help and support as well as to the members of my committee, Dr. Norman Shealy, Dr. Robert Nunley, and Dr. Robert Matusiak. I have truly appreciated the opportunity to learn from each of them and to participate in this wonderful experience that is Holos University Graduate Seminary.

I also wish to acknowledge other special people who have contributed to my education and my dissertation. My wonderful husband, Jim who has been my co-pilot in getting the workbook finished and my project off the ground, without whose help all of this would have not been possible. Priscilla Lindsey the Director of the Albuquerque Area Agency on Aging who was so kind to give me guidance and direction on accessing city services. Share Your Care, Albuquerque's adult daycare service provider who gave me access to their caregivers. Special thanks goes to Directors Jay Rubelet and Bill Keisel, as well as the managers of each of the daycare sites. Much thanks to Judy Devlin and the case management team at St. Joseph Senior Care (PACE) who gave more than expected with their recruitment enthusiasm and moral support. Open Hands Adult Day care in Santa Fe who gave us an extra support and allowed us to spend a few recruitment days at their site. The New Mexico Alzheimer's and Related Disease Association who provided us access to their support group network. To all the support group leaders who so kindly allowed me to attend their meetings and enlist participants. Thanks to Dr. Paul Thomlison who ran my statistics very on a quick turn around to keep this project flowing. Much love and thanks to my wonderful children who have always given me love, support, and encouragement. My friend Marie who is always there to listen. Last but not least, thanks to my great (times 5) grandfather the great scientist, Benjamin Franklin who lives on in family legend and serves as inspiration for me in my desire to innovate and be of service to others.

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BIBLIOGRAPHY

Elizabeth Harwood Cochran
Spiritual Healing/Energy Medicine, 2003
Holos University Graduate Seminary

ABSTRACT

The Effects of a Specifically Designed Alzheimer's Workbook on the Burden of Care and Problem-solving Abilities of Home Caregivers of Persons with Alzheimer's Disease.

Alzheimer's Disease (AD) is a chronic, long-term, debilitating, disease that currently affects millions of people worldwide. Most of the people afflicted with this disease are cared for in the home setting by family members and don't have access to formal community education. Due to the erratic behavioral responses and steady declines in self-care abilities of persons with AD, caregivers face high degrees of physical and psychological stress. With limited options and choices, caregivers fall back on behaviors that do not preserve self-care behaviors in the person with AD, which adds to their stress. The AD workbook, designed by the author for this study, allows caregivers to plot the current abilities and future declines of the person they are caring for in the holistic mental, emotional, physical, social, and spiritual domains. This methodology provides the caregiver with choices that can be matched to individual needs and utilized as problem-solving modalities.

This study tested the hypothesis that the use of this self-directed holistic health workbook would decrease the perceived burden of care and levels of depression as well as increase positive perceptions of problem-solving skills in home caregivers of persons with AD. Forty-nine volunteer caregivers were randomly assigned to either a treatment group or a control wait-list for the program. Subjects in the treatment group were given a copy of the *Alzheimer's Holistic Workbook* and an instruction sheet. All caregivers were given pre- and post-test measures on Novak and Guest's *Caregiver Burden Inventory*, Heppner's *Problem solving Inventory*, and Zung's *Depression Scale*. The results, although not statistically significant did indicate trends toward reductions in burden and improvements in the perception of problem solving abilities. No significant reduction was found in levels of depression, but this sample was not highly depressed on pre-test-only 34% of the sample had some level of depression and 66% of that was mild. There were anecdotal reports of positive experiences in a number of the experimental participants. The lack of significance may be due to random sampling without controlling for either readiness to learn or the threshold of emotional engagement needed to accept new information and adopt new ways of conceptualizing care.

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INDEX OF ABBREVIATIONS

AD	Alzheimer's Disease
ARD.....	Alzheimer's Disease and Related Disorders
DA.....	Developmental Age
PAD	Person with Alzheimer's Disease
PWD	Person with Dementia
CBI	Caregiver Burden Inventory
PSI	Problem Solving Inventory
ZDS	Zung Depression Scale
PRE	Before
POST	After

CHAPTER I INTRODUCTION AND REVIEW OF LITERATURE

INTRODUCTION

Alzheimer's Disease and Related Disorders (ADRD) occupy and destroy the minds of millions of the world's citizens. An estimated 22 million people worldwide have some form of dementia.¹ Some 4 to 5 million Americans suffer from this disease and it ranks as the fourth leading cause of death in America.² By the year 2020, the number of people affected by AD is projected to rise to 14 million.³ There is no known cause for ADRD, but the risk factors have been identified include: aging, genetic predisposition, and head trauma.⁴ Minority populations are at increasing risk because they comprise a fast-growing segment of the aging population.⁵ Because family members or significant others care for 80% of people with dementia in their home environments.⁶, unpaid family caregiving is a major, hidden, critically-important, and fragile part of long-term care in the US.⁷ These caregivers spend every day learning how to cope with the ever-changing face of ADRD. Since the average length of ADRD caregiving is 8 to 10 years, ADRD is unlike other chronic illnesses: it is more disruptive and presents a greater challenge in providing care.⁸ In meeting this challenge, family caregivers face significant emotional and physical impact, which can have lasting effects on their health, well-being, and quality of life.⁹ They can become the "hidden patients" in the world of ADRD care.¹⁰ In some cases there are additional family members who offer concern and support, if not actual supplementary care and respite. Unfortunately, however, for many care of the person with Alzheimer's Disease (PWD) remains a solitary battle. In this study, the author is seeking to improve the interactions between the caregiver and the person with Alzheimer's

disease in the hope that it will result in better functional and health outcomes for the caregiver and PWD. The methodology to be utilized is a self-help workbook specifically designed by the author for home caregivers.

REVIEW OF LITERATURE

Pertinent Characteristics of the Person with Dementia

In general, people can be recognized as holistic beings whose patterns of behavior are in process of becoming organized or disorganized. The trend in normal persons is defined as moving toward increasing organization, complexity, and growth. They are free to make choices and must bear responsibility for the results. Persons are interactive with their environment in a mutual, rhythmical process. They have unique internal and external environments, which enable them to mold and be molded, by their world. Health is the state of well being and actualization that results from a person's interaction with their environment.

In ADRD, all of this normalcy and potential for health is challenged, yet there is a logical need to provide dignity for PWD's. They are moving at times rapidly between disorganization and organization on a path of degenerative decline. In spite of this, their perspectives, experiences, and choices need to be considered in providing care for them.¹¹ The PWD's interactions with his/her environment need to be carefully considered, as they can produce both peace and coping or behavior problems and catastrophic reactions. Living well with a chronic illness can and should be the outcome of a beneficial interaction of these factors.

In more completely defining a PWD and the interactive role played by the caregiver, one must consider the course of the disease. ADRD is a chronic, degenerative, neurological disease that impairs a person's ability to care for self and to interact with the world. A PWD declines relatively slowly (average length of illness 8 to 10 years ranging up to 20 years).¹² Reisberg

developed the most well known Staging of the decline in ADRD, Functional Assessment Staging Tool -FAST (see table 1).¹³

TABLE 1

FAST GUIDELINES	
1. No Cognitive Decline: (Normal) AMMMSE: 29-30	No difficulties, either subjectively or objectively
2. Very Mild Cognitive Decline: (Normal) AMMMSE: 29	Complains of forgetting location of objects; subjective work difficulties.
3. Mild Cognitive Decline: AAMI (Age Associated Memory Impairment--incipient dementia) AMMMSE: 25 Estimated Duration: if dementia, 7 years	Decreased Job functioning evident to coworkers Difficulty traveling to new locations Decreased organizational capacity
4. Modern Cognitive Decline (Mild Dementia) AMMMSE: 20 (range 20-23) Estimated duration 2 years	Decreased ability to perform complex tasks (e.g., planning dinner for guests, handling finances, shopping) Developmental Age (DA): 8-12 years
5. Moderately Severe Cognitive Decline: (Moderately Severe Dementia)	Requires assistance in choosing proper clothing to wear for the day, season, or occasion (e.g., may wear same clothing repeatedly unless supervised) DA: 5-7 years
6. Severe Cognitive Decline (Moderately Severe Dementia) AMMSE: 5 (Range: 0-9)	6a. Improperly putting on clothes without assistance or cueing. DA: 2-4 years
	6b. Unable to bathe properly (difficulty adjusting bath water temperature) DA: 2-4 years
	6c. Unable to handle mechanics of toileting (i.e., forgets to flush, doesn't wipe properly or properly dispose of toilet tissue) DA: 2-4 years
	6d. Urinary incontinence DA: 1-2 years
	6e. Fecal incontinence DA: 1-2 years
7. Very Severe Cognitive Decline (Severe Dementia) AMMMSE: 0	7a. Ability to speak limited to approximately half- dozen intelligible different words or fewer in the course of the average day or an intensive interview. DA: 1-2 years
	7b. Speech ability limited to a single intelligible word in average day or an intensive interview (may repeat the word over and over) DA: 1 year
	7c. Ambulatory ability lost (cannot walk without personal assistance) DA: 6 months to 1 year

FAST GUIDELINES	
	7d. Cannot sit up without assistance (will fall over if no lateral rests [arms] on chair) DA: 6 mo. or less
	7e. Loss of ability to smile DA: 2 mo. Or less
	7f. Loss of ability to hold up head independently DA: 1 mo. Or less - fetal

*Note: AMMMSE stands for the Mini-Mental exam, a measure of cognitive function in ADRD. The scores range from 30 (full normal cognition) to 0 (virtually no cognitive function).

The ADRD decline can produce a reversal of the normal path of growth and development inversely from adulthood (Stage 1-No cognitive decline) back to infancy (Stage 7- Very severe cognitive decline). This reversal process is termed “retrogenesis.”¹⁴ Neural myelin sheath destruction in the brain during Alzheimer’s Disease appears to mirror acquisition in normal development. Stages of AD can now be matched to developmental ages (DA)s (see Table 1).¹⁵ The full range of decline is most likely to be seen in individuals without co-morbidities and whose lives are extended with nutritional support when they can no longer handle oral feedings. The staging theory is predictive, but the course of the disease is still quite individual within the model. The rate and course of symptom development and general decline are highly unpredictable.¹⁶ Stages do overlap and a PWD can have behaviors in several stages at once as well as occasional moments of clarity or lucidity. The powerful, confusing, and devastating effects of ADRD are evident when one examines the magnitude of potential losses that can occur over the life span of the PWD. ADRD caregiving must be seen within the context of this span of individual decline and the need, as well as the challenge of coping must be addressed.

Caregiving in Alzheimer's Disease and Related Disorders

Family caregiving is clearly a powerful and needed resource in the care of chronically ill persons. The defining factors of caregiving are more elusive in the literature than descriptions of its disruption and malfunction. Fawdry, in examining the collaborations that are possible

between nursing professionals and family caregivers in a holistic nursing model, sets the person, their health, and their environment as the core elements around which “caring” takes place.¹⁷

Bowers has defined a list of universal “Caregiving Acts” characterized by the purpose and meaning attributed to them by the caregiver rather than by the nature of the acts.¹⁸ This construct is helpful in the understanding of the role, activities, and difficulties of caregiving in ADRD (see table 2).

TABLE 2
Bowers Caregiving Acts (1987)

Anticipatory	Actions and behaviors based on anticipated possible needs of family members
Preventive	Actions that prevent illness, complications, and physical and mental deterioration
Supervisory	Active, direct involvement that includes arranging for, checking up, setting up, and checking out.
Instrumental	Traditional "hands-on" caregiving, for example, doing for, assisting, providing, and giving.
Protective	Actions and behaviors that protect older adults from threats to their own perceptions of competence and independence.

Anticipatory caregiving is based on anticipated possible needs of family members. In ADRD this dictates the need for disease knowledge in order to know what may be the next loss of functioning that may predict changes in care strategies (i.e. when will the PWD no longer be able dress independently, necessitating a change in the type of clothing used).

Preventative caregiving is based on preventing illness, complications, and physical and mental deterioration. Even though physical and mental decline is probable in ADRD, much can be done to preserve self-care behaviors for as long as possible. Each PWD declines at an

individual rate through the stages outlined in Table 1. Caregivers are constantly challenged to give assistance without completely denying independence. Obtaining appropriate and timely medical care is also a responsibility of the ADRD caregiver. This can be difficult at times when the PWD is unable to explain or describe symptoms as they develop. Nutrition and exercise that facilitates independence can also fall into this category.

Supervisory caregiving consists of active and direct involvement in over-seeing the health and care of the PWD. Frequently the ADRD caregiver performs these tasks in the home, but these activities can be done by non-local caregivers as well. Activities such as setting up and monitoring medications as well as monitoring dietary intake and arranging medical appointments fall into this category.

Instrumental caregiving is the traditional, “hands-on” care. This is certainly where ADRD care can become very involved. As seen in the Reisburg’s FAST model, a PWD requires increased supportive guidance and supervision at Stage 4 (Moderate Cognitive Decline), but as the decline moves into Stages 5 and 6, major “hands-on” care is required. At Stage 7 the PWD is basically constantly in need of total care and often requires institutionalization.¹⁹

Protective caregiving consists of actions that protect older adults from threats to their own perceptions of competence and independence and in ADRD protection from the real dangers as well. Fawdry speaks to the issue of utilizing strategies to protect the elderly from the inevitable loss of self-esteem resulting from directly confronting their functional mistakes and cognitive declines.²⁰ This is indeed an important issue, but the ADRD caregiver none the less has to also be a step ahead to utilize their anticipatory skills and planning to keep the PWD physically safe from him/herself and the environment. At some point, ADRD caregivers will most certainly be confronted with unsafe PWD behaviors such as forgetting to turn the stove off,

unsafe driving skills, and wandering away from the house. Preventative and protective measures become as important in the later stages of ADRD as they are in the life of a parent caring for a two year old, including safety and poison proofing the house. An added stress comes from performing all these tasks while maintaining the dignity and self-esteem of the PWD. In reviewing Bowers' construct of "Caregiving Acts", one can begin to comprehend the dimensions of ADRD caregiving and why supporting the caregivers with various interventions has become so important.²¹

Caregiving Approaches

Wurbel et al. have outlined a construct entitled "Tacit definitions of informal caregiving," which describes three caregiving approaches of : *Engagement, Conflict, and Distance*.²² This descriptive research was done with AIDS caregivers, but it lends insight into other caregiving situations and assists in creating a more complete picture of the challenges of caregiving.

Engagement takes place when caregiving takes priority in the life of the caregiver. The caregiver may have reduced employment in order to be more fully involved in care. The engaged caregiver views caring as nurturance and putting the care receiver first is a way of coping with negative emotions and fears. Though engaged caregivers may give to the point of exhaustion, they experience little burnout.

Conflict describes the state when caregiving is important, but must be weighted against the competing self-care concerns and needs. Caregiving is an obligation, which now has to compete with other obligations in their lives. These caregivers provide care on an "as-needed" basis, urging and supporting the self-care behaviors of the care-receiver. Crisis comes for these caregivers as care demands begin to escalate. They are less inclined to prepare for new care demands and may have the added stress of feeling helpless or ineffective. For these caregivers

inability to meet their own physical and psychological needs typically results in feelings of anger and frustration.

Distance caregiving involves another degree of separation and exhibits the need to keep the care-receiver in charge of his or her own care for as long as possible. In the AIDS community, caregivers had the perspective of supporting autonomy at all cost. These caregivers did not want to get to the stage of “hands-on” care. This pattern of caregiving is inherently frustrating because there are few developed coping skills for escalating care demands.

Variations of this model occur in the ADRD caregiving population. The above behaviors have been observed in ADRD caregivers as reflected in the numerous studies on the burden of care (see tables 3, 4, 5, & 6). *Engagement* is certainly a modality in the later stages of ADRD due to the ever-increasing demand for “hands on” care and in caregivers who find some depth of loving commitment that provides them some protection against burnout. *Conflicted* caregiving is ever-present in ADRD. Spousal caregivers who had difficult relationships before their spouse developed ADRD may feel obligated to provide care yet be angry and frustrated at having to provide too much care. *Distance* caregiving is more of a challenge in ADRD because autonomy is always threatened. The caregiver can hold distance as a value and with proper training and support it can be a positive perspective, but eventually s/he will have to perform more “hands-on” care or abdicate the role.

The dimensions of caregiving for the elderly, disabled, and chronically ill are broad, usually exceed normal daily responsibilities, and can develop into patterns that disrupt all aspects of a caregiver’s life.²³ Butcher, Holkup, and Buckwalter researched ADRD caregiving in the home and identified eight essential structural elements: immersion in caregiving; enduring stress and frustration; suffering losses; integrating the disease into their lives; gathering support; living

with continuous change; and finding joy and meaning.²⁴ A number of these aspects have been identified in the previously cited models: Immersion in caregiving, enduring stress and frustration, and integrating the disease into their lives.²⁵ Woods utilizes the person-centered approach to dementia to increase levels of consideration for the views of the PWD and not just of the caregiver.²⁶ This parallels the emphasis on autonomy found in Wurbel et al..²⁷ As one can imagine caregiver responses are as diverse as individual caregivers, but patterns do emerge and need to be researched.

The Crisis of Caregiver Burden

The responses of ADRD caregivers to their roles and activities have been heavily researched under the category “Burden of Care.” Obviously, with 80% of PWD being cared for in their homes, caregiver distress, stress, strain, and burden present a definite threat to the ability of PWDs to remain out of an institution. Tables 3, 4, 5, & 6 outline the top characteristics of Caregiver Burden divided into “stressors” as defined by Pearlin et al. in their “Alzheimer’s Caregivers’ Stress Model”.²⁸ Primary stressors are described as driving the process of stress or strain and stem directly from the needs of the PWD. Secondary stressors are the problems and hardships that are produced by the Primary chronic stressors. Stressors can be divided into objective (problems that create burden) and subjective (caregiver responses that create burden) categories as well. The following diverse lists of stressors are derived from the large body of literature on Caregiver Burden. They are listed in a table form to show the wide range of characteristics and activities that various authors consider important and have concentrated their research on, as well as the qualitative and quantitative dimensions of caregiver stress, strain and burden in ADRD.

Caregiver Stressors

Primary Objective Stressors

Table 3 encompasses the ADRD stressors that fit the Primary/ Objective category. They stem from the cognitive declines, behavior problems, and activities that the PWD depends on the caregiver to provide.

TABLE 3.

PRIMARY STRESSORS -- OBJECTIVE	
Behavior problems with the PWD, which cause frustration and embarrassment	Acton & Wright, 2000; Almborg, Grafstom, & Winbald, 1997; Asada, Kinoshita, & Kakuma, 2000; Bolger, Carpenter, & Strauss, 1994; Burgio et al., 2001; Burns, 2000; Chou, LaMontague, & Hepworth, 1999; Clark, 2002; Clyburn, Stones, Hadjistavropoulous, & Tuokko, 2000; Croog, Sudilovsky, Burleson, & Baume, 2001; Gaugler, Davey, Pearlin, & Zarit, 2000; Gonzales-Salvador, Arango, Lyketsos, & Barba, 1999; Gwyther, 1998; Haley, 1997; Jann & Brandt, 2000; Kramer, 1997; Levesque, Ducharme, & Lachance, 1999; Perodeau, Lauzon, Levesque, & Lachance, 2001; Pot, Deeg, van Dyck, & Jonker; Robinson, Adkisson, & Weinrich, 2001; Schneider, Murray, Banerjee, & Mann, 1999; Woods, 2001; Stewart, 1995;
Seeing PWDs lose cognitive and self-care abilities (activities of daily living-ADL's and instrumental activities of daily living-IADL's)	Acton & Wright, 2000; Almborg, Gaugler, Davey, Pearlin, & Zarit, 2000; Clyburn, Stones, Hadjistavropoulous, & Tuokko, 2000; Grafstom, & Winbald, 1997; Burns, 2000; Chou, LaMontague, & Hepworth, 1999; Gonzales-Salvador, Arango, Lyketsos, & Barba, 1999; Levesque, Ducharme, & Lachance, 1999; Pearlin, Mullan, Semple, & Skaff, 1990; Thommessen, Aarsland, Braekhus, Oksengaard, Engedal, & laake, 2002;

PRIMARY STRESSORS -- OBJECTIVE	
Memory loss and inability to communicate	Almberg, Grafstom, & Winbald, 1997; Clark, 2002; Hendryx- Bedalov, 2000; Kramer, 1997; Levesque, Ducharme, & Lachance, 1999;
Gradual deterioration until the PWD no longer recognizes people closest to him/her	Almberg, Grafstom, & Winbald, 1997; Gwyther, 1998;
Emotional liability	Croog, Sudilovsky, Burleson, & Baume, 2001;
Destructive behavior (esp. with younger caregivers)	Croog, Sudilovsky, Burleson, & Baume, 2001;
Seeing PWD lose personality (loss of self)	Burns, 2000; Gwyther, 1998; Haley, 1997
Unpredictability of the course of the disease	Gwyther, 1998; Haley, 1997
Lack of consistent environment- moving PWD between homes	Gwyther, 1998;

In examining Table 3, one can see that the leading Primary/Objective stressor is “Behavior problems in the PWD”. There are of course numerous subsets of this stressor but some of the top ones are: agitation, hyperactivity, and depression²⁹; aggressive behavior, sleeplessness, and verbal or behavioral repetition³⁰; excessive night-time activity, immobility or difficulty walking, and incontinence.³¹ Behavioral disturbance in general, is a predictor of institutionalization within two years after a baseline assessment.³² Loss of cognitive and self-care abilities are a major predictor of increasing dependency and “hands-on” care, which can lead to overload and burnout. The magnitude of the workload is by itself not a completely potent stressor; but in combination with resistance from the PWD and a number of other stressors, the potency rises considerably.³³

Primary Subjective Stressors

Table 4 describes Primary ADRD stressors of the subjective type. This category in the “Alzheimer’s Caregivers’ Stress Model” covers overload and relational deprivation.

Table 4.

PRIMARY STRESSORS -- SUBJECTIVE	
Physical stress, i.e. fatigue and poor health	Gwyther, 1998; Hepburn, Tornatore, Center, & Oswald, 2001; Miltiades, & Pruchno, 2002 (study done in African American population); Schofield et al. 1999; Vitaliano, Russo, Young, Becker, & Maiuro, 1991;
Attending to physical needs of PWD (“ hands-on tasks”)-overload	Burns, 2000; Chou, LaMontague, & Hepworth, 1999; Burgio et al., 2001; Gaugler, Davey, Pearlin, & Zarit, 2000; Kleffel, 1998; Levesque, Ducharme, & Lachance, 1999; Mafullul & Moriss, 2000; Newman, 1997; Schofield et al. 1999; Yamamoto et al., 2001
Witnessing decline, suffering, and death	Furlini, 2001; Haley, 1997; Lindgren, Connelly, & Gaspar, 1999
Disturbances of sleep	Thommessen, Aarsland, Braekhus, Oksengaard, Engedal, & Laake, 2002
Relationship imbalance, the reciprocities and give and take that had existed fades into the past	Pearlin, Mullan, Semple, & Skaff, 1990;
Constant vigilance	Burgio et al., 2001; Haley, 1997
Attitude toward the PWD- are the symptoms illness related or deliberate	Donaldson, & Burns, 1999
“Chasing ghosts” –clinging to perceptions of the person the PWD once was	Gwyther, 1998;

Overload and physical stress were highly supported as problems in the literature.

Embarrassment, witnessing the decline of the PWD, and constant vigilance were qualitative aspects that certainly enhance Primary Stressors, but this is a fairly short list. Primary stressors produce the myriad of secondary factors, which give quantification to the amount and combinations of stressors that can occur to create caregiver burnout. These secondary stressors are not less potent.

Secondary Stressors: Caregiver Role Strain

The Secondary Stressors listed in Table 5 that cover Role Strain: include family conflict, job-caregiving conflict, economic problems, and constriction of social life.

Table 5.

SECONDARY STRESSORS -- ROLE STRAIN	
Being single, widowed, or divorced females, older spouses, children, younger, members of low income or minority group, and living in rural area	Gwyther, 1998; Haley, 1997; Keefover et al., 1996; Mafullul & Moriss, 2000; Newman, 1997; Schneider, Murray, Banerjee, & Mann, 1999; Thommessen, Aarsland, Braekhus, Oksengaard, Engedal, & Laake, 2002
Being immersed in caregiving (involvement)	Acton & Wright, 2000; Butcher, Holkup, & Buckwalter, 2001; Chang, 1999; Chou, LaMontague, & Hepworth, 1999; Newman, 1997; Pearlin, Mullan, Semple, & Skaff, 1990;
Isolation	Acton & Wright, 2000; Burns, 2000; Gwyther, 1998; Hepburn, Tornatore, Center, & Oswald, 2001; Kleffel, 1998; Newman, 1997; Pearlin, Mullan, Semple, & Skaff, 1990; Schofield et al. 1999; Yamamoto et al., 2001
Suffering through loss a. Loss of control b. Grief	Almberg, Grafstom, & Winbald, 1997; Butcher, Holkup, & Buckwalter, 2001; Furlini, 2001; Gwyther, 1998; Lindgren, Connelly, & Gaspar, 1999; Loos & Bowd, 1997;
Dealing with continuous change and disruption	Butcher, Holkup, & Buckwalter, 2001; Karlin, Bell, & Noah, 2001; Thommessen, Aarsland, Braekhus, Oksengaard, Engedal, & Laake, 2002
Few resources, esp. financial strain	Douglass, 1999; Haley, 1997; Hepburn, Tornatore, Center, & Oswald, 2001; Schneider, Murray, Banerjee, & Mann, 1999;
Problems with other family members-lack of understanding and support	Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Gwyther, 1998; Newman, 1997; Wuest, Erickson, & Stern, 2001;
Caregiving: a job with no salary, no benefits, sick days, or vacation	Gwyther, 1998; Thommessen, Aarsland, Braekhus, Oksengaard, Engedal, & Laake, 2002
Time	Chou, LaMontague, & Hepworth, 1999; Douglass, 1999;

SECONDARY STRESSORS -- ROLE STRAIN	
Planning, organizing, monitoring, and supervising care	Chou, LaMontague, & Hepworth, 1999; Newman, 1997;
Employment –caregiving conflicts and uncertainties	Newman, 1997; Pearlin, Mullan, Semple, & Skaff, 1990;
Enduring stress and frustration	Butcher, Holkup, & Buckwalter, 2001;
Role exhaustion	Yamamoto et al., 2001
Integrating ADRD into family life and preserving integrity	Butcher, Holkup, & Buckwalter, 2001;
Having to find support	Butcher, Holkup, & Buckwalter, 2001;
Caring for an early onset PWD	Freyne, Kidd, Coen, & Lawlor, 1999;
Perception that formal or informal support was not helpful/ inability to ask for what one wants	Wuest, Erickson, & Stern, 2001;
Having to purchase help and determining the cost	Gwyther, 1998;
Additional demands of other caring obligations in and outside the home	Douglass, 1999; Haley, 1997
Filial obligation	Douglass, 1999;
Inability to obtain accurate medical information	Douglass, 1999;
General disruption in caregivers life	Newman, 1997;
Caregiving is an assigned role	Newman, 1997;

Immersion, suffering, and isolation generated the most concern among the articles researched. An aggregate category was created to contain the following vulnerabilities: being single, widowed, or divorced females, older spouses, children, younger caregivers, members of low income and minority groups, and living in rural areas. These vulnerabilities are related to increased isolation, less informal support, less income, and higher susceptibility to strain/stress. The summary comment made by Gwyther and supported by Thommessen et al. describes in a mildly humorous way the dilemma of caregiving: a job with no salary, no benefits, sick days, or vacation.³⁴ No one would answer a want add for it, but thousands of people perform the job year after year -Intrapsychic Strain

The last category of stressors is contained in Table 6 – Intrapsychic strains encompassing threats to one’s self-concept: self-esteem, mastery, loss of self, and competence.

Secondary stressors: Intrapsychic Strain

Table 6

SECONDARY STRESSORS – INTRAPSYCHIC STRAIN	
Emotion focused coping	Almberg, Grafstom, & Winbald, 1997; Buckwalter et al., 1999; Chou, LaMontague, & Hepworth, 1999; Hepburn, Tornatore, Center, & Oswald, 2001; Hooker, Frazier, & Monahan, 1994; Kramer, 1997; Lazarus & Folkman, 1984; Perodeau, Lauzon, Levesque, & Lachance, 2001
Negative emotions: anger, fear, guilt, insecurity, hopelessness, anxiety, worry, and depression	Almberg, Grafstom, & Winbald, 1997; Woods, 2001; Gwyther, 1998; Acton & Wright, 2000; Haley, 1997; Levesque, Ducharme, & Lachance, 1999; Vitaliano, Russo, Young, Becker, & Maiuro, 1991;
Diminution or Loss of self	Loos & Bowd, 1997; Pearlin, Mullan, Semple, & Skaff, 1990
Caregiver's reactions to problem behaviors	Robinson, Adkisson, & Weinrich, 2001;
Anxious/ambivalence and neuroticism	Markiewicz, Reis, & Gold, 1997
Amount of caregiver's perceived pressure	Pot, Deeg, van Dyck, & Jonker;
Living with ambiguity	Kaplan, & Boss, 1999
Caregiving is unexpected interruption to pervious life plans	Acton & Wright, 2000
Caregiver avoidance in discussing issues of concern	Edwards & Forster, 1999
Learned helplessness	Anderson, 1999
Family/caregiver expectations and subjective perceptions	Gwyther, 1998;
Weakening of or negative changes in caregiver self-concept	Haley, 1997

Although time is an individual factor, self-concept is vulnerable to breakdown under conditions of enduring hardship. This leaves people vulnerable to depression and other negative outcomes. Negative emotions (including depression) is a large item in this category. The other emphasized item was emotion- focused coping. This coping strategy was defined by Lazarus

and Folkman and referenced by numerous other authors.³⁵ Emotion-focused coping is a style utilizing combinations of the following: escape mentation, avoidance of problems, and detachment from situations³⁶, wishful thinking, stoicism, grieving, worrying, and self-accusation³⁷, and passive- avoidance.³⁸ One emotion-focused strategy listed by all the above authors was actually beneficial – acceptance. All the others were seen to contribute greatly to Caregiver Burden. All these stressors listed in Tables 3 to 5 are antecedents to a state of Caregiver Burden and possible burnout.

The Outcomes of Caregiver Burden

Pearlin et al. finish their stress model with a list of outcomes: depression, anxiety, irascibility, cognitive disturbance, problems with physical health, and eventual yielding of the caregiving role.³⁹ Haley notes some of the effects of chronic caregiving on physical health: impaired immune system function, elevated blood pressure, altered plasma lipid levels, poor self-care (lack of exercise and sleep), and relatively high use of psychotropic drugs.⁴⁰ Depression was referenced in much of the literature as the most prevalent psychoactive outcome of stressed caregiving.⁴¹ Small et al. cited that nearly half of all caregivers of PWD become depressed and the fact that psychotherapeutic intervention is often indicated.⁴² The largest non-caregiver outcome of excessive stress and “Burden” is the eventual institutionalization of the PWD. If one considers that the home environment is usually the most comfortable and beneficial for the PWD, then this can be a dear price to pay for runaway stress that could be mitigated and prevented.

Mitigating or Protective Factors against Caregiver Burden:

Vitaliano et al. developed an explanatory model, which has structural validity in examining the process of accumulating “Burden” from caregiving.⁴³ The model states that:

$$\text{Psychological distress} = \frac{\text{exposure to stressors} + \text{vulnerability}}{\text{Psychological and social resources}}$$

Vulnerability factors are less controllable influences on the caregiver that place him or her at risk. The Pearlin et al. model places these vulnerability factors as “the background or contexts of the stress process.”⁴⁴ One example of vulnerability is that of being a female caregiver. Women are more susceptible to “Burden” and poor health outcomes.⁴⁵ Both models assign value to mitigating or protective factors sourcing from psychological and social resources, which can balance or cancel out some of the potency of Caregiver Burden. Table 7 is a compilation of these factors from the literature surveyed.

TABLE 7

Protective Factors	
Caregiver involvement	Chang, 1999; Levesque, Ducharme, & Lachance, 1999;
Personal and job satisfaction	Alexander & Klein, 2001
Reliable expert primary medical care	Gwyther, 1998; Haley, 1997
Recognition of family efforts and skills	Gwyther, 1998;
Finding support (interpersonal connectedness)	Acton & Wright, 2000; Butcher, Holkup, & Buckwalter, 2001;
Respite or Sabbatical from duties	Douglass, 1999; Gwyther, 1998;
Being part of a family(i.e. multigenerational) and having their support	Gwyther, 1998; Newman, 1997;
Filial obligation- freely chosen role	Chou, LaMontague, & Hepworth, 1999; Douglass, 1999; Newman, 1997; Shaw et al., 1997 (Chou and Shaw studies done with a Chinese population)
Flexibility of expectations	Gwyther, 1998;
Reduction in perceived pressure	Pot, Deeg, van Dyck, & Jonker;
Adaptability	Smerglia & Deimling, 1997

Protective Factors	
Problem focused coping	Almberg, Grafstom, & Winbald, 1997; Buckwalter et al., 1999; Chou, LaMontague, & Hepworth, 1999; Hepburn, Tornatore, Center, & Oswald, 2001; Hooker, Frazier, & Monahan, 1994; Kramer, 1997; Lazarus & Folkman, 1984; Perodeau, Lauzon, Levesque, & Lachance, 2001
Self-control skills	Intrieri & Rapp, 1994
Letting go of beliefs that are unrealistic about ADRD and the caregiving role	Hepburn, Tornatore, Center, & Oswald, 2001
Resourcefulness	Gonzalez, 1997; (study done with African American population)
Hardiness- high level of commitment to one's life, a sense of control, and a perception of change as a positive challenge	Clark, 2002;
High cognitive empathy	Lee, Brennan, & Daly, 2001
Religious coping	Miltiades, & Pruchno, 2002 (study done in African American population)
Movement from self-absorption toward an expanded view of life	Acton & Wright, 2000;
Spiritual emergence in response to bitterness, anger and resentment	Acton & Wright, 2000
Peace and contentment in the midst of a difficult life experience.	Acton & Wright, 2000
Ability to integrate the past and present into hope for the future	Acton & Wright, 2000
Strength from a higher power (transpersonal connectedness)	Acton & Wright, 2000
To make supportive connections to create Strength to look within themselves and realize inner strengths and attributes, to find choices and options, and to make decisions (intrapersonal connectedness)	Acton & Wright, 2000
Moving beyond the tasks of caregiving, describing meaning and purpose in their lives with hope for a positive future (transcendence)	Acton & Wright, 2000; Pearlin, Mullan, Semple, & Skaff, 1990;
Self-transcendent views and behaviors which could lead to increased perceived health, purpose in life, self-worth, well-being, self-healing, acceptances, and positive growth and development	Acton & Wright, 2000
Involvement in roles outside of caregiving, which bolster self-esteem	Haley, 1997;

Protective Factors	
Finding meaning and joy	Butcher, Holkup, & Buckwalter, 2001;
Successfully undertaking a valued responsibility and coping with personal challenge (self-efficacy)	Chou, LaMontague, & Hepworth, 1999; Newman, 1997;

This Table is constructed to move from more external to internal resources. Two factors are on both the stressor list and protective factor list: caregiver involvement and filial obligation. Involvement can lead to Caregiver Burden or it can be a source of meaning and commitment depending on the caregiver's attitudes and levels of internal resources. Filial obligation also fits this paradigm. A family member can choose to stay in the caregiving relationship because of loyalty and obligation. This action can create purpose in the role and create increased tolerance for stressors. On the flip side, if the caregiver is pressed into service because of filial obligation, the relationship can develop into a burden. Shaw et al. found in a comparative study of family caregivers in Shanghai, China, and San Diego, California that although coping strategies were similar, cultural ideas promoting acceptance of family roles, interdependence, and veneration of elderly family members reduced some of the psychological distress (esp. anxiety and depression) in the Chinese caregivers.⁴⁶

If the caregiver has flexibility in his/her expectations of the role, there can be a reduction in perceived pressure accompanied by a letting go of beliefs that are unrealistic about ADRD and the caregiving role. Another personal factor, hardiness is defined as a commitment to life, looking at challenge as change, and perceiving control over one's life.⁴⁷ A person with high hardiness may appraise events as being less stressful. Resourcefulness is another intrapersonal protective factor. Interestingly, Gonzalez found that African American caregivers had higher scores in resourcefulness than Anglo-American caregivers, with no difference in coping skills.⁴⁸ Janevic & Connell performed a cross cultural (African Americans, Chinese, Chinese Americans,

Koreans, Korean Americans, Latinos, whites, and residents of 14 European Union countries) analysis of previous research on aspects of dementia caregiving.⁴⁹ Their results showed that White caregivers were more likely to be spouses, tended to report greater depression, and characterized caregiving as more stressful than African Americans. Minority groups were not found to have substantially more available support than Whites. Knight et al. found lower levels of appraisal of caregiving as burdensome in African American caregivers, but the effect was counterbalanced by a tendency to use emotion-focused coping (see discussion of table 6), which can increase distress.⁵⁰

Another part of a flexible view is adaptability and problem-focused coping. In the discussion of Table 6, emotion-focused coping was discussed as leading to increased stress. Problem-focused coping is the other side of this paradigm leading to less Caregiver Burden.⁵¹ Problem-focused strategies are comprised of confronting the problem, and seeking information and social support⁵² as well as planning care with the PWD's strengths and losses in mind and anticipating problematic changes.⁵³ As mentioned previously, the only emotion-focused coping strategy that had protective value was acceptance. When one accepts, after careful analysis that the situation cannot be changed it can be a very effective strategy, influencing the experience of physical and emotional exhaustion.⁵⁴ Acceptance and problem-solving coping can be an effective combination of caregiving strategies.

Spirituality and Religious Coping in Caregivers

Spirituality and religious coping are another important group of protective factors. Miliades & Prucho explored the relationship between race and religious coping.⁵⁵ They found that black women were more likely to use religious coping and experience higher levels of caregiving satisfaction. Similarly to the balancing effects cited in Knight et al., Miliades &

Prucho found that Blacks experienced higher levels of Caregiver Burden due to poor health.⁵⁶ In spite of these balancing issues, the potency of the protective factors of spiritual engagement and religious coping should not be underestimated, especially when perceptions and attitudes can play such a pivotal role in mitigating stress.

Acton & Wright have explored the realm of self-transcendence with caregivers of PWD's.⁵⁷ The aspects they have identified are outlined briefly in toward the end of table 7. In this construct, self-transcendence is defined as an out growth of the human developmental process, which produces the movement beyond personal needs to a sense of unity with others. Fahlberg, Wolfer, & Fahlberg postulate that self-transcendence can be a result of spiritual emergence, when an individual faces loss, fear, confusion, and grief from attempting to give up the current self-concept in favor of an expanded sense of self.⁵⁸ This embodies the movement from a self-identity to a transpersonal identity. Life crises like those found in long-term caregiving can provide the impetus to move from the limitations of self-involvement to the broader perspectives of caring for others. Acton & Wright also cite two aspects of self-transcendence: intrapersonal and interpersonal.⁵⁹ The intrapersonal is the deeper connection with the self that leads to awareness of personal strengths and limitations and eventually feelings of contentment. The interpersonal is a sense of connectedness with others, including a higher power, nature, or the universe. This sense of something greater than one self can produce feelings of being uplifted and being released from burden. Self-transcendence is a special natural resource that can be used to cope with stressful caregiving events. Healing and transcendence can be discovered within the caregiving experience. Through integrating the past and present, a new reality can emerge that contains hope for the future and ultimately the attainment of transcendence.

Spirituality and Religious Coping in PWD's

The possible effects of the transcendent state are not solely limited to the caregiver. ADRD does produce altered states of consciousness and these states are not likely to be merely passive periods of confused brain function, but possibly periods of some receptivity and perception.⁶⁰ Could spiritual activity or growth be taking place? Carolyn Myss has postulated that:

In some of the cases of these types of disorders, the individual withdraws his or her normal consciousness in order to have access to processes of spiritual development that we as yet know nothing about. And thus, we only can assume that the state of consciousness the person is in is dysfunctional and seemingly without 'purpose' as we understand purpose.⁶¹

Currently, Dr. Elmer Green has done the most groundbreaking exploration of the possibilities of transpersonal spiritual consciousness in ADRD. In his 3-volume work entitled The Ozawkie Book of the Dead, he discusses his experiences caring for his wife who had ADRD.⁶² He chronicled his observations of her behaviors and her states of mind. His conclusion is that AD is a *Bardo* state.

The most familiar state of the *Bardo* is the *after death* realm but that is only one aspect of this Tibetan construct. In Tibetan, *Bardo* simply means transition or gap between one situation and another. "'Bar' means 'in between' and 'do' means 'suspended' or 'thrown.'"⁶³ There are four defined *Bardos*:

- ◆ The "natural" bardo of this life: ...spans the entire period between birth and death...time to prepare for death: by becoming familiar with the teaching and stabilizing the practice.
- ◆ The "painful" bardo of dying: ...from the process of dying right up until ...the "inner respiration"- this in turn culminates in the dawning of the nature of mind, what we call the "Ground Luminosity."
- ◆ The luminous bardo of dharmata: ...encompasses the after-death experience of the radiance of the nature of mind, the luminosity or "Clear Light."
- ◆ The "karmic" bardo of becoming ...intermediate state, which lasts right up until the moment we take on a new birth.⁶⁴

Within this spiritual construct one can recognize the “in between” nature of the Alzheimer’s state. We recognize that death will come, but a person with AD may spend years “suspended” in a physical and cognitively regressive state. AD has been referred to as a “living death” or an “ongoing funeral.”⁶⁵

Dr Green (2001) describes AD consciousness as wavering in and out between “ the physical –astral world of the personality and the more-subtle astral world of the soul.”⁶⁶ This astral body has telepathic and intuitive senses that the physical body lacks. Inherent in this contact with spiritual senses is a potential to “become aware of the LIGHT of their own SOUL, and merge with it.”⁶⁷ Dr. Green believes that we can potentiate the spiritual progress of a person with AD by:

Facilitating their ‘waking up’ in the next world before they vacate the physical body, and then they can intentionally make an effort to shift from the bardo state of consciousness to SOUL consciousness, thereby hastening their graduation from Earth school.⁶⁸

A person with AD has some advantage over those who are imminently dying because they have a long slow path, with time to become conscious of the “Light of the Soul” or the “higher self “ and possibly merge the “mortal self” with it. Obviously this is not an easy path for a person to take, there must be some facilitation. Dr. Green’s very personal exploration is based on this idea. He worked closely with his wife over the time she was consumed with her disease and acted as her guide and support. He read aloud to her during her *living bardo* in much the same way the Tibetan’s read to the dead to guide them through the *after death Bardo*. What this produced was, in Dr. Green’s terms, “psychokinesis” in which his wife Alyce was able to come out of an inarticulate state and speak with perfect diction and syntax “without mediation of the brain and nervous system.”⁶⁹ Alyce’s ability to speak seemed to be beyond her brain capacity

and the infant-like cognitive level she had regressed to. Although this could be considered a “moment of lucidity”, this state is very rare at the infantile regressive level.

In Buddhist terms, Dr. Green’s dedicated caregiving of his wife during the course of her illness falls under directed compassion for self and others or *Bodhicitta*.⁷⁰ Rinpoche poetically calls this state of compassion the “wish-fulfilling jewel.”⁷¹ and Chodron calls it a “tender place.”⁷² Caregiving for a person with ADRD is truly about compassion and with the contributions of Dr. Green, can be seen as a spiritual undertaking as well. To act as a spiritual guide and a caregiver over the long years of illness is a difficult and dedicated process. Whether or not other caregivers who attempt to guide persons with ADRD through a similar process, will be able to reproduce (in some undoubtedly personal way) Dr. Green’s spiritual results is a question for future experimentation. The door has been opened to a new view AD consciousness. In this light, caregiving may also be seen in a new way as a transcendent selfless act, which can bring a special dignity to both the person with the disease and their caregiver.

Overview of Caregiver Education:

Heightened awareness of the positive and negative experiences of caregivers is vital to the community of professional and volunteer caregivers, who wish to provide care that will make a difference in the quality of life of the caring dyad (ADRD caregiver and PWD). Numerous educational interventions have been designed to educate the caregiver about ADRD, their roles, and coping strategies. All these studies have had the overarching goal of decreasing caregiver “Burden.”

Components of Caregiver Education

Table 8 outlines the top components of caregiver education found in this literature review.

TABLE 8

COMPONENTS OF CAREGIVER EDUCATION	
Improving knowledge of ADRD	Burgener, Bakas, Burns, 2000; Burgio et al. , 2001; Doody et al., 2001; Gonzalez-Salvador, Arango, Lyketos, & Barba, 1999; Graham, Ballard, & Sham, 1997; Hepburn, Tornatore, Center, & Oswald, 2001; Morano & Bravo, 2002; Murray, Dunahee, & Tossey, 1998; Stewart, 1995; Sullivan & O’Conor, 2001; Toseland et al., 2001; Werner, 2001
Managing patient problems/disturbing behaviors such as agitation and depression	Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Burgener, Bakas, Murray, Dunahee, & Tossey, 1998; Grants, 1999; Ham, 1999; Logsdon, McCurry, Moore, & Teri, 1997; Robinson, Adkisson, & Weinrich, 2001; Robinson & Yates, 1994; Talerico & Evans, 2001
Problem-solving skills	Chang, 1999; Chou, La Montague, & Hepworth, 1999; Cooke, McNally, Mulligan, Harrison, & Newman, 2001; Corbeil, Quaygen, & Quaygen, 1999; Doody et al., 2001; Gitlin et al., 2002; Grants, 1999; Houts, Nezu, Nezu, & Bucher, 1996; McKee et al., 1997; Toseland et al., 2001;
Coping with the demands of caregiving	Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Gonzalez-Salvador, Arango, Lyketos, & Barba, 1999; Logsdon, McCurry, Moore, & Teri, 1997; Morano & Bravo, 2002;
Cognitive stimulation for PWD	Greenwood, Loewenthal, & Rose, 2001; Quaygen et al., 2000; Quaygen, & Quaygen, Corbeil, Roth, & Rodgers, 1995.
Managing behaviors with the PLST model (Progressively Lowered Stress Threshold)	Buckwalter et al. 1999; Hall et al., 1995;
Behavior modification for PWD	Chang, 1999; Doody et al., 2001; Gugel, 1994;

COMPONENTS OF CAREGIVER EDUCATION	
Functional independence	Doody et al., 2001;
Role coaching	Hepburn, Tornatore, Center, & Oswald, 2001;
Work of caregiving- skills, & beliefs	Hepburn, Tornatore, Center, & Oswald, 2001;
Person centered approach	Gwyther, 1997; Woods, 2001;
Understanding communication decline	Hendryx-Bedalov, 2000; Toseland et al., 2001;
Effective communication with health care providers	Toseland et al., 2001;

The value of many of the components is self-explanatory, but there are a few that should be explained. Cognitive stimulation for the PWD has been shown to have some benefits in alleviating mood and behavior problems⁷³ and in reducing caregiver depression.⁷⁴ Cognitive stimulation was found by Snowden to have a general protective factor in the development of ADRD.⁷⁵ This has generated even more interest in Cognitive stimulation as a strategy to manage behaviors.

Managing behaviors utilizing the PLST (Progressively Lowered Stress Threshold) model was posited as an intervention by Buckwalter et al. and Hall et al.⁷⁶ This model suggests that reducing or modifying environmental demands to meet the cognitive skill levels of the PWD promotes functional behavior and decreases anxiety, agitation, and catastrophic reactions. This model may not be widely distributed, but the concept of environmental adaptation has a great deal of validity for incorporation in broader educational models.

Another educational component that was marginally mentioned but also has potential for broader inclusion is the person-centered approach. This concept has emerged from a new, growing emphasis on the experience of the PWD. The PWD is seen as trying to manage and cope with the disease. Many of the difficult behaviors seen in ADRD may be better understood with an appreciation of their emotional underpinning (feelings of fear, insecurity, anger, and

hopelessness).⁷⁷ This highly empathetic perspective can enhance the quality of life for the PWD and the caregiver.⁷⁸

Educational Models:

A number of studies contained analysis of educational interventions for ADRD caregivers. Table 9 describes these various programs and their outcomes.

TABLE 9.

PROGRAM	TYPE	OUTCOME	AUTHORS
PTSL (Progressively Lower Stress Threshold) (n=80) control and treatment	Community based-services provided in the clinic and home 2 weeks training 6 months of bi-weekly phone calls	Decreased depression (geriatric depression rating scale)	Buckwalter et al., 1999
Health Education Group (HEP) (n=58) (n=47) control	Classroom education at HMO site 8 weekly 2 hr sessions	Decreased depression in caregivers Did not reduce caregiver burden, role strain, or the physical and emotional demands of caregiving	Toseland et al., 2001
Psycho-educational Model for Hispanic Alzheimer's Disease Caregivers (n=20) No control	Classroom education at community site 5 days/ 20 hrs	Improvement in scores on Caregiver Knowledge Survey	Murano and Bravo, 2002
Dementia Family Caregiver Training (n=94) divided between treatment and controls	Classroom education at community site 7 weekly 2 hr sessions =14 hrs	Improvements in burden and decrease in depression	Hepburn, Tornatore, Center, & Oswald, 2001
Cognitive- Behavioral Intervention for homebound caregivers of PWD's (n=31) treatment (n= 34) placebo telephone calls	Nurse contacts (one home visit and then phone calls) and video instruction	Decrease in depression and anxiety. No decrease in burden	Chang, 1999

PROGRAM	TYPE	OUTCOME	AUTHORS
Caregiver Training Programs (CPT's) (n= 33) treatment and controls	Two types of programs were created- behavior management and social skills- 6 sessions	Decrease in objective burden and a more positive attitude toward seeking help	Robinson & Yates, 1994

Most of the programs were classroom models requiring a fair amount of hours of attendance (2 to 8 weeks). All programs had some benefit for the caregiver. Of the 4 that measured Caregiver Burden, only 2 were able to decrease it. Depression appears to be the factor most susceptible to positive change. Cooke et al. reviewed 40 studies looking at the efficacy of psycho-educational interventions.⁷⁹ They found that approximately two-thirds did not show any improvement in outcomes. The studies that did demonstrate improvements included providing social support and problem solving education.

Popular Literature on Alzheimer's Disease and related Dementia's:

There are numerous books available in the popular literature. A current search (August, 2002) of "Books in Print" yielded 650 titles available. At any one time, most bookstores carry 5 to 10 ADRD titles on the shelf. In a random sample of 200 of the current books available from an on line bookseller, content matter and percents of books in a content category were found to be the following:

- ◆ Personal experiences 28%
- ◆ Clinical treatment, diagnosis, and research 27%
- ◆ General information 15%
- ◆ Manuals for handling patient behaviors 14%

- ◆ Coping suggestions for caregivers 5%
- ◆ Communication 3%
- ◆ Activities for the PWD 2%
- ◆ Changes for the home environment 2%
- ◆ Religion and ethics, 2%
- ◆ Prevention ideas, 2%.

A number of these popular books especially in the categories of Clinical treatment, diagnosis, and research; and General information are written to professional standards with reading levels well above the popular educative reading standard of 4th to 5th grade. These books are excellent for practitioners but are a problem for the average stressed caregiver who is often looking for behavioral problem solving ideas or for resources. The books on personal experiences are entertaining, often comforting, but only lightly educational. The books on coping strategies for caregivers posit many ideas for decreasing stress but offer little on handling day to day problems. The manuals for Handling behavioral problems are the most valuable for daily management, but on content analysis many of these had as little as 20 % of their text concerned with actual problem solving strategies. These strategies are often imbedded in various chapters creating the need for a time consuming search to identify useful ideas. A number of books were found to have lower reading levels, more accessible content, and larger print (fewer words on the page improves accessibility).

In ADRD there is an ongoing need to solve problems prompted by the decline of the person with Dementia. Behavior management is an ever-changing reality. Caregivers do not find themselves with much time for relaxation or education. Reading highly dense books is not easy, restful, or practical. Manuals need to be created to meet the actual needs of the ADRD

caregivers for accessible content, ease of reading, as well as holistic content and problem solving ideas that can stimulate creativity.

Holistic Health Education in a Self-help workbook:

None of the articles reviewed had any formal designs for educational interventions, which would be oriented toward encouraging utilization of internal spiritual resources in ADRD caregiving. A number of articles did promote spirituality as a protective factor against Caregiver Burden and depression. Caregiver education programs, which included knowledge of ADRD, managing behavior problems, problem-solving, coping skills, and encouragement for seeking social support are supported by the literature.

Caregiver access to classroom training has been a problem. It is often difficult to find respite care for the PWD while the caregiver is in class. Isolation is a problem in general with ADRD caregivers. The caregiver and PWD may live in a rural area with little or no access to educational programs.⁸⁰ Ham cites the benefits of improving caregiver skills but notes that their availability is variable.⁸¹

Self-care models in ADRD have rarely been studied. Lazes, Kaplan, & Gordon state that “the individual and family have always been the primary unit of health when it comes to health promotion, prevention, care for minor illnesses and injuries, daily care for chronic conditions, and efforts to restore health.”⁸² In general, Self-care education emphasizes practical skills for real-life situations, personal empowerment, critical analysis of medical alternatives, and more authentic and caring interactions with health professionals. Patients and caregivers who choose an active, self-care, problem-solving approach can have an increased sense of self-esteem, control, and improved attitude to help them cope with chronic illness and the caregiving role.

Chang created an intervention for homebound caregivers that included video taped information on managing problem behaviors and modeling of positive roles.⁸³ The study was able to effect depression but not Caregiver Burden. The main weakness cited was that the educational videotapes were not evaluated alone to determine efficacy. Graham, Ballard, & Sham discuss the need for more evaluation of the effectiveness of educational materials as well as full classroom interventions.⁸⁴

Page & Hagenbach in their “ Mind Body Spirit Workbook” speak of the concept underlying the workbook format, that the realizations and skills that have “the greatest power to transform peoples lives are those they reach for themselves.”⁸⁵ The workbook devised for this intervention is a holistic, self-educative one with easily accessible, practical problem solving strategies combined with an emphasis on the spiritual nature of caregiving as well as providing quality of life and spirituality for the PWD. It is hoped that the by providing pre-analyzed step by step content combined with the global trial and error creative methodology that caregivers with a number of learning styles⁸⁶ will be able to increase their problem solving abilities, decrease their burden, and decrease depression.

CHAPTER 1: ENDNOTES

¹Howard Gruetzner, *Alzheimer's: a Caregiver's 5Guide and Sourcebook*. (New York: John Wiley & Sons, 2001), 8.

²L. Burgio et al. "Judging outcomes in psychosocial interventions for dementia caregivers: the problem of treatment implementation," *Gerontologist* 41(4, 2001): 481-9; Gruetzner, *Caregiver's Guide*, 9 ; M. H. White, & S. M. Dorman "Online support for caregivers. Analysis of an Internet Alzheimer mailgroup". *Computer Nursing* 18 (4, 2000): 168-76.

³Carmen Morano & Marina Bravo, "A psychoeducational model for Hispanic Alzheimer's Disease caregivers," *Gerontologist* 42(1) (2002): 122-6; Alzheimer's Association, (2000).

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CHAPTER 2 METHODOLOGY

STATEMENT OF RESEARCH QUESTION

Research Hypothesis:

Home caregivers of persons with Alzheimer's Dementia who are directed in utilizing a specifically designed self-help workbook will show decrease levels of burden of care and depression, and an increase in problem solving.

Null Hypothesis:

Home caregivers of persons with Alzheimer's Dementia who are directed in utilizing a specifically designed self-help workbook will not show decrease levels of burden of care and depression, nor an increase in problem solving.

CONCEPTUAL FRAMEWORK

Subjects:

The target population for this study was determined to be home caregivers of persons with Alzheimer's or related Dementias (ADRD). Home caregiver was operationally defined as any person (a relation or friend) not being professionally paid to care for a person with ADRD who is living in the community not in an institution (assisted living or nursing home). The caregivers did not have to reside with the person with ADRD but did have primary responsibility for their care. If a couple was performing the care, only one person per unit was enrolled in the study. The most frequent volunteers were spouses and adult children.

Various community organizations in Albuquerque and Santa Fe, New Mexico were contacted including the Office of Senior Affairs, The Area Agency on Aging, and the New

Mexico Alzheimer's and Related Disease Association. These contacts led to face to face recruitment in Adult Day Cares and support groups. Later contacts led to mail recruitment through community case managers. In this circumstance, case managers contacted their clients and offered them an opportunity to participate in this study. If they agreed, their names and addresses were released to the study and contact was made via the mail. Follow up phone calls were made to all volunteers who were given applications but did not return them within a week. Within a 2-month period over 100 people were contacted either by face to face meeting or via mailers and 80 of these accepted applications packets. 50 people returned their test materials and were enrolled in the study.

Research Design and Procedures:

This study was structured using an experimental design with a pre and post-test modality to measure differences in the dependent variables-levels of burden, depression, and problem solving to support the research hypothesis. The intervention used in this study is a problem solving workbook specifically designed to be content accessible, requiring less reading time and offering lists of behavioral suggestions beginning with the least invasive (to the person with Dementia's autonomy) to the most invasive. The workbook also offers informational chapters with a Holistic Health perspective encouraging a caregiver to work with the whole person. Specific innovative spiritual health suggestions are placed in several locations within the workbook. Although no specific attention has been called to these areas to keep from impeding the general approach of the study, it is hoped that a number of the subjects will access, utilize, and evaluate these sections.

Subjects were obtained from a volunteer sample and randomly assigned to experimental and control groups. The need for the direct recruitment by visiting many Adult Day cares and support groups prevented using a blind technique. Subjects were randomly assigned using an every other person modality. This helped to keep the experimental and control groups comparable and gave subjects at each recruitment site a 50/50 chance of being in either group. Each volunteer subject was given an enrollment packet consisting of a demographic sheet and consent (see Appendix A) plus the three self-administered study inventories: Heppner's Problem Solving Inventory, Novak and Guest's Caregiver Burden, and Zung's depression scale (see Appendix B). The informed consent document created for this study consisted of information concerning what was required of each participant and a statement of assurance that their names would not be released in or outside the study. There were no invasive procedures used in this study. These tests were chosen for their content and their ease of self-administration. The estimated time to complete the tests was 15 to 20 minutes. Subjects recruited in a face to face encounter were verbally informed of steps of enrollment and the activities required for participation. Subjects recruited by mail were sent letters informing them of the steps of enrollment in addition to their enrollment packets and a stamped return envelope (see Appendix C for copies of letters sent to subjects).

After enrollment each participant was immediately randomized on a master list and notified of the status of their enrollment. Controls were informed that they would receive another set of tests in the mail in approximately 3 to 4 weeks and they were to complete and return them in an addressed stamped envelope. When their post-tests were logged, they would then receive their complementary copy of the workbook. The experimental group was informed that they would immediately receive a copy of the workbook and an instruction sheet that would direct

them in workbook exercises that would need to be preformed over the next month. In 3 to 4 weeks they too would receive their posttests in the mail plus a workbook evaluation that would give them an opportunity to give input into the efficacy of the workbook and it's various sections (see Appendix E).

The instruction sheet accompanying the workbook placed emphasis on the utilization of the **Behaviors list/log** and problem solving using the **Behaviors Discussions and Coping Strategies** section. The participants were encouraged to read the material in the **Chapters 4 to13** that most interested them (see Appendix D for copy of instruction sheet). This suggestion was made with caregiver time issues in mind. It was hypothesized that if they had limited time to read, their first priority would be to utilize the problem solving modalities in the book and then read other parts at their leisure. It was projected that a profile of chapters containing information/topics that are of greatest concern to caregivers could be developed from this data. This recommendation did allow for those who might have more time and be able to read the entire book.

The intervention time was chosen to be 3-4 weeks. This was thought to be sufficient time to accomplish the requested workbook exercises with consideration for the time difficulties of a caregiver of a person with Dementia. The workbook was designed to be used as a resource over the possible years of a caregiving experience (from one to twenty). There was little data in the literature on the time it might take to improve problem solving skills. This researcher chose a medium range of time in which to accomplish the task but not so long as to get distracted and cast aside the project.

Post-testing was done entirely through the mail. Subjects were logged onto a master list with their enrollment dates and sent post-tests plus workbook evaluations (experimental group

only) in approximately 3-4 weeks. Stamped return envelopes were included in the post packets and follow up phone calls were made to caregivers to encourage prompt return of the test materials.

All demographic identifiers were removed and subject numbers assigned before tests were scored. Pre and post-test results were logged onto the spread sheet.

CHAPTER 3 PRE-TEST RESULTS AND DISCUSSION

Population Description from Pre-test Scores

This study is based on a sample of 50 caregivers with one mortality on pre-test in the experimental group. One subject had 4 life changing events in one month: her husband obtained a new job, she had to resign from her job, her house sold in a day, and she had to place her mother in an assisted living near another relative. The threat of life changing events intervening in this population was quite high having only one mortality was considered fortunate. One experimental did have to be changed to a control because her workbook did not arrive in the mail.

This sample was obtained from a number of community sources (see Figure 1).

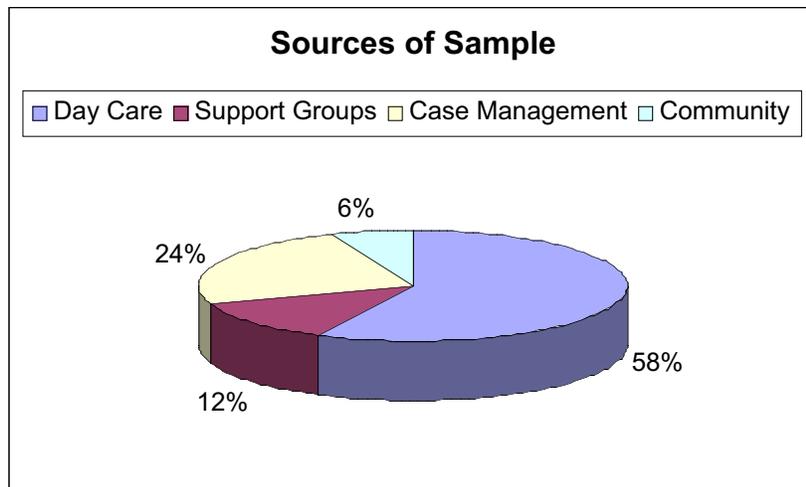


Figure 1

The largest group (58%) came from the Albuquerque Adult Day Care system run by a local subcontractor-Share Your Care. Support groups run by the New Mexico Alzheimer's and Related Disease Association yielded 12 %, which was less than expected. It was found that in this area a majority of support group participants had already placed their family

members with AD in assisted living facilities or nursing homes. It seemed to fit their grief and separation processes to utilize the support group at that time. A few had joined their group during the nursing home transition process and the rest shortly after. At least one member's husband was deceased and she also came for grief support. General membership in each support group was found to be rather low, ranging from two to seven members.

Case management was found to be a surprise viable source of subjects (24%). This modality is a fairly recent resource for New Mexico, created in the last five years. In other larger metropolitan areas, it has been present within the last ten years. Alzheimer's, as yet is not considered a health crisis to managed care because families still bear the brunt of the problems and the costs of care. Thus these case management organizations have been created in the private sector as all-inclusive models. Medicare and Medicaid dollars are used to pay for the patient's total care, including doctors visits, medications, adult day care, and case management with the goal of keeping person's with AD living at home.

Only three people were obtained from the community at large with no affiliation to any of the other types of service. In this study sample, these individuals were in the minority, but in the overall population of Alzheimer's caregivers they are the majority. Unfortunately because they have not sought out community resources, they are isolated and are not easily accessible for sampling. These caregivers are the most vulnerable to burden and depression. In general, the entire sample does have a bias toward help-seeking behavior because they were obtained from community resource organizations (see Table 10).

Table 10

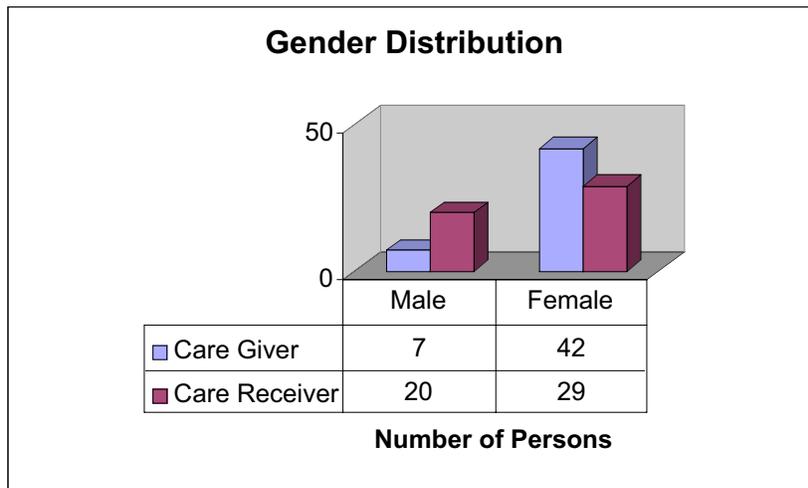
Levels of Help-seeking Behavior	
0	Some awareness of symptoms but no diagnosis
1	Diagnosis and support from MD
2	Written information from Alzheimer's Disease Association and other sources
3	Alzheimer's Support Groups
4	Adult Day Care
5	Case Management and Classes
6	Combination of 1-2-3 and 3-4-5

The more isolated community population referred to in the above discussion is either at zero or may have only accessed levels 1 and 2. They then make the best of what information they have obtained. Many caregivers stop at level 2 because of time burdens. The everyday care of a person with AD can be very overwhelming and the threshold of engaging a new resource may be too high for the perceived benefit. The sample population for this study fits into levels 3 through 6, which is above average help-seeking for this caregiving population. Help-seeking behavior is in itself a mitigating factor against the levels of various negative test values and in obtaining significant experimental results.

Gender distribution of the sample

The caregivers in this sample were preponderantly female, as were the care receivers or persons with AD (see Figure 2). In our society, caregiving still tends to fall to women although it is heartening to see a number of men in this role. In the gender distribution of the care receivers, the split is more even. The bias toward women (29 vs. 20) can be attributed toward the slight longevity edge women have over men. The disease itself does not seem to favor one sex over the other.

Figure 2



Age distribution of the sample

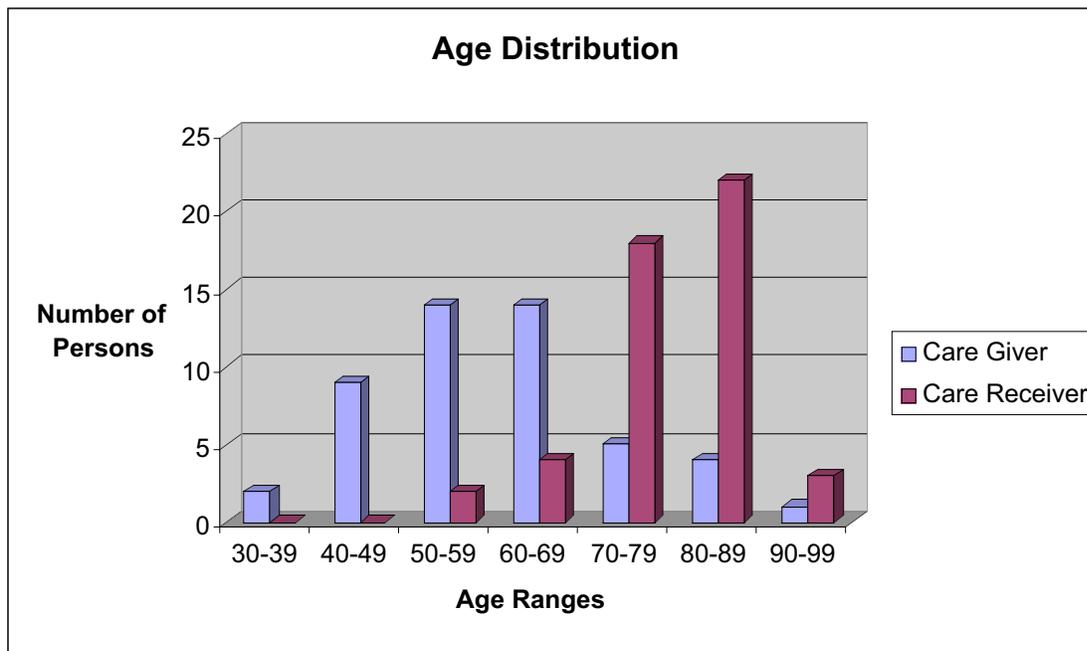


Figure 3

There was an interesting spread in the comparison between the ages of caregivers and care receivers (see Figure 2). This researcher could find no national trending age data on caregivers but there are trends for persons with AD that cite increasing incidence with age. The caregivers in this study were on average much younger than their care receivers (average age = 60 with a range of 37 to 91). While this is somewhat logical, it does reflect the growing impact on adult children, which in turn means a growing impact on families possibly with children. This is not a necessarily negative for the person with AD, but it can be a special challenge for the families' resources.

On the other hand the care receivers, who are persons with Alzheimer's disease, have a mean age of 79 with a range of 57 to 91. Their ages do reflect the increasing incidence of AD, as a person grows older. Certainly there is a challenge for aging caregivers in bearing the physical burden of caring for an elderly spouse or parent with AD. Much would depend on help-seeking behavior and the families' economic resources. The 91-year-old caregiver in this study was caring for a person of the same age, but had a burden score below the mean and a mild depression score, which probably meant she had help in the home and community support.

Relationships between caregivers and care receivers

Another descriptive element related to age and gender is the types of relationships between the dyads of caregivers and care receivers (see Table 11).

Table 11
Familial Relationship Table

Caregiver	Care Receiver					
	Mother	Father	Wife	Husband	% of Sample	Spouses v. Children
Son/In-law	3 / 6%	0	0	0	6%	65%
Daughter/In-law	29 / 49%	5 / 10%	0	0	59%	
Husband	0	0	4 / 8%	0	8%	35%
Wife	0	0	0	13 / 27%	27%	

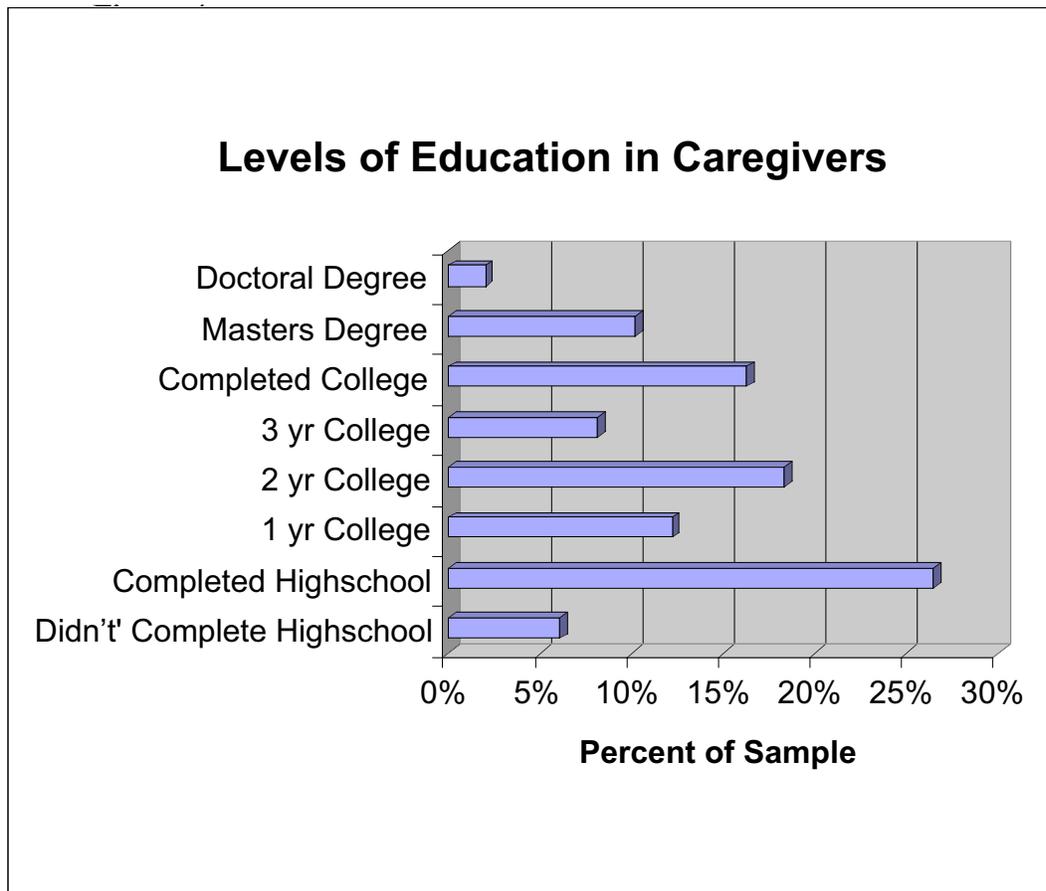
All relationships in this study were classically familial although a number of different arrangements were cited during the sampling process (i.e. cousins, aunts, and uncles). Professional or lay hired caregivers were excluded from this study. The women in this study were the majority caregivers. The youth of our sample is clearly related to the role, as daughter/in-law was the most prevalent relationship, especially in caring for mothers (and in-laws). The male care receivers in this study were cared for by either their wives or daughters, but not their sons. There is no way to know if this is representative of a very low incidence of this familial combination, but given our societal tendency toward women more readily accepting the role of caregiver it is likely that it does occur less frequently than the other combinations.

The fact that 65% of the caregivers are adult children versus 35% spouses seems to represent a shift. Early data fifteen to twenty years ago placed more emphasis on spousal caregiving.

This shift may represent a trend toward more widowed or divorced women needing care, which would naturally have to come from their children, a hired caregiver, or an institution. At least one of the adult children reported that she was living in the house with both parents because her father could not care for her mother alone. In the Novak and Guest sample of AD caregivers (n=107) 44.9% were spouses but only half of them were living outside of an institution.¹ The preponderance of adult child caregivers in this study could be a variance deviating from the general population due to a possibly higher level of help seeking behavior in this group. It would still seem that adult children are playing an important role in caring for PWDs even if there is a spouse involved.

Levels of Education

Figure 4.



The education levels of the AWBS group ranged fairly widely from 8th grade to a doctoral degree. Figure 4 graphs out the various levels, grouping the three people who completed less than a high school diploma into one category. These levels represent the full range of educational offerings in the U.S. thus giving the sample an appropriate educational representation. The mean of this spread was 13.87 or essentially two years of college. The standard deviation was +/- 2.11, which shows the scores to be fairly tightly grouped around the mean. With a mean of two years of college the reading level of this sample is likely to be above average making it easier for them to utilize a workbook for behavior change and improvements in problem solving.

The Problem Solving Inventory

This test designed by P. Paul Heppner, measures the study participants' levels of perceived problem solving skills. It provides researchers with a way to gauge how well a population may be dealing with any number of types of problems in their lives without having to utilize close observation of individual behavior. Obviously with a perceived measure an individual could over or under estimate his/her skills, but this problem should randomly distribute itself in a representative sample. Heppner suggests that false positives may be related to type A behavior.² The sub-tests represent the following areas:

- **Problem-Solving Confidence** = self -assurance while engaging in problem solving activities.
- **Approach Avoidance Style** = a general tendency to approach or avoid problem-solving activities.
- **Personal Control** = the extent to which one believes s/he is in control of his/her emotions and behavior while problem-solving.³

The test has a wide range of total scores from 32 (high levels of perceived success at problem solving) and 192 (very low levels of perceived success at problem solving). The range of the total scores for the AWBS sample was from 35 to 174, a bit more compressed than the full range of scores but still wide. The mean score was 84.

No firm normative levels have been established for this test, and it has not been used on this population before. The author of the measure uses comparative data from a number of different sample groups. Table 12 provides a comparison between the authors sample data and the Alzheimer's caregivers in this study. Since the male caregivers only numbered 6, they were not separated out for comparison and the study sample was considered as a whole.

Table 12

PSI: comparative means and standard deviations

	Sex	N	Problem Solving Confidence		Approach-Avoidance Style		Personal Control		Total PSI	
			M	SD	M	SD	M	SD	M	SD
Normal Adults	M	23	21.8	8.6	40.2	11.5	14.9	6.2	76.9	22.9
	F	73	24.9	7.7	44.2	12.3	17.1	5.2	86.2	21.9
Inpatient Alcoholics	M	77	27.0	8.1	46.2	13.0	18.8	5.5	92.1	21.7
Adults with MS	M	15	18.6	4.4	42.2	14.7	14.7	5.6	75.5	18.9
	F	93	24.5	9.3	44.0	14.2	17.1	5.7	85.6	24.8
Elderly Adults	M	22	24.2	6.9	40.6	9.7	14.8	5.4	79.6	17.0
	F	57	23.8	9.1	43.0	14.9	15.1	5.3	81.2	23.4
AD Caregivers	M/F	50	24.6	10.53	43.7	15.51	15.14	6.79	84.1	28.37

The sub-test and total score means closely approximate adults with MS and elderly adults. The mean scores were not as high as inpatient alcoholics who would seem to

perceive themselves as challenged but not quite as low as normal adults. The standard deviations are in general higher than any of the other research samples indicating a wider range of scores from the mean. The means for the AWBS group were surprisingly closer to the range of normal adults than expected. It would seem that for this sample, AD may pose a challenge to their problem-solving abilities, but the average participant thinks s/he has the skills to meet the need. One should still note that the AWBS scores do reflect a range from exceptional perception (35) to nearly incapacitated (174) and Heppner states that individuals can perceive their abilities to be high but still find the problems s/he faces to be overwhelming and burdensome.⁴

Caregiver Burden Inventory

When care of someone with AD is so time consuming, problematic, and lengthy in years; levels of burden are an important measure in building a profile and tracking attitudinal change in AD caregivers. The CBI test comes closest to capturing levels of burden that reflect some of the factors discussed in the review of the literature under stressors: "Primary subjective" Table 4. (pg. 21), "Secondary stressors- caregiver role strain" Table 5 (pg. 24), and "Intrapsychic strain" Table 6. (pg. 26). The CBI test was chosen because it had 5 sub-tests that measure different kinds of burden. These are listed below:

- **Time Dependence Burden** = due to restrictions on the caregiver's time
- **Developmental Burden** = describes the caregivers' feelings of being "off-time" in their development compared with their peers.
- **Physical Burden** = describes caregiver's feelings of threat or damage to their physical health.

- **Social Burden** = describes caregivers' feelings of role conflict- having to argue with family members about managing care as well as feeling unappreciated and neglected by others in general.
- **Emotional Burden** = describes caregivers' negative feelings toward their care receiver.⁵

These areas of burden create a more explicit picture of the multidimensional nature of caregiving. The 24 question test has a likert scale starting with 0 = not at all descriptive to 4 = very descriptive. Sub-tests for Time, Developmental, Social, and Emotional contain 5 questions and the scores range from a minimum of 0 to a high of 20. Physical burden is measured with only 4 questions and the scores range from 0 to 16. The possible total CBI scores range from 0 to 96. The authors, Novak and Guest have not establish a normative scale for this test but compare scores to the means on their original test data. Their mean for the total score on the original CBI was only 22 verses 48 or half the total score of 96. The range of total scores for the AWBS group was a low of 19 to a high of 74 with a mean of 36.44. Without a specific scale to measure low to high, scores become relative to the group and research means. The authors also recommend using the scores to create individual profiles for counseling purposes. Table 13 establishes a comparison between the sub-test and total score means between the Novak and Guest research population (NGR) and the AWBS sample. It should be noted that the Novak and Guest population consisted of 107 caregivers of persons who had dementia. Of these caregivers, half were caring for someone who had been institutionalized. The authors did not compare the caregivers of institutionalized persons to the caregivers of persons still living in the community but

measured their scores as a group. The authors do say that uni-dimensional measures of burden do tend to show lower scores for caregivers of institutionalized

Table 13
CBI comparative means and standard deviations

Areas of Burden	Population	Means	Standard Deviations
Time	*NGR	6.98	5.89
	*AWBS	13.46	4.08
	Ratio of difference	1:1.9	
Development	NGR	7.08	5.89
	AWBS	10.89	4.9
	Ratio of difference	1:1.5	
Physical	NGR	5.47	5.9
	AWBS	4.9	4.2
	Ratio of difference	1:1.89	
Social	NGR	2.5	3.54
	AWBS	4.02	3.44
	Ratio of difference	1:1.6	
Emotional	NGR	2	3.04
	AWBS	3.24	3.38
	Ratio of difference	1:1.62	
Total	NGR	22.14	16.3
	AWBS	36.44	14.38
	Ratio of difference	1:1.64	

*NGR – Novak and Guest Research Population

*AWBS – Alzheimer’s Workbook Study Research Population

persons.⁶ It may be that the differences in perceived burden in these NGR subgroups (institutionalized and non-institutionalized) were significant, and this may have deflated the overall scores. The means of the scores for the AWBS sample were 1.5 times and greater than the NGR group on the sub-tests for time, development, social, and emotional

burden. The only score that was very close was physical burden. The total score means were also higher for the AWBS group at 1.64 times the NGR group. The standard deviations for the AWBS group were slightly lower than the NGRs. The scores are more tightly clustered around the mean. It would seem that these values concur with the assumption that primary caregivers of persons with dementia who are still living in the community are at a higher risk for burden than those whose care receivers are institutionalized. Although, the way the questions are worded makes any positive response evidence of some problematic level of burden (see CBI Appendix B). Thus evaluating burden solely by the extremely high values may not be a reliable benchmark for estimating problematic levels of burden. Slight to moderate scores may well mean a troubling level of stress, which could impact the quality of life for the caregiver and care receiver. Extremely high scores could be close to being emotionally and mentally paralytic.

The profile of the AWBS group indicates that time and developmental burden scores were the highest and closest to the mid-point of the scores. The higher levels of these scores are consistent with the verbalizations and complaints of a number of caregivers interviewed during recruitment for this study. These remarks expressed very strong feeling. This does seem to support the above theory that distress can occur at scores closer to the midpoint.

The physical burden mean was somewhat low, being slightly above the lower quarter of the highest score of 16. The mean for social burden was also in the lower quarter of the high score of 20 but well above the NGR mean. The only score that seems quite deflated was that of emotional burden. The NGR mean was only 2 out of a possible score of 20. The AWBS mean was higher at 3.24 but still only in the lower quarter.

There seemed to be some variability in the CBI scores relating to the AWBS means and the test medians. When means were compared with medians and modes on the PSI and Zung tests these scores were all fairly close. Table 14. shows these values for the CBI test.

Table 14
CBI Means, Medians, and Modes

Test	CBTime	CBDev	CBphysical	CBSocial	CBEmot	CBTotal
Mean	13.46	10.89	4.9	4.02	3.24	36.44
Test Median	10	10	8	10	10	48
Median	14	12	4	3	2	32
Mode	16 (6)	12 (5)	0 (6)	1 (10)	0 (11)	23 (3)
		14 (5)	1 (6)	2 (8)	1 (10)	30 (3)
		15 (5)	2 (6)	4 (8)	2 (8)	32 (3)
			6 (6)			

* (x) number of scores

For the area of time burden, the AWBS mean was well above the test median as was the median and mode. The range was 2-20 with 16 scores in the 16 to 20 range (33%). 36 scores were above the test median of 10 representing 73% of the sample. Time burden was clearly an issue for the AWBS group. The developmental burden mean was only slightly higher than the test median, but the modes were much higher with 15 scores between 12-15 and 9 scores above 15. 55% of the scores were above the test median. This was also a troubling issue for the AWBS group.

Some of the variability began to appear in the area of physical burden, where the mean scores for both the NGR and the AWBS group were below the test median of 8. 72% of the scores were below 8 and so were all the various modes. If a participant had a higher level of physical burden then their total scores were high.

The rest of the variability was contained in the last two areas of social and emotional burden. The means for both areas were a great deal lower than the test median of 10, 4.02 and 3.24 respectively. Examining the social burden scores, the median of 3 and the modes of 1, 2, and 4 show that most of the scores were fairly low (81%). The emotional burden scores were similar with a mean of 3.24; a median of 2; and modes of 0,2,and 1. In this case, 94% of the scores were below the test median of 10. Looking at this data, one could conclude that neither social nor emotional burden was much of a problem for the AWBS group, until one reads the content of the questions in this section of the test. The questions are very emotion laden, containing trigger words like: embarrassed, ashamed, resent, uncomfortable, and angry. If a participant had a positive response to any of them even without the weighting, it may mean that s/he could be in some emotional difficulty and may be basing his/her decision making on troublesome emotional baggage. Table 15 displays the social and emotional questions with the number of singular positive responses without any of the weighting from the likert scale. With such low over all scores it might seem that caregivers were being reluctant to admit their feelings so boldly on a test. Looking at the data in Table 15, it is clear that many people did express some degree of negativity about their life situations. 65% expressed resentment against relatives who would not help, 45% felt their efforts were not appreciated by their families, and 30% expressed that they did not get along with their family members as well as they had before. In the AWBS group family relations was a troubling problem.

Table 15**CBI Social and Emotional questions with number of positive responses.**

CBI QUESTIONS	Number of positive responses	
	Un-weighted	percent
SOCIAL		
0 = no positive to any of the five questions	3	6%
15. I don't get along with other family members as well as I used to.	15	30%
16. My caregiving efforts aren't appreciated by others in my family.	22	45%
17. I've had problems with my marriage.	12	24%
18. I don't do as good a job at work as I used to.	17	35%
19. I feel resentful of other relatives who could but do not help.	32	65%
EMOTIONAL		
0 = no positive to any of the five questions	11	22%
20. I feel embarrassed over my care receiver's behavior.	25	51%
21. I feel ashamed of my care receiver.	7	14%
22. I resent my care receiver.	19	39%
23. I feel uncomfortable when I have friends over.	18	37%
24. I feel angry about my interactions with my care receiver.	30	61%

In considering the area of emotional burden, 22% declared they had no issue with this at all; but 51% were embarrassed by their care receiver's behavior. 61% were angry about their interactions with their care receiver, and 39% resented their care receiver. From a mental health standpoint, even without the weighting there would be cause to be concerned about the mental health trends in this sample. Again, this is a fair amount of emotional encumbrance that could certainly influence problem solving, communication, and quality of life. Any downward trend in the social and emotional scores on the CBI test could be seen as a step toward more positive mental health.

Zung Depression scores

In general the depression scores for the AWBS group were lower than expected.

The scores were evaluated using the Zung SDS index:

- **Below 50** = within normal range
- **50 to 59** = minimal to mild
- **60 to 69** = moderate to marked
- **70 to 100** = extreme

Figure 5

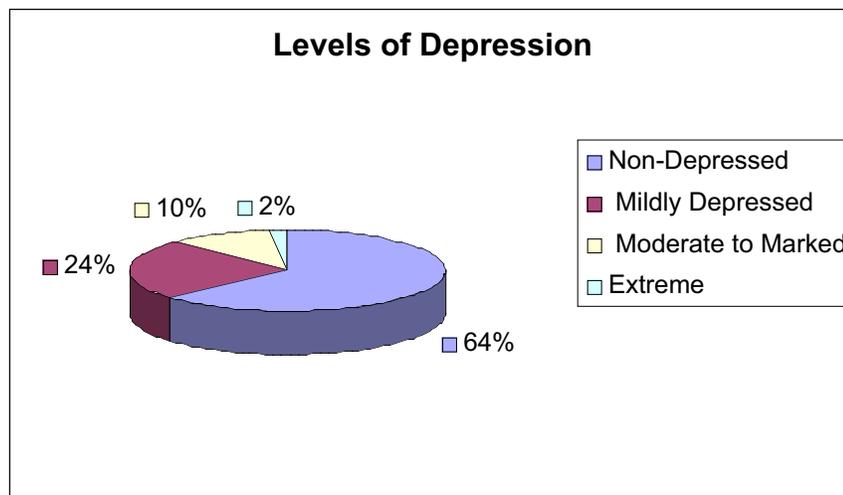


Figure 5 shows the levels of depression expressed as percents of the sample. A majority of the sample was not depressed (64%). Only 36 % were considered depressed and a majority of those were mild (66%). One person had score of 79, which was in the extreme category. Small et al. cited that nearly half of all caregivers of PWD become depressed.⁷ It would appear that AWBS sample population is below average and more stressed and burdened than actually depressed. The mean for the total SDS scores was 44.06 (13.70), which is clearly not in the depressed range.

Test Correlations

After reviewing the pre-test data, it became clear that the various tests were correlated. Pearson correlations (2 tailed) were run to define the significance and direction of these correlations. No negative correlations of any significance were found. Very significant positive correlations were found for all three tests (see Table 14.). The link most likely is due to the fact that they all measure people's feelings and perceptions on how they are coping in their lives. The following positive correlations were most significant:

- **CBI - Time:** related to physical burden
- **CBI - Developmental:** related to physical, emotional, and social burden plus problem-solving confidence and depression
- **CBI - Physical:** related to all the other areas of burden plus problem-solving confidence, the PSI total score and depression
- **CBI - Emotional:** related to physical, developmental, and social burden plus all the PSI sub-tests, total, and depression
- **CBI - Social:** related to physical, developmental, and emotional, burden plus PSI personal control and depression
- **PSI - Problem Solving Confidence:** relates to developmental, physical, emotional burden, The CBI total plus all other PSI scores and depression
- **PSI - Approach Avoidance Style:** relates to emotional burden, The CBI total plus all other PSI scores.

Table 16

Pearson Correlations for all tests

Pearson Correlations	CB TIME	CB DEV	CB PHYS	CB EMOT	CB SOC	CB TOTAL	ZUNG
CB TIME	1	.179	.399**	.274	-.017	.532**	.191
CBDEV	.179	1	.532**	.471**	.629**	.792**	.516**
CBPHYS	.399**	.532**	1	.548**	.402**	.808**	.676**
CBEMOT	.274	.471**	.548**	1	.588**	.768**	.553**
CBSOC	-.017	.629**	.402**	.588**	1	.690**	.534**
CBTOTAL	.534**	.792**	.808**	.768**	.690**	1	.678**
PSIPSC	.281	.402**	.549**	.602**	.335	.603**	.587**
PSIAAS	.322	.167	.298	.510**	.258	.431**	.278
PSIPC	.039	.267	.308	.596	.387**	.415	.484**
PSITOTAL	.309	.292	.431**	.621**	.343	.551**	.479**
ZUNG	.191	.516**	.676**	.553**	.543**	.678**	1

** Correlation significant at the 0.01 level (2tailed)

- **PSI - Personal Control:** relates to social, emotional burden, and The CBI total plus all other PSI scores and depression.
- **Zung - Depression:** relates to all levels of burden except time plus all levels of the PSI except approach avoidance.
- **Test Totals:** all test totals were correlated

Among these various correlations, several stand out. Time burden, which was high in the AWB study, was related to no other scores but physical burden. The relationship between time and physical burden seems logical. The lack of relationship to any of the problem solving scores would point to the fact that time may only have a temporary effect on problem solving perceptions, unless the time pressure is so chronic that one never gets the sense of being successful. Anecdotally, many members of the AWBS group complained heartily about time burden; but the group PSI score was only slightly higher than the mean for elderly adults and slightly lower than normal adults. A number of participants stated that the problem crunch (a relationship between the number of problems

faced and the time allotted) actually made them feel more confident in problem solving rather than less. Not having the time to consider whether or not the information one is using to drive problem solving is of quality, may be a short-term coping strategy. It is difficult to say when this approach would begin to fail consistently. In many cases it may fail intermittently creating it's own level of behavioral reinforcement. Both the caregiver and care receiver would have a fairly low quality of life, but this may be managed emotionally by considering it as one's lot in life. What is considered as an acceptable quality of life for caregivers of persons with dementia is lower than that of the general public. Resignation is at some level homeostasis in their lives. This may also be why time pressure in the AWBS group does not appear to correlate to depression levels and why some caregivers do not seek help.

Physical burden is a very interrelated score. If perceived as being high or low all the other scores will also be significantly high or low. In the AWBS group the mean of the physical burden scores (4.9) was below the test median (8) and below the NGR mean of 5.47. This lower score may have been driven by the fact that so many participants were in adult day care (58%), which is a substantial factor in remediating physical burden. This factor may also relate to the fact that 64% of the AWBS group was not depressed and the mean for the Zung test was 46. Physical burden was also related to problem solving confidence or one's self-assurance at solving problems. How difficult the care is for the caregiver to provide can create an increase in burden. If many things are perceived as problems, this could affect one's sense of success or failure in the problem solving process. If the caregiver becomes overwhelmed then depression levels could rise.

Developmental, emotional, and social burden were all correlated for the AWBS group and seem naturally connected due to the emotional nature of the questions (see the CBI test in Appendix B.). All three are also related to depression for the same reason. If a participant is filled with enough emotion to feel these levels of burden then it would probably spill over into a feeling of depression. If one does not feel these three levels of burden then there would be less chance of depression. The AWBS group mean for developmental burden was slightly higher than the test median of 10 (10.89). Social and emotional burden means were higher than the NGR means (apx 1.6 times) but lower than the test median of 10. This score cluster tends to point toward some levels of developmental, social, and emotional burden in the AWBS group. This certainly correlates with the 36% of the participants who were depressed.

In the area of problem solving only emotional burden was related to all the sub-tests and the total score. It would seem that if one were feeling high emotional burden then all the problem solving scores would be high, meaning that problem solving skills were being compromised. If one were feeling low emotional burden then problem solving scores would also be low and problem solving would be enhanced. This is logical in the sense that intense emotions with a feeling of burden and perhaps resentment would not lead to the clarity of thinking need to analyze choice and make appropriate decisions or even commit to the trial and error process.

Developmental burden was only correlated to problem solving confidence. If one feels that s/he is missing out on the positive experiences of life and suffering in the caregiving role then this could affect one's ability to feel self-assured about problem solving, again leading to depression. In the converse, if one feels that the sacrifice of

caregiving is given freely and no burden is experienced then there would be little compromise to problem solving and no tendency for depression. Social burden was correlated specifically to the personal control sub-test of the PSI, which measures whether a person feels in control of his/her emotions and behavior while problem solving. The questions in the area of social burden tend to express an underlying resentment of caregiving and of relatives who do not volunteer to help. If social burden scores were high, then this kind of emotional bias can seem overwhelming and could easily taint one's feelings of being clear headed and in control while trying to engage the problem solving process, again leading to depressive feelings.

Problem solving confidence or self-assurance is correlated only to physical, developmental, and emotional burden sub-tests and total burden. In this case what is not related is interesting. Time burden as stated above may actually create pressure and more responsive problem solving. Social burden although close in meaning to developmental and emotional burden was only mildly correlated. The total burden score, if high would logically lead to less self-assurance in the problem solving process and create depression.

Approach avoidance style or the tendency to either approach or avoid problems was only related to emotional burden, which expresses levels of resentment toward the care receiver. If a caregiver is feeling high levels of resentment then avoidance could be a way of coping with those emotions. If the caregiver were feeling very little resentment the approach and engagement of problem solving would probably be the way of coping. Avoidance is not significantly related to depression. This may be due to the possibly temporary value of avoidance as a coping strategy. Eventually problems will catch up to a

caregiver and then another dynamic may occur leading to an increase in the other scores and depression.

Personal control logically is correlated with social and emotional burden. When scores in these two volatile areas are high then a caregiver would have a hard time feeling in control of his/her emotions and this would interfere with the problem solving process. If social and emotional burden is low then personal control score would be low and clearer problem solving could occur.

All the test totals were positively correlated, which points to the interconnectedness of these tests. Problem solving is clearly affected by a caregiver's level of burden and depression. These three tests can capture a profile of a caregiver's approach to caregiving. How a caregiver perceives s/he is doing in the areas of problem solving and burden are subjective measures, but their relationship to depression creates a link to an affect on behavior. One cannot truly determine how well a caregiver actually solves a problem without empirical observation of a caregiver/care receiver interaction or with a discussion of all the elements of a sample decisional/ problem solving process. However, if a caregiver has the perception that s/he is doing well at problem solving, expresses no conscious burden, and is not depressed then very likely s/he is engaged in a fairly positive problem solving process. This may not speak to the quality of the information base s/he has to use to drive problem solving, which could influence the quality of life for the caregiver and care receiver. On the other hand, if a caregiver were perceiving a great deal of burden it is likely that s/he would have some of all of the various types of burden as they are all positively correlated to the total burden score. With the feelings of time pressure, missing out on life, burden of physical care, that relatives are not helping, friends are

slipping away, and resentment of the care receiver; a care giver could find problem solving overwhelming and this could easily result in depression and hopelessness.

This grouping of tests could give case managers a picture of coping strategies and a prediction of positive or negative behavioral outcomes for the care giver/care receiver dyad. It would also be an excellent support for the care planning and a behavioral intervention process as well as assisting in finding those dyads who are in priority need of help.

CHAPTER 3: ENDNOTES

¹Mark Novak & Carol Guest, "Application of a multidimensional caregiver burden inventory," *Gerontologist*, 29(6, 1989): 799.

² P. Paul Heppner, *The Problem Solving Inventory*. (Palo Alto, California: Consulting Psychologist Press, 1988), 2.

³ Ibid., 1-2.

⁴ Ibid., 2.

⁵ Novak & Guest, *Caregiver Burden Inventory*, 800.

⁶ Ibid., 803.

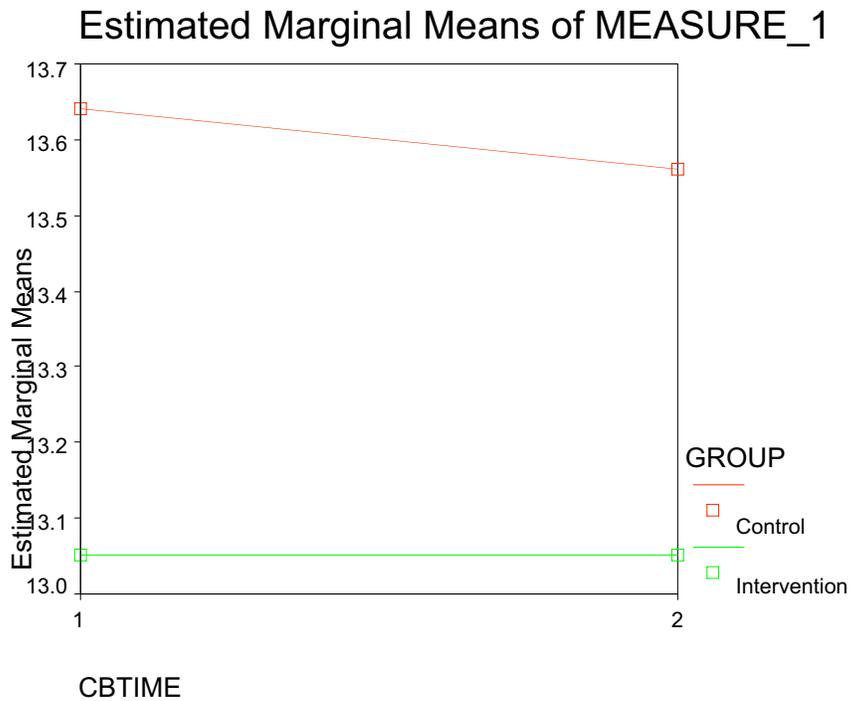
⁷ G. W. Small et al., "Diagnosis and treatment of Alzheimer's Disease and related disorders. Consensus statement of the American Association for Geriatric Psychiatry, the Alzheimer's Association, and the American Geriatrics Society," *Journal of the American Medical Association* 278(16) (1997): 1363-71.

CHAPTER 4: POST-TEST RESULTS AND DISCUSSION

Pre and post-test score differences were analyzed by using 2 X 2 mixed ANOVAs, examining the repeated measures between and within group factors.

The following are the graphs depicting the between subject group effects and their levels of significance for each measure use in the AWB study:

CBI: Time Burden



Tests of Between-Subjects Effects

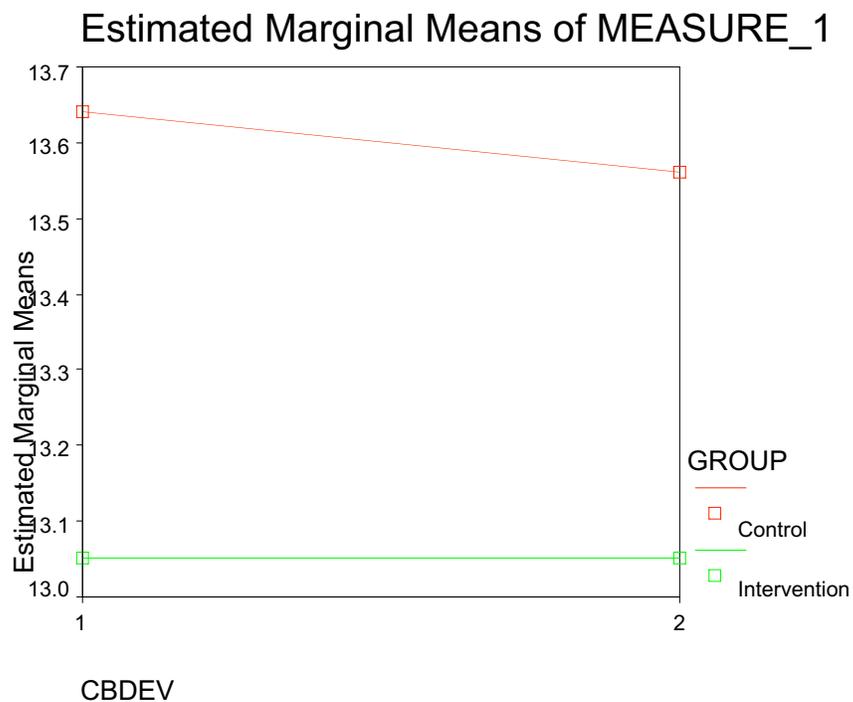
Measure: MEASURE_Time
Transformed Variable: Average

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	15337.378	1	15337.378	499.397	.000
GROUP	6.469	1	6.469	.211	.649
Error	1289.895	42	30.712		

Figure 6

No level of significance was found for this factor ($p = .649$). The control group dropped a small amount and the experimental group experienced no significant change. This factor did seem intractable at the onset of the experiment and through out the study due the consistent external and internal pressure the caregivers felt to manage many daily chores and activities. This was a factor even in obtaining the pre and post-tests. Caregivers were consistently apologizing for their tardiness and citing time as the major factor.

CBI: Development Burden



Tests of Between-Subjects Effects

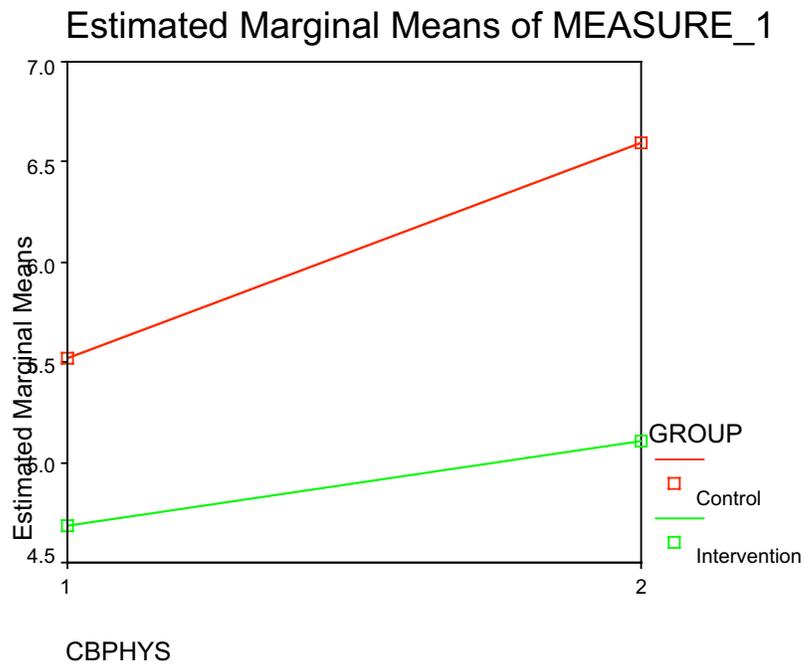
Measure: MEASURE_Development
Transformed Variable: Average

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	15337.378	1	15337.378	499.397	.000
GROUP	6.469	1	6.469	.211	.649
Error	1289.895	42	30.712		

Figure 7

No level of significance was found for this factor ($p .649$). The control group dropped a small amount and the experimental group experienced no significant change.

CBI: Physical Burden



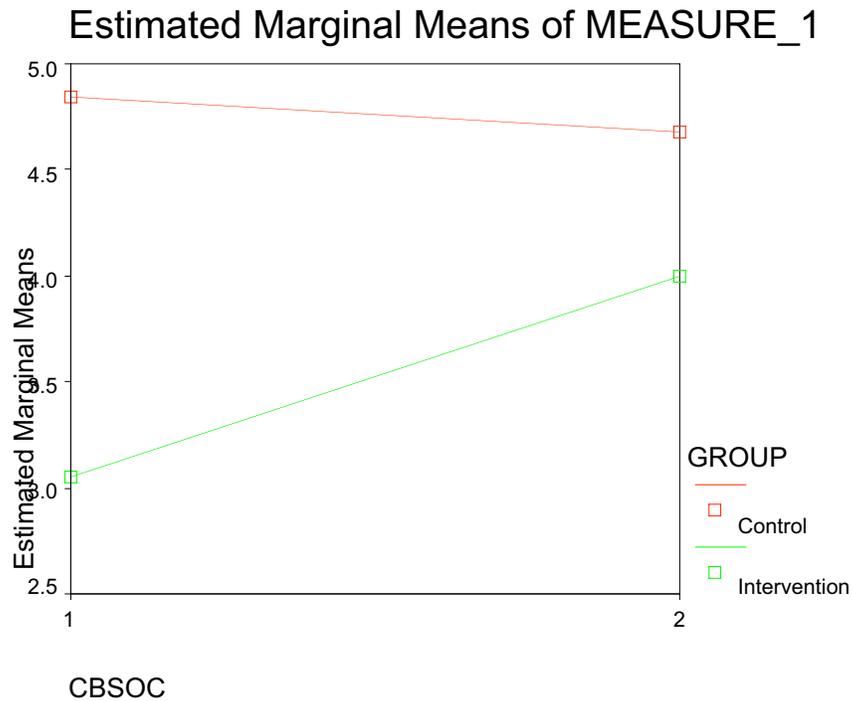
Tests of Between-Subjects Effects

Measure: MEASURE_Physical
Transformed Variable: Average

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	2591.044	1	2591.044	77.460	.000
GROUP	29.317	1	29.317	.876	.355
Error	1404.899	42	33.450		

Figure 8

No level of significance was found for this factor ($p .355$). Both groups rose a small amount but it was not a significant. Physical burden levels are vulnerable to the needs of the care receiver for help with activities of daily living and his/her levels of AD and may only be perceived differently. The actual needs for care are objective.

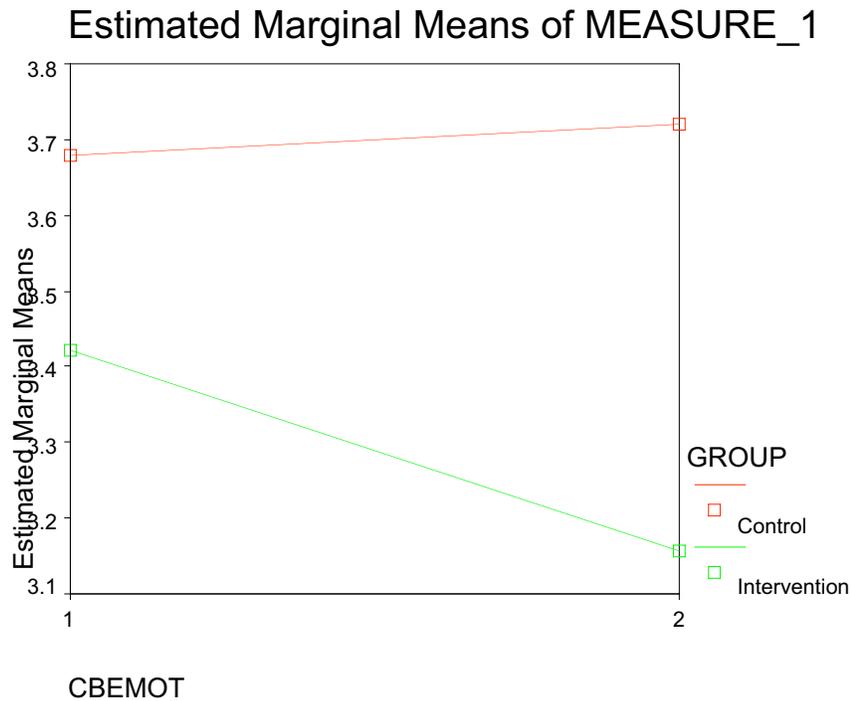
CBI: Social**Tests of Between-Subjects Effects**

Measure: MEASURE_Social
Transformed Variable: Average

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	1482.497	1	1482.497	60.241	.000
GROUP	32.861	1	32.861	1.335	.254
Error	1033.594	42	24.609		

Figure 9

No level of significance was found for this factor ($p .254$). In this case the experimental group had a slight rise in their social burden scores of approximately 1 point, but this was not found to be significant. The control group scores remained essentially the same.

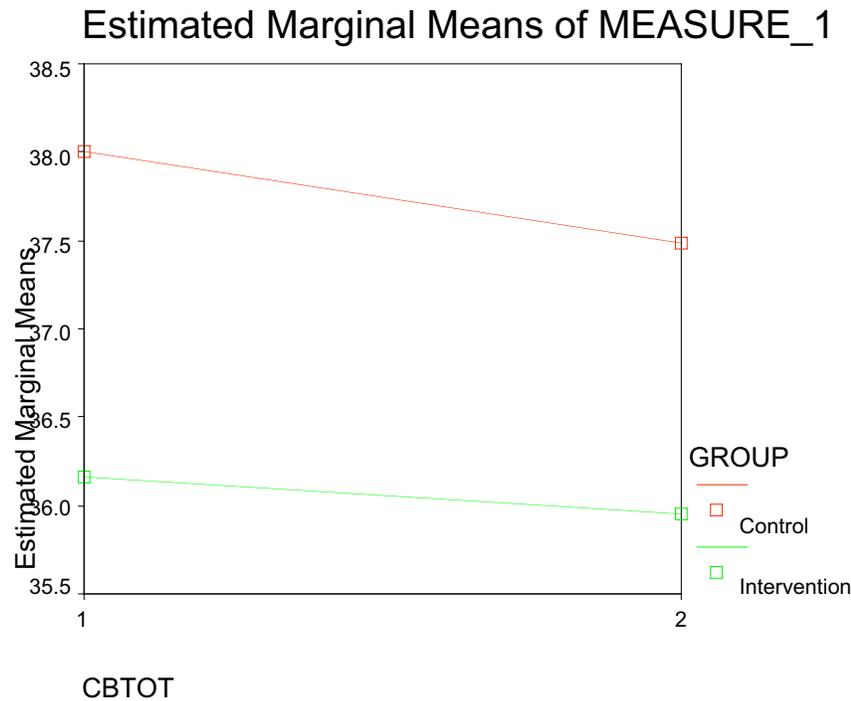
CBI: Emotional**Tests of Between-Subjects Effects**

Measure: MEASURE_Emotional
Transformed Variable: Average

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	1054.775	1	1054.775	48.826	.000
GROUP	3.639	1	3.639	.168	.684
Error	907.316	42	21.603		

Figure 10

No level of significance was found for this factor ($p .684$). In this case the experimental group had a slight decrease in their emotional burden scores of approximately .3 point, but this was not found to be significant. The control group scores remained essentially the same.

CBI: Total Score**Tests of Between-Subjects Effects**

Measure: MEASURE_Total Score
Transformed Variable: Average

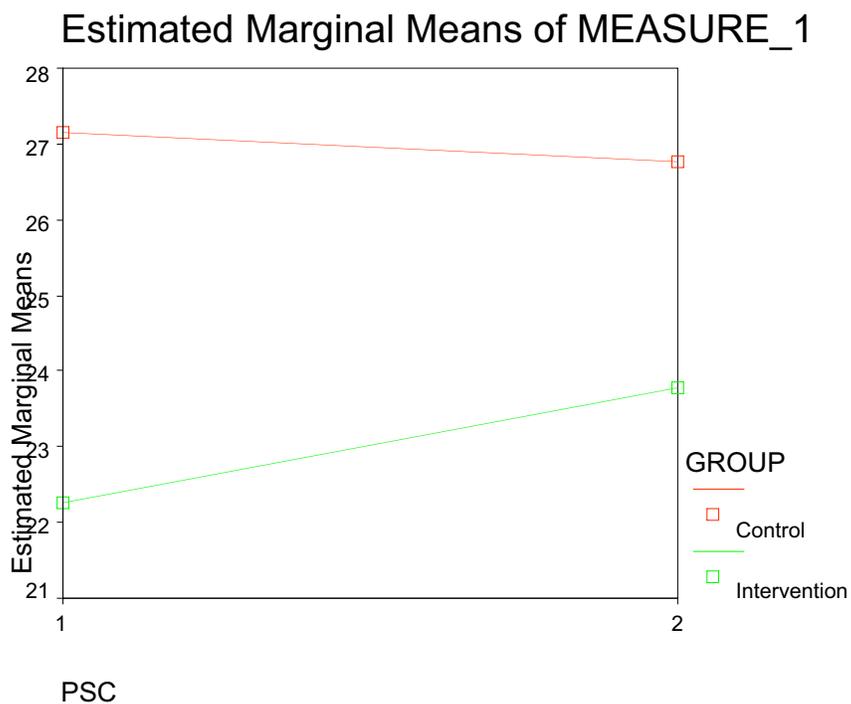
Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	117570.110	1	117570.110	303.574	.000
GROUP	61.474	1	61.474	.159	.692
Error	16266.015	42	387.286		

Figure 11

No level of significance was found for this factor ($p = .692$). In this case, the experimental and control group remained essentially unchanged. It would seem that more time in the experiment might have made a difference in this factor, but it is more likely the random spread of readiness in this sample was part of the problem. Subjects were randomly assigned to either the treatment or control. No attention could be paid to intuitive assessments that certain participants expressed more motivation than others and would perform better in the experimental group. 55% of the experimental group didn't engage the experiment fully due to personal crises

with time and motivation. The group that did engage the material will be more closely examined in a later section.

PSI: Problem Solving Confidence



Tests of Between-Subjects Effects

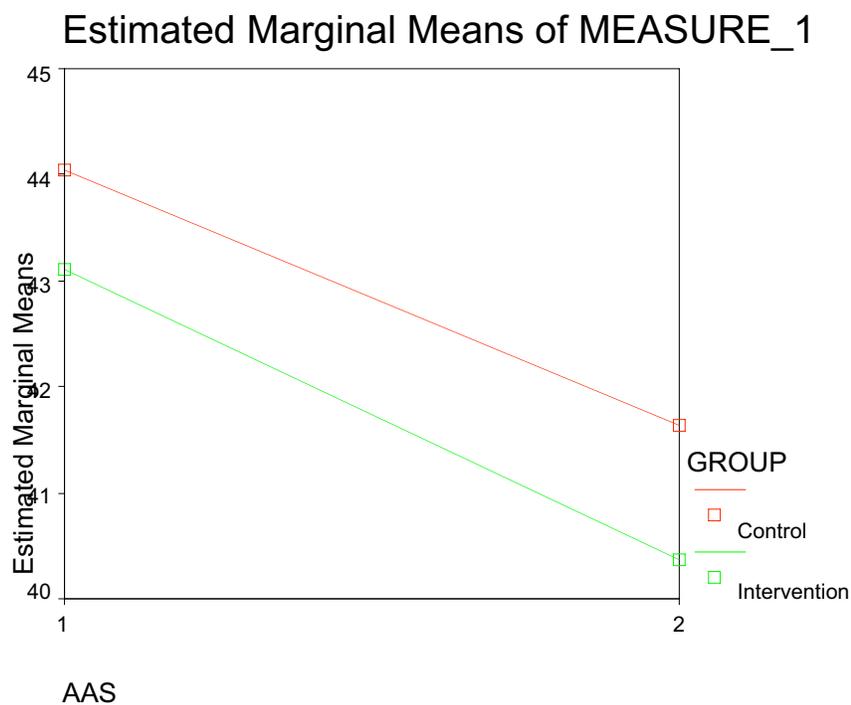
Measure: MEASURE_PSC
Transformed Variable: Average

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	53947.731	1	53947.731	364.665	.000
GROUP	334.095	1	334.095	2.258	.140
Error	6213.394	42	147.938		

Figure 12

No level of significance was found for this factor ($p = .140$). In this case, the experimental group experienced a small rise in this problem solving score and the control group remained essentially unchanged. This small rise for the experimental group could show temporary fluctuations in their confidence as they trial or even think about engaging a new method of problem solving.

PSI: Approach Avoidance



Tests of Between-Subjects Effects

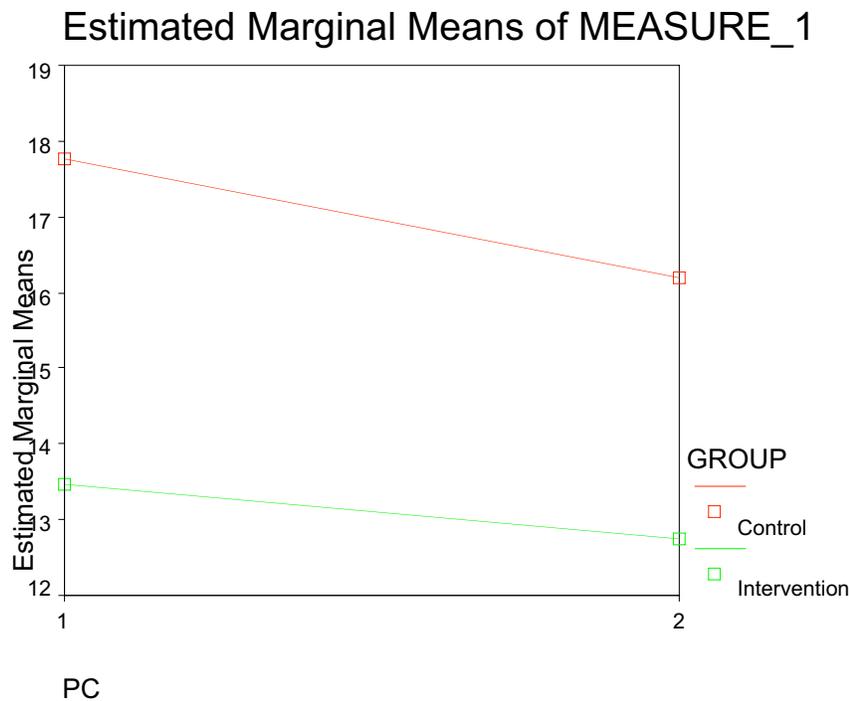
Measure: MEASURE_AAS
Transformed Variable: Average

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	154445.002	1	154445.002	377.658	.000
GROUP	26.275	1	26.275	.064	.801
Error	17176.088	42	408.954		

Figure 13

No level of significance was found for this factor ($p = .801$). In this case, both the experimental and control group experienced a decrease in the approach avoidance score but the difference between groups was not significant.

PSI: Personal Control



Tests of Between-Subjects Effects

Measure: MEASURE_PC
Transformed Variable: Average

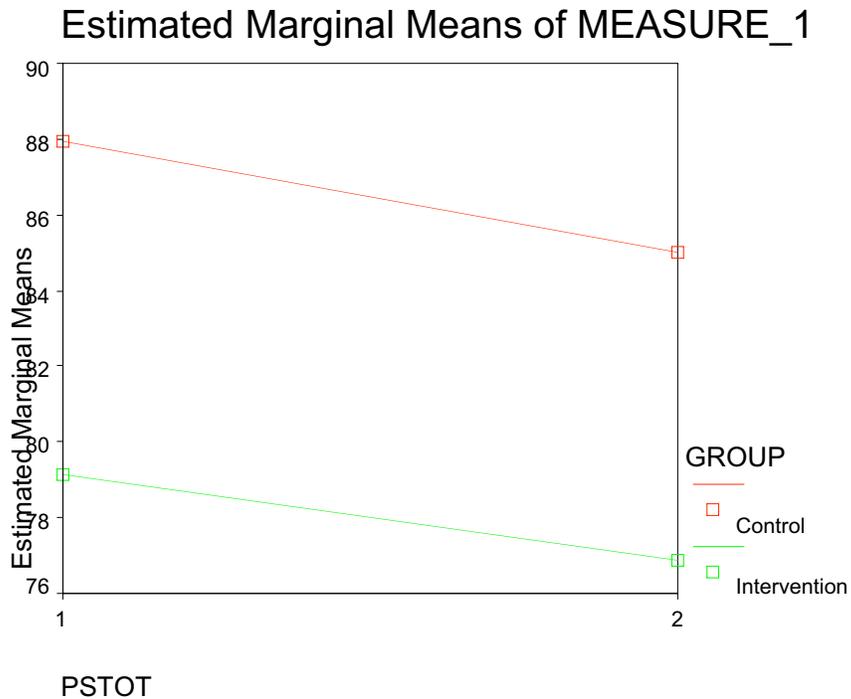
Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	19542.430	1	19542.430	367.395	.000
GROUP	324.157	1	324.157	6.094	.018
Error	2234.059	42	53.192		

Figure 14

This factor came closest to achieving significance compared to the other factors ($p = .018$). It is possible that this trend may indicate that this is the most vulnerable area of change in the experimental group. Personal Control is the extent to which one believes s/he is in control of their emotions and behavior while problem solving. Experimental group

participants may have found this to be the first move toward constructing rational paradigms and preceding fully engaging the problem solving process.

PSI: Total Score



Tests of Between-Subjects Effects

Measure: MEASURE_Total
Transformed Variable: Average

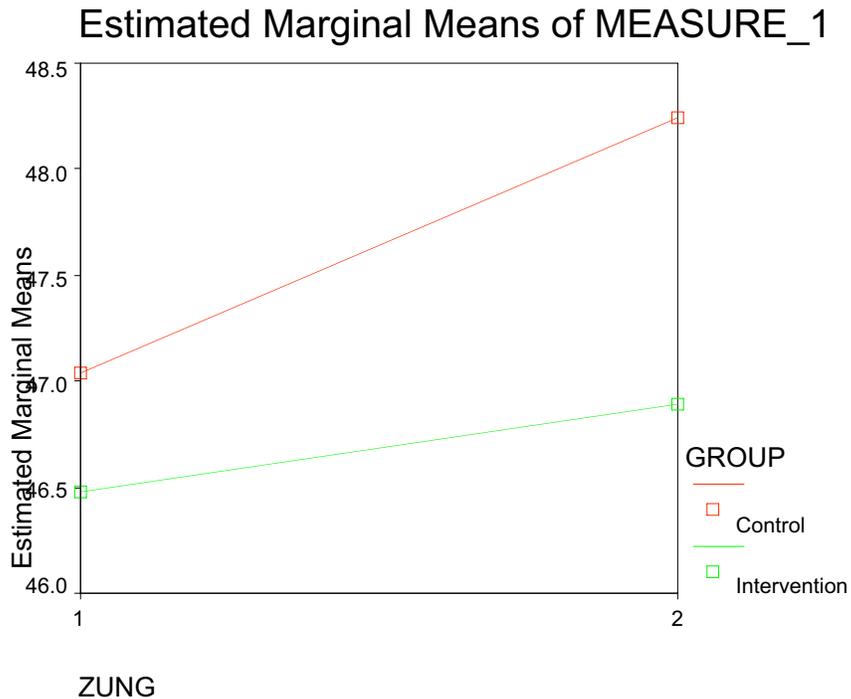
Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	584158.197	1	584158.197	469.182	.000
GROUP	1535.697	1	1535.697	1.233	.273
Error	52292.394	42	1245.057		

Figure 15

Although the differences in the groups total problem solving scores failed to achieve significance ($p = .273$), this p value was one of the lowest in the test battery. Undoubtedly, this effect was probably caused by the nearly significant personal control and marginal personal confidence values. This trend seems to point to the possibility that the Problem Solving

Inventory scores could achieve significant difference over time. How much time remains the question in such a mixed group?

ZUNG: Depression Scores



Tests of Between-Subjects Effects

Measure: MEASURE_ZUNG
Transformed Variable: Average

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	192095.542	1	192095.542	777.061	.000
GROUP	19.724	1	19.724	.080	.779
Error	10382.731	42	247.208		

Figure 16

No level of significance was found for this factor ($p = .799$). In this case, both the experimental and control group experienced an increase in their depression scores. The difference in the increase was not found to be significant and did not take either group up to a level of clinical significance. This small rise could be do to the general upset of life and the stress of meeting another deadline (i.e. the study). This group of caregivers experienced quite a

bit of life change. In the control group, a couple of care receiver's had short hospitalizations. Caregivers of persons with Dementia are very vulnerable to stress and life's chaos.

Discussion of Results

In examining the raw scores for this study, a fair amount of variability was noted. Participants in both the experimental and control groups went up and down in seemingly random fashion. Several participants in the control group with very high problem solving scores did experience significant drops in their scores (i.e. 174 to 145 = 16% and 155 to 118 = 24%). It is likely that this is due to a test /re-test interaction. The PSI was structured with questions that could guide someone into the steps of problem solving. The CBI can raise a person's awareness of their feelings and possibly precipitate a period of introspection that could lead to some management of feelings. The Zung also contains strong emotional content and could also possibly bring a person to similar awareness of feelings. In a true experimental design this factor should be controlled for by randomization, but with results this close it is likely to have pushed the means closer together.

The flatter than expected mean scores of the experimental group may have been due to a possible emotional upheaval cause by trying a new system of approach to daily activity. In this case the participants past knowledge may have initially caused them to be more judgmental about their previous modes of behavior and former approaches to problems. Essentially a period of excitability was created where their emotions were labile, as were their self-assessments. This changeable state could cause diverging scores depending on the state of the individual's life at the time thus canceling out each other's scores and creating flatter means.

Another factor working to diminish differences in the means was the levels of engagement within the experimental population. The workbook evaluations expressed a great

deal of positive acceptance of the text and informational content, but also a variable rate of engagement of the requested exercises. Random selection was not an asset in this circumstance. A number of the experimental participants had a low readiness for change, which would occur in any random grouping of caregivers. Table 17. Illustrates the levels of engagement found in this study. The workbook evaluations were used to produce this data.

Table 17. Levels of Engagement

Level 1	Tackling Blockers
15% (3) n=20	Intra-psycho strain-fear, anger, resentment, stress, confusion, fatigue; excessive time burden; general role strain; self-judgement & guilt over negative responses; ability to accept the positive instead of the "should be;" poor reading and organizing skills. Low readiness for change
Level 2	Trial Engagement
40% (8)	Still working with level 1 blockers but able to commit some time to the task; still ambivalent but interested in some new information; still worried about time commitment. Low to moderate readiness for change
Level 3	Experienced Evaluation
20% (4)	Individuals in this category have been caregivers for many years (5-15 years); not interested in a full commitment to a new system but always interested in new resources, enthusiastic evaluators of informational materials, more easily attached to concept information. Have been practicing skills in real life situation for many years- may not perceive need to change physical activity but can adopt information easily- Moderate readiness for change
Level 4	Open Engagement
25% (5)	May still be working with level 1 blockers but have some readiness for change; looking for new ideas and possibly ways of being; easily engaged in the trial and error process, may experience chaos of change, potential for transcendent experience. Moderate to high readiness for change

As one can see, fully 55% of the experimental sample (Level 1 and 2) did not engage or only partially engaged the workbook exercises, which were hypothesized to lead to the levels of behavior change desired in this study. These participants fell into the low to moderate readiness for change levels. From their responses on the evaluations, they could be seen as being very susceptible to self-judgement and defensive conclusions promoted by some level of guilt for not

fully participating in the experiment but not dropping out. All of these participants rated the workbook as a good resource for a future time.

Participants at levels 3 (20% of the sample) wrote very objectively in their analysis of the workbook content, but often stated they did not feel the need at this time to engage in the exercises. Level 4 (25% of the sample) expressed active engagement on their evaluations. These participants wrote most prolifically about their thoughts on and experiences with the workbook. One level 4 participant even made a phone call to state how successful the whole experiment was for her and her care receiver. This was a clear indication that the goals of this study had been accomplished in at least one case. This case will be discussed in more detail later. Unfortunately the experiential success of case 6E was not entirely reflected in all her scores (see Table 18).

Table 18. CBI: Pre-test and Post-test score differences- Level 3 & 4

	TIME	DEV	PHYSICAL	SOCIAL	EMOTION	TOTAL
Level 3						
1E	3	5	3	0	0	11
3E	0	-1	3	1	2	5
5E	1	3	0	0	2	6
24E	1	2	0	0	0	3
Mean	1.25	2.25	1.5	.25	1.5	6.25
Level 4						
6E	1	-7	-3	0	-2	-11
14E	1	1	0	-3	2	1
15E	0	2	-3	-1	0	-2
16E	1	1	1	4	1	8
19E	-2	4	-4	0	1	-1
Mean	.2	.2	-1.8	.4	1.2	-1
Group mean	0	-1	-1	-1	0	-1

Note: Negative values indicate scores that increased

Level 3 participants are those who were more experienced and engaged the intellectual content but were not interested in actively engaging the problem solving activities. They had their own systems developed over the years of caregiving, which they considered quite adequate. The workbook was seen as an excellent resource. Their CBI raw score differences between pre-test and post varied but their means were above the means for the scores for the experimental group as a whole (total 6.25 vs. -1, the larger group mean of 0, and the control group mean of 1). It may have been that this small group experienced an overall change by some attitudinal adjustment produced by reading new material. They may also have experienced a decrease in burden due to a "better off" phenomena. They all wrote about how the workbook would have been an even better resource for them in the past when they were having more problems with their care receivers. It was as if they were thankful that the more troubling and emotional stages were behind them.

Level 4 participants were the ones who completed the experiment as requested. They expressed a great deal of experiential positivity in their evaluations, but their CBI score differences show no specific trend. Rising overall by one point, their total scores reflected the mean of the experimental group (-1). There was a slight effect on the issue of emotional burden, where the mean score fell by 1.2. Participant 6E who reported the most positive experience actually increased her caregiver burden scores by 11 points from 26 to 37 (she had been lower than the pre-test mean of 36.44). It is possible that the score went up due to the lifting of denial; clearer assessment of her needs and the needs of her care receiver; and the turmoil of the early stages of trial and error experimentation. Some of this static would presumably clear up when she fully incorporates problem-focused coping into her daily life as a caregiver. From her

evaluation responses and the verbally feedback she gave, she has had positive reinforcement and intends to continue working on this new coping strategy.

Although no additional anecdotal information is available on 16E, this participant's scores show a greater level of improvement than 6E with a decrease in the burden score of 8 points. Her workbook evaluation does indicate a very positive approach to the material.

Table 19 shows the pre and post-test differences on the PSI and Zung tests for the level 3 and 4 participants in the experimental group.

Table 19. PSI and Zung: Pre-test and Post-test score differences- Level 3 & 4

	PSI-PSC	PSI-AA	PSI-PC	TOTAL	ZUNG	Z-Range
Level 3						
1E	-7	8	-4	-3	-3	28-31 L
3E	14	24	8	46	-16	49-65 M
5E	-5	0	6	1	12	45-33 L
24E	11	-4	5	12	6	54-48 L
Mean	3.25	7	3.75	14	.2	
Level 4						
6E	2	4	6	12	-5	46-51 M
14E	-15	-6	4	-11	10	65-55 M
15E	-2	0	-1	-3	-8	45-53 M
16E	3	16	-1	18	-2	53-55 M
19E	-9	-4	2	-11	-9	39-48 L
Mean	-4.2	2	1.2	1	-2.8	
Group mean	-2	3	1	2	0	

Note: Negative values indicate scores that increased

The Zung values reflect the differences in the SDS index scores.

Again the Level 3 participants had improvements in their problem solving scores greater than the mean for the experimental group (14 vs. 2 =7X and 4.6 X the whole and control group mean of 3). Their Zung scores were consistent with the group mean (.2 vs. 0) and the whole group mean of 0 as well as the control group mean of -1. Participant 3E did have a rise in the Zung scores from sub-clinical to moderate depression, which could easily have been an environmental change considering the potential for illness, death, a general upheaval in a group

of caregivers and care receivers. Especially the AWBS group when there were 3 deaths and a couple of hospitalizations right at the end of the experiment.

Level 4 participants were fairly variable in their PSI scores, reflecting a probable excitability due to attempting to incorporate new information, rating one's own skills, and initiating trial and error problem solving. The Zung mean score in this sub-group was slightly worse than the experimental group mean (-2.8 vs.0) and closer to the control group mean (-1).

Participant 6E had the second to the largest drop in her PSI total score indicating an improvement in her perceptions of her problem solving ability. Her Zung score increased by 5 points placing her in the borderline area of mild depression (46 to 51). It is possible that this increase was caused by environmental issues, the excitability of emotions due to an attempted behavior change, or a slight lifting of denial about the totality of the job ahead. As a caregiver one has to focus mostly on the day to day. Thinking about the total picture and the possible number of years ahead has to be done only periodically or the whole task can seem overwhelming. New information can awaken these feelings and create some degree of existential crisis. Another factor that may play into this is an increase in the feelings of "responsibility to do the right thing." The workbook does not support this perspective but endorses a more forgiving attitude about the failures that may arise from trial and error problem solving. It is probable that each individual will go through some period of emotional adjustment based on his/her past experiences and potential for self-judgement verses self-assessment. In her phone discussion 6E did not express any depressed feelings and seemed quite pleased with her new choices. She was however reporting on the best of her experiences and may have had some personal worries that affected this score.

Participant 16E continued the downward trend in her scores by dropping 18 points on her PSI but increased her depression score by 2 points (53 to 55). The latter change does not seem substantial since she is still in a mild stage of depression and the previous reasons cited would seem to apply to this case as well.

After examining all of these changes in scores without the benefit of inferential statistical tests for the significance of these differences, one can only tentatively project possible trends. The level 3 and 4 scores indicate a hopeful pattern that could have been more significant if the experiment had run longer, but this sub-group only consists of 9 people. Not a large enough sample with or without more time. The true experimental nature of this research created the need to treat all participants as equal at the outset, which was not true when it came to learning readiness and their willingness to engage. This factor greatly reduced the data that could be used for projections. With all of this in mind, Table 20 contains a representative model of projected effects that could be used as a construct for future descriptive or experimental research using periodic repeated measures. In this table all the previous levels of engagement have been adapted to reflect adoption behaviors after exposure to the Alzheimer's workbook. The behavioral criteria are the same. Level 3 Early Attitudinal Adopters have shown the best trends in the data as discussed previously. Level 4 Early Experiential Adopters seem to have been in a period of variability probably caused by the process of change and also resulting in labile emotional responses. Their scores reflect a fluctuating pattern. Level 5 Full Adopters is a category created to project the possibility of achieving the hypothesized effects of an improvement in problem solving skills, a decrease in burden, and a decrease in depression.

Table 20. Projected Trends in Tests

Level 1	Reluctant Adopters	Potential trends in test changes
15% (3) n=20	Tackling Blockers Uncommitted -dealing with blockers Low readiness for change	PSI = no change CBI = no change ZUNG = slight increase
Level 2	Trial Adopters	
40% (8)	Trial Engagement Approach tentative-still ambivalent but interested in some new information; still worried about time commitment. Low to moderate readiness for change	PSI = no change CBI = no change ZUNG = slight increase
Level 3	Early Attitudinal Adopters	
20% (4)	Experienced Evaluation: Individuals in this category have been caregivers for many years (5-15 years); not interested in a full commitment to a new system but always interested in new resources Moderate readiness for change	PSI = decrease -indicating improved problem solving CBI = decrease ZUNG = no change
Level 4	Early Experiential Adopters	
25% (5)	Open Engagement: looking for new ideas and possibly ways of being; easily engaged in the trial and error process, may experience chaos of change with labile emotions Moderate to high readiness for change	PSI = slight decrease - CBI = variable ZUNG = slight increase
Level 5	Full Adopters	
	Experienced Engagement: Have implemented new system and have had perhaps 6 months to a number of years of experience with the system. Behavior change accomplished	PSI = decrease - indicating improved perceptions of problem solving ability CBI = decreased burden ZUNG = decreased depression

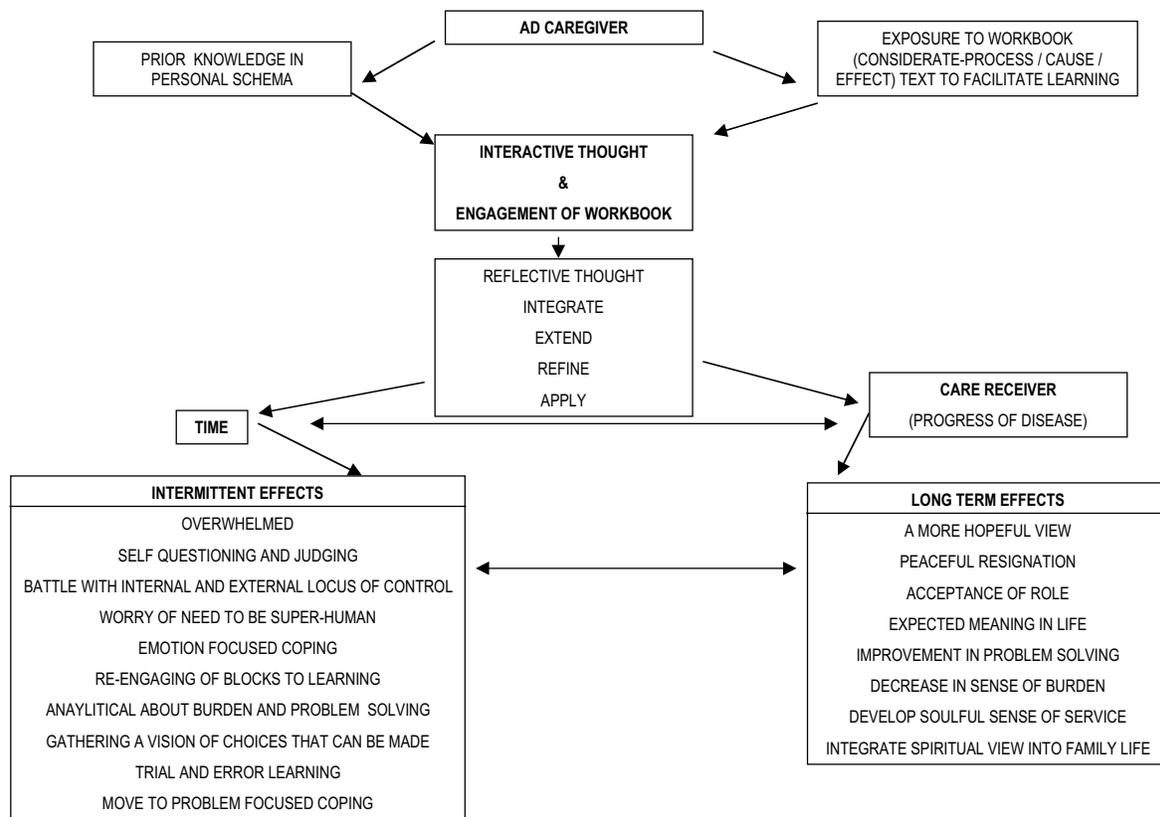


Figure 17. Process Model for Engagement of AWB

In the discussion of this experiment some behavior patterns of engagement of the workbook and adoption of some degree of behavior/attitudinal change have been elucidated and a possible process model of adoption has been created (see Figure 17). Engagement is clearly a powerful factor in the adoption process. If one is held up at level 1 or 2 (Reluctant and Trial Adopters-see Table 16.), then the workbook becomes an intellectual resource and the potential for attitudinal and behavioral change becomes slimmer. All people have some potential to move from level 1 or 2 if they should find themselves unblocked at some point in their future. Level 3 (Early Attitudinal) adopters have a potential to become Experiential adopters, but this is unlikely (see Table 20). They are experienced caregivers and have built systems that satisfy their situations. Their situations can be improved with shifts in attitude, contemplation on end of life

issues, and possibly the use of the spiritual exercises contained in the workbook. These exercises have not been fully tested but could be helpful for the soul of the PWD whatever stage of AD s/he is in. Level 4 (Early Experiential) adopters are those individuals with high readiness to learn. They tend to be in the earlier stages of the caregiving process where the needs and behaviors of the PWD keep them off balance and in need of a systematic but flexible approach to care. Figure 17. Contains a process model that projects the steps in the path of engagement taken by level 4 users to move eventually to level 5. The potential user brings together his/her prior knowledge and combines it with a preview of the workbook material. If s/he can get past any emotional and situation blocks at this stage then the mind engages the material- reflecting, integrating, extending thought patterns, refining thinking processes, and applying the material through attitudinal changes and the application of trial and error problem solving process. All this is deeply impacted by life situations but what has emerged from this research, as the most problematic factors are time and the progress of the disease of the care receiver. These two issues create a great deal of threat to the balance of the life of the caregiver and care receiver dyad. The intermittent effects of the process are listed on the left side of the diagram and contain negative and positive effects and outcomes. It seems clear from this research that in the often volatile world of caregiving for a person with AD that caregiver emotions move up and down a continuum and are not maintained in a static direction. Even with the best support, resources, and a systematic approach the caregiver will inevitably be thrown off balance and have to recover. If the caregiver engages a considerate (easily accessible content), process oriented, cause and effect text like the Alzheimer's workbook, s/he may over time experience the long term effects listed on the right side of the model. When achieved these would be positive and long lasting. The question that remains unanswered from this research is how long it would take

and what levels of personal spiritual change it would take for a caregiver to achieve these effects. These positive levels would not preclude plunges into imbalance, but one would project that the depth of these valleys of emotional difficulty would be shallower and of less duration.

One key factor that did not get tested by any of the caregivers was the spiritual material. Several participants did read that section and reported the material was interesting. Whether or not the caregiver wishes to engage the care receiver in the spiritual realm, it would seem that for the caregiver to achieve true peace s/he must work and progress in their own spiritual realm.

Identifying factors that might contribute to and elements of the process a caregiver could go through to accomplish this is an area of future research. The potential for spiritual transcendence exists when engaging in service to another human being who could not have any quality of life without one's gift of help. This service is seen as the realm of saintly people like Mother Teresa, but everyday people offer service in this same way and their actions are seldom noticed and build no acclaim. The spiritual definitions of caregiving need to change as part of the transcendence of humanity.

A gift from God: the case of one

As cited previously, case 6E stood out in this research as a case of one. She took the time to make a phone call to report her positive experience with the workbook. She expressed fear that she would not be able to articulate all of her feelings on the workbook evaluation. This did turn out to be the case as her spoken words were far more powerful than the written ones. She stated that her first realization from engaging the material was that she had been doing too much for her mother. Her mother was very unhappy and she had not known why. After reading the appropriate parts of the book, she remembered that her mother had enjoyed doing the laundry and the dishes. She went through an analysis of her mother's current abilities and realized that

she could not start, load, or empty the washer or the dryer, but she could still fold clothes. She began having her mother perform that activity. She also recognized that the only part of dishwashing that her mother could still perform was drying (not putting away, if you ever wanted to find things again). She was beginning to think about how to structure other ADLs for her mother so that she would be able to do more for herself. This caregiver reported that she and mother were now working together and that her mother was much happier. Her last and most poignant/transcendent comment was that she and her mother were now "making happy memories for the future."

This was a gift from God and a sign that success is possible.

Workbook Evaluations

1. Which sections were you able to read? 17 surveys were complete enough to total

Summary of a sample of the comments are listed below:

_ **Introduction = 100%** (percent of responders who read section)

Comments:

- Felt that the author understood obstacles (going through same obstacles) therefore, felt her insight valuable
- I found most of info "right on" with my experience.
- Information was good and lots of details.
- Excellent-personal experience with the disease is the best teacher.
- I certainly related to the #2 on p.7 (middle madness).

_ **How to use this book = 100%**

Comments:

- Easy to follow directions/instructions
- The arrangement of behaviors and solutions were very helpful and easily accessed
- Very precise and well organized. Obviously thoroughly thought through.
- Clear and useful. The behaviors List/Log helped me get a handle on how advanced my mom is or isn't.

_ **Chapter 4 Alzheimer's Disease = 75%**

Comments:

- The explanation of the myelin sheath development was very interesting. Good explanation of the process of retrogenesis.

- Reading this area helps me to see the progression of dementia such things as getting lost while driving, reading and writing problems.
- Disease stages enlightening.
- Very informative/Good information

_ Chapter 5 Whole person concept and living well with chronic illness = 75%

Comments:

- Gave good tips, but I also viewed caretaking as a "all consuming" job after reading this section. I can't think of it in such a way. I would just give up-very overwhelming.
- I find the emotional issues the hardest to deal with at this stage in my husband's disease.
- Emotionally/Socially/& Spiritual. I found my self lacking and wonder if I'm really doing this right.
- Social and physical capabilities need work. Approaching stage in getting help and assistance, which this chapter gives advice.
- Very well written, good comments for caregivers.

_ Chapter 6 Behavioral/Problem solving vs. Medical/Disease approach = 95%

Comments:

- Would say that approaching the middle stage and good explanation of how to handle these areas.
- I think the book will be helpful when future problems arise.
- Informative
- I have found creativity is the main key. At some points it's like working with big child. Bathing is a problem. I solved with ice cream.
- Information good for a caretaker in which family member is in the first stage of AD.
- Good for early stage caregiver.

_ Chapter 7 Care Management and working with the medical profession = 88%

Comments:

- Good information for caretaker to work closely with medical profession and support groups and other potions the caretaker has.
- I had a very difficult time getting my husbands PCP to listen to my concerns regarding my husband's early memory problems!
- I found mom's Dr. has his own agenda and not very helpful to me. Power of Atty. is essential!!! It makes them pay attention to you.
- Worth re-reading several times-need to follow suggestions offered.
- This is a good reference for me in the future.
- Good for early stage caregivers.
- Fairly hopeless.

_ Chapter 8 Coping perspectives for caregiving = 88%

Comments:

- This was one of the best chapters for helping caretakers understanding the process of AD.
- Very reassuring to me. "Been there, done that" with all these emotions. Thanks for the part about no one escaping the anger.
- Very perceptive. I've run most of the emotions. I really understand why they call this Middle Madness. I know it is only going to get worse which is my stress point and I try not to dwell on it.
- The explanation of retrogenesis was particularly helpful because I do tend to react to my mom, as I knew her and become very frustrated and angry with her perservations.
- Thought provoking.
- Will be helpful as the disease progresses.
- Good/comforting

_ Chapter 9 Relationship dilemmas in caregiving = 88%**Comments:**

- The explanation of regression was helpful because although I sense some of this I kept thinking I could fix it with "adult" remedies. Thank you.
- As an "adult child" of my mom-I have to keep continually "upbeat" and positive or the caregiving becomes very difficult.
- I feel at this time I should belong to a support group and get some ideas. Families should understand what caregivers are doing and also how dementia works on their minds.
- Good chapters for all members of the family.
- Very important information.
- Very true.

_ Chapter 10 A spiritual perspective = 65%**Comments:**

- Helps to understand the spiritual perspective of a person with AD.
- She sings spiritual songs with karaoke at day care. She went through a stage where she prayed on her own to Brother Martin, Brother John, and occasionally God if her constant needs were not being met.
- Spiritual advice is great. Compassion has to be developed, and comfort in prayer does help.
- Very interesting-for me probably the most difficult to deal with.
- Inspirational.

_ Chapter 11 Working with Complimentary therapies = 59%**Comments:**

- Discusses how to go about helping the AD person have the highest quality of life they can.
- Physical exercise works well. Interesting alternatives outlined in this chapter-good resources.

- Alternative therapy, I am a believer. Need help in this area and suggestions are good to see what can work with.

_ Chapter 12 Accepting and building support = 82%

Comments:

- ****Best Chapter for me.** This is the hardest thing for me. I did get her into day care. The peace of mind it gave me and happiness it brought her made me feel so silly for feeling guilty about putting her there. I felt I should have been able to do it all myself which is self-destructive.
- Just read books-no time to attend meetings at night. She calls for me constantly now. Can only do things when she is at day care. Hard for my 89 year old father, also.
- Gave good advice on looking for help. Luck has to be with you in getting compatible people to assist.
- Good- remember to use support members.
- Lots of good ideas.
- Helpful information.
- Excellent resource reference.

_ Chapter 13 Long term care placement and *End of Life* decisions = 82%

Comments:

- Good information-but more info on consequences related to hospital stays and consequent billing.
- We're attempting to plan for LTC-End of Life decisions- not discussed before she developed signs of AD.
- This is the hardest stage at the end. Certainly know about hospice and checked on some homes where there is good care.
- I'm not ready for this yet. Don't want to think about it ever.
- Something to think about.
- Helpful information.
- A lot to think about.
-

2. Were you able to mark your person's behaviors on the List/Log? Yes 70% No 30%

3. If you were able to perform this activity did you find it helpful? Yes 45% No 53%

Comments:

- Read the list but did not mark and fully experience because of time.(5) 55%
- Experienced caregiver and did not feel the need.(4) 45%

4. Which Behaviors on the List/Log were you able to work with? (examples)

- A variety of behaviors listed- personal choice - no pattern.

5. Were you able to find ideas that helped you work with your Person with Dementia?

Yes = (15) 89%. (examples)

- The overarching idea of retrogenesis and to constantly remember myself that very little will remain constant. What I think is a great solution may be great for a day or not at all. The workbook is a constant reminder that there is help out there.
- My PWD was refusing showers. She seemed afraid of the water spraying on her. I installed a hand held shower. It seemed to help. I have used your suggestions in everything from money to obsessions.
- The coping perspective helped me. Just to remember to let her do what she is able instead of me doing it all.
- When I questioned myself if I was doing things correctly it was good to see that a professional was handling the problem as I .
- Practice being direct and literal.

No (2) 11% (examples)

- My AD person is very near final stage. Workbook would have been helpful 5 years ago.
- Have been a caretaker of a family member with AD for 15 years.

6. List your favorite sections of the Workbook

- Chapter 3 -Behaviors
- The emotional, social, and some physical.
- Behaviors list/log and pages that can be referred to.
- Being able to identify problems then reading suggested solutions
- I think the behavior list keyed by page number to the coping strategies is an excellent way to organize such a huge amount of information into a very user-friendly format.
- Chapter 12 (Accepting and building support)
- Chapter 5- (The whole person concept) summarizes the entire workbook and the problem of AD.
- Chart.

7. List your least favorite sections of the Workbook.

- Chapter 11 (Working with complimentary therapies)
- Chapter 11- I've worked with 2 people who had AD (for apx. 10 years) and from my experience with them, alternative therapies would not help mostly because of a lack of cooperation from the person with AD. Some of the suggestions would help on occasion.
- It seemed after reading workbook that my whole life should consist of monitoring, guiding, and catering to my PWD. I finally had to skim these sections and focus on what I could do personally. I am doing what I can with love, patience, and a tight timeframe.
- Chapter 13.(Long term care placement and *End of Life* decisions) This part of me is still in denial.

8. Was there anything left out of this Workbook that you would like to see included?

- I feel that the workbook is geared more toward women than men- no mention is made of men working with tools, automotive repair, gardening, and such. I understand why this might be

so, but I personally I've had lots of trouble with my PWD wanting to "fix" things and botches them up completely.

- Some things like where to go for help would be helpful.
- Preservation and the constant repetition of questions. How to deal with anger -not hers but mine.
- Hospital insurance and Medicare billing.
- Maybe more information about nursing homes or insurance to help.
- Tabs.

9. Would you recommend this Workbook to other caregivers. Yes 100%

10. General Comments:

- It is amazing in your writing and understanding of Alzheimer's. Having been through the situation you can understand the problems of the caregiver.
- Would be very helpful for early stage AD especially for the young caregiver.
- I would recommend this book to a caretaker who is new to AD.
- It was more than I expected-excellent!
- I wish I had more time to spend on it. I will use it a little at a time.
- More than what the neurologist has ever talked about.
- This book would have been lots of help about 8 years ago. I've learned by trial and error.
- This book was well organized and full of good information. It's obvious that personal experience and much work went into it. The content is excellent.
- I was in a group for caregivers that I told the whole group to contact you.
- I haven't had the time nor the necessity to use the book in this short time. I'm sure I will refer to it often as the need arises.
- Extensive description of Alzheimer's patients and good examples of how to deal with different stages.

Essentially this information speaks for itself. One can see reflected in these comments the pressures of time and the general duress of being a caregiver for a PWD. Information from these evaluations has been used to create models for the levels of engagement (Table 16.) and the process model for the engagement of the AWB (Figure 17.). It is interesting to note that the two least favored sections (Chapter 10 -spirituality = 65% and Chapter 11 -alternative therapies = 59%) were the most controversial and both contain information not widely known or considered in the community of AD professionals and caregivers. The suggestion about strengthening issues surrounding the needs of men was well taken and will be used in the next round of editing

on the workbook. It was heartening that all participants felt it was an excellent resource (no matter what the level of engagement) and would recommend it to other caregivers.

CHAPTER 5: Conclusions

Due to lack of significance on the 2X 2 repeated measures ANOVAs for all the scores on sub-tests and total tests administered in this study, the null hypothesis had to be retained. In spite of this, much descriptive information was gathered about this population of caregivers of persons with Alzheimer's Disease and test trends were identified. On examination of the raw scores and workbook evaluations, a larger picture emerged. 55% of the experimental caregivers did not engage the workbook materials due to time pressure (personal and environmental) and stress blocks. The remaining 45% engaged at two different levels, experienced caregivers (level 3) and early caregivers (level 4) with high to moderate levels of readiness for change. Caregivers in the early stages of their caregiving experience with moderate to high readiness for change were found to be the most receptive to the workbook information, format and problem solving exercises. Although their test scores did not reflect the hypothesized changes, they did trend in a hopeful direction. Scores for experienced caregivers showed a stronger trend in a positive direction possibly due to attitudinal shifts from exposure to the workbook material. Within the experimental group a *case of one* was identified by voluntary phone contact, which reflected complete success in engaging the workbook exercises and positive outcomes. It is still possible that self-motivated learners (moderate to high readiness for change) can engage the Alzheimer's workbook and overtime experience attitudinal and behavioral changes. The length of time for this to occur remains undetermined. In 5 cases, the shift had begun (demonstrated by their written evaluations), but the change was not reflected (in a statistically significant way) in the scores at one-month duration. The workbook is best targeted toward early caregivers who meet the readiness and engagement profiles identified in this study.

Future research could focus on developing a case management/advice model from the materials tested in this study. The instruments used can create a profile of the caregiver's perceived problem solving approaches and levels, levels of caregiver burden with specific subsets, and levels of depression. This data could be used to identify the immediacy of the caregiver's needs for support, advice, information, and medical help if high levels of depression are discovered. The workbook *care receiver behavioral profile* could be used separately from the workbook to identify areas of need for the care receiver. The workbook could then be tagged with areas of first concern, giving the caregiver a more focused place to begin. This data in combination could be used to create a highly effective counseling profile and used in a face to face or phone encounter. Ongoing sessions could be greatly enhanced through the use of the workbook.

In addition to the above measurements, another caregiver profile could be created to include questions that identify all the areas of stress and strain outlined in Tables 3-6 as well as the mitigating factors in Table 7. This inventory could look at perceived sources of burden in greater detail. The burden test could be matched to or included in this new measure. A balance or ratio score could be created to help professionals help caregivers examine deficits and strengths for a holistic look at their caregiving world.

Another avenue of research could be to extract the spiritual exercises from the workbook, creating an experimental pamphlet that could be used with a targeted group of caregivers. These caregivers would work with their care receivers for at least a year. Some measures of spiritual states would have to be identified or created for this population to develop a baseline and be administered at several different intervals to track changes in the caregiver and care receiver over time. This type of research would be limited in its generalizability except to motivated caregivers

and their PWDs, but that could be acceptable, as it would potentially help to identify stages of and methods to enhance spiritual growth in both members of the AD dyad.

Descriptive research also needs to be done in the area of spirituality and caregiving. A caregiver must look to his/her own spiritual growth to experience transcendence and peace in the role. Identifying factors that might contribute to and elements of the process a caregiver could go through to accomplish this, is an area of importance. The potential for spiritual transcendence exists when engaging in service to another human being who could not have any quality of life without one's gift of help. This service is seen as the realm of saintly people like Mother Teresa, but everyday people offer service in this same way and their actions are seldom noticed and often do not build self-esteem. Utilizing an inter-denominational approach would be important to unite disparate sectarian viewpoints and to reveal a path of spiritual commonality. The spiritual definitions of caregiving need to change as part of the transcendence of humanity.

This study focused on the caregivers of persons with dementia and their abilities to independently engage a self-educative process with a content accessible workbook. Although the null hypothesis had to be retained, as the measures did not change as definitively as hoped; much descriptive information was gathered creating an insightful profile of this population their perceptions of their problem solving abilities, levels of burden, levels of depression, and their abilities to engage the educative process. All the participants in the experimental group rated the workbook as an excellent resource. With or without dramatic test results the Alzheimer's workbook has the potential to do a great deal of good. The *case of one* clearly demonstrates that creating successful attitudinal and behavioral change utilizing the Alzheimer's workbook is a reality; but unfortunately, one that lies just beyond the realm of measurable science at this moment.

APPENDIX A. ENROLLMENT DOCUMENTS

Alzheimer's Workbook Study Project ENROLLMENT FORM

Ref # _____

CARE GIVER

Name: _____

Address: _____

City: _____ ST. _____ Zip _____

Phone #: (H) _____ (O) _____ (Cell) _____

Sex	M	F	Age
	-	-	_____

Level of education: (circle/check highest level completed)

Grades 1 -2-3-4-5-6-7-8

High School Grades 9-10-11-12

College 1-2-3-4

Masters Degree _

Doctoral Degree _

CARE RECEIVER

Name: _____

Sex	M	F	Age
	-	-	_____

SOURCE OF REFERRAL

Day care: _____

Support Group: _____

Other: _____

Contact information:**Elizabeth Harwood Cochran RN MS****Office: (505) 559-6038****Address: 805 Guadalupe Circle NW Albuquerque, NM 87114**

INFORMED CONSENT FORM

I _____ (print name) consent to participate in Alzheimer's workbook project conducted by Elizabeth Harwood Cochran Th.D., Ph.D. candidate. The project will consist of the following:

- ◆ Gathering of demographic enrollment information (all participants).
- ◆ Taking 3 short written pre and post-tests approximately 3- 4 weeks apart (all participants).
- ◆ Being randomly sorted into either a control or experimental group.
- ◆ Reading instructions on the program (experimental group)
- ◆ Receiving a copy of Alzheimer's Workbook-Holistic Health and Problem-Solving for Everyday Care (experimental group).
- ◆ Utilizing the workbook for 3-4 weeks (experimental group).
- ◆ Completing an evaluation on the contents of the workbook (experimental group).
- ◆ Persons in the control group will be on a waiting list and will receive their copy of Alzheimer's Workbook-Holistic Health and Problem-Solving for Everyday Care *after* the post-testing.

There will be confidentiality of records and although portions of this study may be recorded in scientific publications, your name will not be identified.

_____ (Signature)

_____ (Date)

APPENDIX B: TESTS

Caregiver Burden Inventory

M. Novak and C. Guest

We'd like to know how you see your experience as a caregiver and what your feelings are about giving care.

Think of your experiences as a family caregiver. How well does each of the following statements describe your experience in caring for your care receiver in the past month?

0	1	2	3	4
NOT AT ALL	SLIGHTLY	MODERATELY	QUITE	VERY
DESCRIPTIVE		DESCRIPTIVE		DESCRIPTIVE

- ___ 1. My care receiver needs my help to perform many daily tasks.
- ___ 2. My care receiver is dependent on me.
- ___ 3. I have to watch my care receiver constantly.
- ___ 4. I have to help my care receiver with many basic functions.
- ___ 5. I don't have a minute's break from my caregiving chores.
- ___ 6. I feel that I am missing out on life.
- ___ 7. I wish I could escape from this situation.
- ___ 8. My social life has suffered.
- ___ 9. I feel emotionally drained due to caring for my care receiver.
- ___ 10. I expected that things would be different at this point in my life.
- ___ 11. I'm not getting enough sleep.
- ___ 12. My health has suffered.
- ___ 13. Caregiving has made me physically sick.
- ___ 14. I'm physically tired.
- ___ 15. I don't get along with other family members as well as I used to.
- ___ 16. My caregiving efforts aren't appreciated by others in my family.

0	1	2	3	4
---	---	---	---	---

NOT AT ALL SLIGHTLY MODERATELY QUITE VERY
DESCRIPTIVE DESCRIPTIVE DESCRIPTIVE

- ___17. I've had problems with my marriage.
- ___18. I don't do as good a job at work as I used to.
- ___19. I feel resentful of other relatives who could but do not help.
- ___20. I feel embarrassed over my care receiver's behavior.
- ___21. I feel ashamed of my care receiver.
- ___22. I resent my care receiver.
- ___23. I feel uncomfortable when I have friends over.
- ___24. I feel angry about my interactions with my care receiver.

The Problem Solving Inventory

Form B

P. Paul Heppner, Ph.D.

Name _____ Date _____

Sex _____ Age _____

Directions:

People respond to personal problems in different ways. The statements on this inventory deal with how people react to personal difficulties and problems in their day-to-day life. The term "problems" refers to personal problems that everyone experiences at times, such as depression, inability to get along with friends, choosing a vocation, or deciding whether to get a divorce. Please respond to the items as honestly as possible so as to most accurately portray how *you* handle such personal problems. Your responses should reflect what you *actually* do to solve problems, not how you think you *should* solve them. When you read an item, ask yourself: Do I ever behave this way? Please answer every item.

Read each statement and indicate the extent to which you agree or disagree with that statement, using the scale provided. Mark your responses by circling the number to the right of each statement.

1	2	3	4	5	6
Strongly Agree	Moderately Agree	Slightly Agree	Slightly Agree	Moderately Disagree	Strongly Disagree

1. When a solution to a problem has failed, I do not examine why it didn't work.....	1 2 3 4 5 6
2. When I am confronted with a complex problem, I don't take the time to develop a strategy for collecting information that will help define the nature of the problem.....	1 2 3 4 5 6
3. When my first efforts to solve a problem fail, I become uneasy about my ability to handle the situation	1 2 3 4 5 6
4. After I solve a problem, I do not analyze what went right and what went wrong	1 2 3 4 5 6
5. I am usually able to think of creative and effective alternatives to my problems	1 2 3 4 5 6
6. After following a course of action to solve a problem, I compare the actual outcome with the one I had anticipated	1 2 3 4 5 6
7. When I have a problem, I think of as many possible ways to handle it as I can until I can't come up with any more ideas.....	1 2 3 4 5 6

Read each statement and indicate the extent to which you agree or disagree with that statement, using the scale provided. Mark your responses by circling the number to the right of each statement.

1	2	3	4	5	6
Strongly Agree	Moderately Agree	Slightly Agree	Slightly Disagree	Moderately Disagree	Strongly Disagree
8.	When confronted with a problem, I consistently examine my feelings to find out what is going on in a problem situation.....				1 2 3 4 5 6
9.	When confused about a problem, I don't clarify vague ideas or feelings by thinking of them in concrete terms				1 2 3 4 5 6
10.	I have the ability to solve most problems even though initially no solution is immediately apparent.....				1 2 3 4 5 6
11.	Many of the problems I face are too complex for me to solve.....				1 2 3 4 5 6
12.	When solving a problem, I make decisions that I am happy with later.....				1 2 3 4 5 6
13.	When confronted with a problem, I tend to do the first thing that I can think of to solve it				1 2 3 4 5 6
14.	Sometimes I do not stop and take time to deal with my problems, but just kind of muddle ahead				1 2 3 4 5 6
15.	When considering solutions to a problem, I do not take the time to assess the potential success of each alternative				1 2 3 4 5 6
16.	When confronted with a problem, I stop and think about it before deciding on a next step				1 2 3 4 5 6
17.	I generally act on the first idea that comes to mind in solving a problem				1 2 3 4 5 6
18.	When making a decision, I compare alternatives and weigh the consequences of one against the other				1 2 3 4 5 6
19.	When I make plans to solve a problem, I am almost certain that I can make them work				1 2 3 4 5 6
20.	I try to predict the result of a particular course of action				1 2 3 4 5 6
21.	When I try to think of possible solutions to a problem, I do not come up with very many alternatives				1 2 3 4 5 6
22.	When trying to solve a problem, one strategy I often use is to think of past problems that have been similar				1 2 3 4 5 6
23.	Given enough time and effort, I believe I can solve most problems that confront me				1 2 3 4 5 6
24.	When faced with a novel situation, I have confidence that I can handle problems that may arise				1 2 3 4 5 6
25.	Even though I work on a problem, sometimes I feel like I'm groping or wandering and not getting down to the real issue				1 2 3 4 5 6
26.	I make snap judgments and later regret them				1 2 3 4 5 6
27.	I trust my ability to solve new and difficult problems				1 2 3 4 5 6
28.	I use a systematic method to compare alternatives and make decisions				1 2 3 4 5 6
29.	When thinking of ways to handle a problem, I seldom combine ideas from various alternatives to arrive at a workable solution				1 2 3 4 5 6
30.	When faced with a problem, I seldom assess the external forces that may be contributing to the problem				1 2 3 4 5 6
31.	When confronted with a problem, I usually first survey the situation to determine the relevant information				1 2 3 4 5 6
32.	There are times when I become so emotionally charged that I can no longer see the alternatives for solving a particular problem				1 2 3 4 5 6
33.	After making a decision, the actual outcome is usually similar to what I had anticipated				1 2 3 4 5 6
34.	When confronted with a problem, I am unsure of whether I can handle the situation				1 2 3 4 5 6

35. When I become aware of a problem, one of the first things I do is try to find out exactly what the problem is 1 2 3 4 5 6

	CON	AA	PC	
Page 1 Subtotal	_____	_____	_____	
Page 2 Subtotal	_____	_____	_____	
Score	_____	_____	_____	Total _____

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Name _____

Age _____ Sex _____ Date _____

		None or a little of the time	Some of the time	Good part of the time	Most all of the time	
1	I feel down-hearted, blue and sad					
2	Morning is when I feel the best					
3	I have crying spells or feel like it					
4	I have trouble sleeping through the night					
5	I eat as much as I used to					
6	I enjoy looking at, talking to and being with attractive women/men					
7	I notice that I am losing weight					
8	I have trouble with constipation					
9	My heart beats faster than usual					
10	I get tired for no reason					
11	My mind is as clear as it used to be					
12	I find it easy to do the things I used to					
13	I am restless and can't keep still					
14	I feel hopeful about the future					
15	I am more irritable than usual					
16	I find it easy to make decisions					
17	I feel that I am useful and needed					
18	My life is pretty full					
19	I feel that others would be better off if I were dead					
20	I still enjoy the things I used to					
				SDS Raw score		
				SDS Index		

APPENDIX C: LETTERS TO PARTICIPANTS

Alzheimer's Workbook Study

February 6, 2004

Dear Study Participant,

Thank you so much for volunteering to participate in this study. Enclosed you will find a packet with an enrollment sheet and the three initial caregiver tests. Please complete these documents and return them in the enclosed postpaid envelope as soon as possible. When I receive your packet I will contact you by phone and let you know whether you are in the intervention or control group. If you are in the intervention group, I will send you a workbook and study instruction sheet. If you are in the control group, you will receive your workbook after you have completed the second set of tests in 3-4 weeks. Please feel free to call me if you have any further questions.

Sincerely,

Elizabeth Harwood Cochran RN MS
Doctoral Candidate - Holos University Graduate Seminary

Ms Elizabeth H. Cochran
805 Guadalupe Circle NW
Albuquerque, NM 87114
559-6038

Alzheimer's Workbook Study

February 6, 2004

Dear Study Participant,

Thank you so much for volunteering to participate in this study. Enclosed you will find your copy of the Alzheimer's workbook. Attached to this letter is your study instruction sheet. This sheet details the steps I would like you to take over the next month during your trial of the workbook. In 3-4 weeks, you will receive your second set of tests as well as an evaluation. I encourage you to mark sections in the workbook that are especially meaningful and keep other notes to include in your evaluation. Your comments will be very valuable to the pre-publication rewrite of the workbook. Please feel free to call me if you have any further questions.

Sincerely,

Elizabeth Harwood Cochran RN MS
Doctoral Candidate - Holos University Graduate Seminary

Ms Elizabeth H. Cochran
805 Guadalupe Circle NW
Albuquerque, NM 87114
559-6038

Alzheimer's Workbook Study

February 6, 2004

Dear Study Participant:

Thank you so much for volunteering to participate in this study. You have been enrolled in the study for the prescribed 3-4 week period. Enclosed is your posttest packet. Please fill out all of these documents as soon as you can and return them in the enclosed postpaid addressed envelope. If you have been in the waitlist group, your free workbook will be mailed to you (or left at your daycare facility-after notice by phone) as soon as your posttests are logged in. Please feel free to call me if you have any further questions.

Sincerely,

Elizabeth Harwood Cochran RN MS
Doctoral Candidate - Holos University Graduate Seminary

APPENDIX D: INSTRUCTIONS FOR WORKBOOK STUDY

- This is an educational study designed to test a specially designed content accessible workbook containing problem solving suggestions on behavioral issues that come up in the everyday care of a person with Alzheimer's disease.
- You need to read the *introduction* and *how to use this book* sections of the workbook.
- Basically we are asking you to follow the instructions in those two sections.
- Mark (on the *behaviors list/log*) all the behaviors that your person with Alzheimer's disease is able to do or does at this time.
- Pick some of the behaviors that are causing you some problems.
- Refer to the specified pages in the *behaviors discussions and coping strategies* section. Mark some suggestions that you would like to try. Note: the ideas are listed from the most supportive and usually easiest to do, to the more complicated and restrictive. It is usually best to start simple.
- The *behaviors discussions and coping strategies* section is not designed to be read straight through like a regular book. It is more of a reference.
- We encourage you to mark up the workbook, as you like. Put tabs on the pages. Mark the sections you are working on. Use the note sections to write your own suggestions.
- Read the back chapters at your leisure over the next month. They contain many interesting and helpful perspectives on caregiving but do not have to be read as part of the problem solving process.
- Mark any parts of the chapters that you found meaningful and or helpful.
- We will have you fill out an evaluation of the workbook when the study is over.

Thanks for participating in this study.

Contact information: Elizabeth Harwood Cochran RN MS Office: 559-6038

APPENDIX E: WORKBOOK EVALUATION

ALZHEIMER'S WORKBOOK EVALUATION

Answer all relevant sections:

1. Which sections were you able to read?

Introduction

Comments: _____

How to use this book

Comments: _____

Chapter 4 Alzheimer's Disease

Comments: _____

Chapter 5 Whole person concept and living well with chronic illness

Comments: _____

Chapter 6 Behavioral/Problem solving vs. Medical/Disease approach

Comments: _____

Chapter 7 Care Management and working with the medical profession

Comments: _____

Chapter 8 Coping perspectives for caregiving

Comments: _____

Chapter 9 Relationship dilemmas in caregiving

Comments: _____

_ Chapter 10 A spiritual perspective

Comments: _____

_ Chapter 11 Working with Complimentary therapies

Comments: _____

_ Chapter 12 Accepting and building support

Comments: _____

_ Chapter 13 Long term care placement and *End of Life* decisions

Comments: _____

2. Were you able to mark your person's behaviors on the List/Log? _ Yes _ No

3. If you were able to perform this activity did you find it helpful? _ Yes _ No

Comments:

4. Which Behaviors on the List/Log were you able to work with? (give some examples)

Behavior

#1 _____

Behavior

#2 _____

Behavior

#3 _____

Behavior

#4 _____

Behavior

#5 _____

5. Were you able to find ideas that helped you work with your Person with Dementia?

_ Yes give examples _____

_ No give examples _____

6. List your favorite sections of the Workbook. _____

7. List your least favorite sections of the Workbook. _____

8. Was there anything left out of this Workbook that you would like to see included?

9. Would you recommend this Workbook to other caregivers. **_ Yes _ No**

**10. General
Comments**

APPENDIX F: THE WORKBOOK

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