



132
702
THS



This is to certify that the

thesis entitled

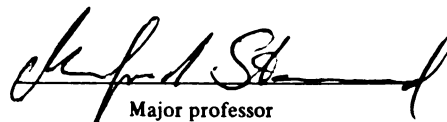
DIFFERENCES IN THE LEVEL OF DEPRESSION
BETWEEN SPOUSE AND DAUGHTER CAREGIVERS
OF ELDERLY DEMENTIA PATIENTS

presented by

Juliet Alfonso-Santos

has been accepted towards fulfillment
of the requirements for

M.S. degree in Nursing


Major professor

Date 4/30/98

LIBRARY
Michigan State
University

PLACE IN RETURN BOX
 to remove this checkout from your record.
TO AVOID FINES return on or before date due.

DATE DUE	DATE DUE	DATE DUE
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

**DIFFERENCES IN THE LEVEL OF DEPRESSION BETWEEN
SPOUSE AND DAUGHTER CAREGIVERS OF ELDERLY
DEMENTIA PATIENTS**

By

Juliet Alfonso-Santos

A THESIS

**Submitted to
Michigan State University
in partial fulfilment of the requirements
for the degree of**

MASTER OF SCIENCE

College of Nursing

1998

ABSTRACT

DIFFERENCES IN THE LEVEL OF DEPRESSION BETWEEN SPOUSE AND DAUGHTER CAREGIVERS OF ELDERLY DEMENTIA PATIENTS

By

Juliet Alfonso-Santos

This study examines the level of depression experienced by wife, husband and daughter caregivers of elderly dementia patients. Its main focus is to identify which group is most at risk for developing depressive symptomatology (measured in terms of the 15 question, gender bias free CES-D Scale). Results revealed that there were no substantial differences in the mean levels of depression among the three caregiver groups. However, there were two significant findings: 1) the average depression scores among all caregiver groups are high and points to clinical depression risk, and 2) high care demands explain part of the reason for increased depressive symptomatology. Caregiver age, relationship to patient and duration of care appeared to have little impact on depression.

Copyright by
JULIET ALFONSO-SANTOS
1998

DEDICATION

To my husband, Melvin,

whose genuine concern for my success
supported my endeavor by taking on my
role for a time with a positive
attitude..

To my 8 years old, Elizabeth,

whose piano music and singing relaxed
and rejuvenated me...

To my 5 years old, Lauren,

whose contagious laughter,
charisma and sense of humor kept a smile
on my face...

To my 3 1/2 years old, Michael,

our "Angel Boy", whose hugs and kisses
constantly kept my priorities in
perspective...

To my mother, Juana Alfonso,

whose goal oriented, persevering genes
pervade my being and whose prayers gave
me courage to achieve and succeed...

....you are all heaven sent.

ACKNOWLEDGMENT

To Dr. Manfred Stommel.....

my professor, thesis chairman,

mentor and friend....

whose expert guidance, dedication to

excellence and love for teaching

patiently assisted me in completing this

thesis in a timely manner...

...and whose encouragement made the

process *almost* bearable...

To Dr. Georgia Padonu & Dr. Celia Wills...

my thesis committee members...

whose insightful suggestions and kind

words made this challenging process a

little less stressful...

Thank you does not seem to suffice...

TABLE OF CONTENTS

LIST OF TABLES.....	vii
LIST OF FIGURES.....	viii
INTRODUCTION.....	1
Purpose of the Study.....	4
Key Concepts.....	4
LITERATURE REVIEW.....	5
Influencing Factors on Depression.....	9
Hypothesis.....	11
THEORETICAL FRAMEWORK.....	12
Study Model.....	14
NEED FOR STUDY.....	17
METHODOLOGY.....	17
Original Studies.....	17
Sample for Current Analysis.....	18
Operational Definitions & Instrumentation.....	19
ANALYSIS.....	21
RESULTS.....	23
Socio-Demographic Characteristics of Caregivers.....	23
Socio-Demographic Characteristics of Care Recipients.....	25
CES_D Scale Scores.....	26
Caregiver Health.....	26
Care Demands.....	26
Caregiver Relation to Patient.....	29
DISCUSSION.....	30
Implications for Advanced Nursing Practice & Primary Care.....	33
Limitations of Research.....	35
Future Studies.....	37
LIST OF APPENDICES	
A - Items from the Center for Epidemiologic Studies Depresson Scale (CES-D).....	38
B - Revised 15 Items CES-D Scale.....	40
C - Cognitive Deficit Scale.....	42
REFERENCES.....	44

LIST OF TABLES

I.	Table 1	Socio-Demographic Characteristics of Caregivers.....	24
II.	Table 2	Socio-Demographic Characteristics of Caregivers Recipients.....	25
III.	Table 3	CES-D Scale Caregiver Depression Scores.....	26
IV.	Table 4	Weekly Involvement In Tangible Care Tasks by Caregiver.....	28
V.	Table 5	Depression Scores Regressed on 7 Covariates Representing 6 Issues.....	29
VI.	Table 6	Caregiver Unadjusted and Adjusted Mean Depression Scores.....	30

LIST OF FIGURES

I.	Figure 1	Lazarus & Folkman's Model of Stress Adaptation.....	13
II.	Figure 2	Dementia Caregiver's Model of Stress Adaptation.....	15

INTRODUCTION

Dementia is a major source of morbidity in the elderly in the United States. Between 6 and 7 percent of persons 65 years or older suffer from moderate to severe dementia and, among those 85 years or older, the prevalence is at least 20 percent (Baumgarten, Hanley, Infante-Rivard, Battista, Becker & Gauthier, 1994). It is estimated that over 50% of all nursing home patients suffer from dementia (Fujimoto & Shimomura, 1996) and unfortunately, no specific treatment or cure exists for most progressive dementias (Boss, 1994). Therapy is primarily focused on maintaining and maximizing the remaining physical and mental capacities, restoring functions if possible, and adjusting to lost abilities.

The dementia syndrome may be caused by over 60 different disorders, most are due to Alzheimer's disease, followed by multi-infarct dementia or a combination of the two (Fujimoto & Shimomura, 1996). It is a commonly occurring neurologic disorder with unknown etiology, however, several possible theories of disease etiology are currently under investigation. A key theory is that a loss of central nervous system stimulation by acetylcholine is responsible. This neurotransmitter is needed for recent memory at the biochemical level (Boss, 1994). As the level of acetylcholine is reduced, the individual is less and less able to store information until all recent memory is lost. Other possible causes of dementia include infections, other neurodegenerative disorders, toxins and metabolic disorders (Fujimoto & Shimomura, 1996).

The initial clinical manifestations of dementia are insidious, developing over months or years, and often attributed to "normal" forgetfulness, emotional instability, or some illness. As the disorder advances, there are progressive memory loss, emotional lability, disorientation, confusion and inability to concentrate. Abstraction, problem solving and judgment gradually deteriorate while failures in arithmetic calculation ability, language and visuospatial orientation occur (Boss, 1994). Motor changes may occur if posterior frontal lobes of the brain are involved causing rigidity, flexion posturing, propulsion and retropulsion. There may be a loss of executive cerebral functions with declining intellectual ability. As a result, the affected person regresses mentally, physically and emotionally to a debilitated, dependent state thereby requiring increasing assistance with basic needs until death ensues from complications of immobility in the terminal stage (Aneshensel, Pearlin & Schuler, 1993).

It is well documented that caring for an elderly relative with dementia results in considerable stress (Haley & Pardo, 1987; Shields, 1992; Robinson, 1989; Collins, Stommel, Wang & Given, 1994b; Baumgarten, Hanley, Infante-Rivard, Battista, Becker, & Gauthier, 1994). In particular, empirical evidence strongly support clinical observations that primary caregivers experience substantial negative social, psychological and health effects related to the caregiving role. Providing care and support to a dementia, patient has been likened to exposure to multiple and severe long term stressors. Thus, it would seem reasonable to expect that caregivers' physical and psychological stamina are depleted over time compromising their own health (Schultz & Williamson, 1991; Baumgarten, et al., 1994). Common responses to the stress of dementia care include anger, depression, guilt, worry and marital stress (Anthony-Bergstone, Zarit &

Gatz, 1988). It has been documented that 50 percent of all caregivers experience emotional and physical stress at a level that meet the criteria for a diagnosis of depression (Shields, 1992).

The 1982 National Long Term Care Survey and Informal Caregivers Survey provided descriptive information regarding family caregivers (Gallagher, Rose, Rivera, Lovett & Thompson, 1989). In this sample, the majority (72%) were women, with adult daughters comprising 29% of all caregivers and wives constituting another 23%. Husbands accounted only for 13% of the sample. During the time the patient first begins to deteriorate, one member of the family, usually a spouse or a daughter (Shields, 1992), assumes the primary responsibility for the elderly dependent relative. The burden of care quickly rests upon this individual with other family members most often helping only on occasion. The 1997 American Psychiatric Association Practice Guideline for the Treatment of Patients with Alzheimer's Disease and other Dementias of Late Life suggests that health care providers must be vigilant in detecting negative experiences in caregivers which increase the risk for substandard care, neglect, or abuse of patients which are indicative that caregivers themselves are in need of care (1997).

From a clinical point of view, however, there is a need to know whether different caregivers, such as wife, husband, or daughter, experience significantly different levels of depression. This would allow targeting of high risk populations for depression in order to provide support early on to prevent adverse health effects in caregivers.

Purpose of the Study

Thus, the purpose of this study is to identify those caregiver groups that may be at highest risk for depressive symptomatology. In particular, this study will examine which among the following groups- wives, husbands, or daughters- are at highest risk to suffer from depressive symptomatology. For the purpose of this paper, sons will not be included in the study because very few son caregivers were included in the original study due to the degree of difficulty in finding son caregivers in the community.

Key Concepts

This research focuses on the following key concepts: dementia, depression, primary caregiver, family relationship, and gender differences.

- 1) **Dementia** is referred to as an insidious cognitive impairment which results in labile emotions, hostility, mood swings, confusion, loss of judgment and executive functions thereby rendering an individual physically and emotionally dependent.
- 2) **Major depression** is defined as a mental disorder marked by altered mood, loss of interest in all usually pleasurable outlets such as food, sex, work, friends, hobbies or entertainment. Diagnostic criteria include the presence of altered moods nearly every day, significantly diminished interest or pleasure in most or all activities, and three or more of the following: (DSM-IV, 1994)

- a) Poor appetite significant weight loss, or increased weight gain
 - b) Insomnia or hypersomnia
 - c) Psychomotor agitation or retardation
 - d) Feelings of hopelessness
 - e) Loss of energy or fatigue
 - f) Feelings of worthlessness, self reproach or excessive inappropriate guilt
 - g) Complaints or evidence of a diminished ability to think or concentrate
 - h) Recurrent thoughts of death, suicidal ideation, a wish to be dead, or attempted suicide
- 3) **Primary caregiver** refers to the individual providing the majority of the care to the elderly dependent individual.
- 4) **Family relationship** refers to the family member category of the patient's caregiver, either the husband, wife, or daughter.
- 5) **Gender difference** refers to the differential response to caregiving and difference in the level of depression between male and female caregivers.

LITERATURE REVIEW

It is well documented in the literature that wives make up 2/3 of the spouse caregivers and, among child caregivers, it is mostly daughters, as well as daughters-in-law, who care for elderly dependent parents (Barnes, Given & Given, 1992). There is also substantial evidence that different types of family caregivers, such as wives, husbands, and daughters differ in their susceptibility to depression. For instance, Schultz

and Williamson (1991) found wives are especially vulnerable to the stress of caregiving and tend to be in the higher risk group for depression when compared to daughters (Robinson, 1989; Hooker, et al., 1992; Gallagher, et al., 1989). In part, this appears to be due to the fact that wife caregivers are older, more infirm, have more chronic conditions (Baumgarten, et al., 1992), often live without a child at home, and must assist the dementia spouse alone (Robinson, 1989). Thus, wives are more likely to be cut off from people with whom they formerly associated or interacted. In addition, there often is a great difference in the meaning of an illness in one's husband or in one's father. Adult children as well as other relatives often go through a decision process of whether or not to take on the caregiving role, whereas wives do not have this prerogative. They are more burdened with day to day care and have taken on the role due to an overwhelming sense of duty (Horowitz & Shindelman, 1983; Robinson, 1989). This is consistent with the study by Haley and Pardo (1989) which claimed that with the progression of dementia, behavioral problems and caregiving stressors develop in a mounting fashion. It is assumed that caregiving stressors increase steadily over time as the patient deteriorates.

The best predictors of depression among wife caregivers were found to be:

1) caregiver health, and 2) attitude (Robinson, 1989). It seems that wife caregivers have a negative attitude toward seeking outside assistance due to their view that caregiving is part of their marital responsibility. This belief seems to give rise to feelings of failure and dependency when they have to ask for help. When wives do seek assistance and the desire for support is unmet, greater stress is experienced and depression is more likely to occur (Robinson, 1989). George and Gwyther (1986) further supported this finding upon discovery that wife and husband caregivers report significantly more physician visits and

poorer health than adult children caregivers.

Many wife caregivers refuse the idea of vacationing away from their dependent spouse. It seems that the more mentally or physically disabled the dependent is, the less likely it is that the carer goes on vacation---a fine example of the "inverse care law" (Jones & Peters, 1992). This implies that those most needing a holiday are the ones least likely to receive it, claiming that there is no one else who can care for the elderly, not even available respite care. Among those having the option of respite care, 17% of wife caregivers simply reported that they did not want to have a vacation away from their loved one. Instead, they would like their dependent spouse to go with them.

A study by Cohen, et al. (1990) explains the reactions of 516 primary caregivers of patients with Alzheimer disease or related dementia, registered at University Medical Center hospital in Wisconsin, Florida and Illinois. The caregiver groups were as follows: 38.2% spouses, 45.3% adult children, 16% below age 45, 35% ages 45-59, 28% were 60-74, 21% were over 75; and 73.3% of caregiver were female. Consistent with other literature, the authors discovered that wife caregivers had the highest rates of depressive symptomatology. Often the wife caregivers perceived little or no help even if there were more people in the same household, and frequently this meant more work and responsibility (Bourgeois, Beach, Schultz & Burgio, 1996). Residing with the patient was not associated with increased depression or symptomatology.

In contrast, there is also research which claims that daughters are the most likely to report deleterious effects on their lives as a result of caregiving (Jones & Peters, 1992). These authors assert that lack of privacy and personal freedom greatly affects family life negatively. The Equal Opportunity Commission supported the finding that for non-

spouse carers, caring for elderly dependents, while trying to meet the needs of the immediate family, is a major problem (Jones & Peters, 1992). According to the authors of the study, one fourth of the daughter caregivers had not had a vacation in 5 years. A tenth of the sample, mostly daughters, also reported giving up employment to become a caregiver for the dependent parent. One fifth of the sample reported unbearable amounts of stress as a consequence to their role.

There are few documented instances of middle aged daughter caregivers who were frequently characterized as caught between the competing demands of parents, spouse, children, home and career (Bergstone, et al., 1988) and have been referred to as "women in the middle" (Brody, 1990). This is in conflict with the expectation of many daughters in their middle years that their caring responsibilities and ties to the home will be reduced, not increased. The unforeseen requirement to provide care brings with it major alterations in lifestyle and future plans regarding occupational and leisure activities which had to be sacrificed temporarily. This is consistent with other findings (Franks & Stephens, 1996) that adult-daughter caregivers are extremely overwhelmed and taxed by their caregiving responsibilities due to interference with other social roles.

Although the majority of caregivers are women, several studies have noted a substantial number of husbands who are primary caregivers for their wives (Fuller-Jonap & Haley, 1995). According to the 1982 Long-Term Care Survey, 28% of caregivers are men, most of whom are husbands (Stone, Cafferata & Sange, 1987). Male spousal caregivers of dementia patients are of particular interest since gerontologists have forecasted an increase in the actual percentage of men serving as caregivers (Stone, et al., 1987). In addition, husband caregivers could be a group particularly vulnerable to stress

given that older men have shorter life expectancies and greater health difficulties than women. This finding is consistent with George and Gwyther (1986) who report that spousal caregivers have greater numbers of disability days and increased physician visits for respiratory infections.

Schultz and Williamson (1991) have found that male spousal caregivers of dementia patients were the only group within a longitudinal sample to show increased depression over time. This is consistent with the study by Collins, Stommel, Wang and Given (1994b) whose findings revealed that female bereaved caregivers experienced a pattern of decreasing depression following their dependent's death, while male caregivers experienced a rise in the level of depression. This may be due in part to having chosen to be the caregiver for someone with whom they have had a very positive, loving relationship. If true, these men experience the loss much harder. However, the depression level during caregiving may be related to difficulty in adapting to the mounting demands of the patient as the disease progresses.

Influencing Factors On Depression

There are various other factors known to influence depression among caregivers of the dementia patient. However, for the purpose of this paper only four have been chosen for discussion: 1) age, 2) health, 3) caregiving demands, and 4) duration of care.

Anthony-Bergstone, Zarit & Gatz (1988), in studying the symptoms of psychological distress among caregivers of dementia patients, found that, in any caregiving sample, age is confounded with the relationship of the caregiver to the

dementia patient. Older caregivers tend to be spouses and younger caregivers tend to be sons or daughters, however, child caregivers can sometimes be quite old. Obviously, younger caregivers would tend to be stronger, more agile than older spouse caregivers often suffering from numerous chronic conditions such as osteoporosis, arthritis, and other painful, physically limiting diseases. These confounding variables along with age and its cohort effects may contribute to depressive symptomatology.

Robinson (1989) asserted that caregiver health was the best predictor of depression. Health has been consistently identified in the literature as an important variable of concern for caregiving wives. In this study, only 30% of wife caregivers reported their health as excellent, the majority rated their health as good to fair. Overall, most literature asserted that good health has a positive impact on the duration of care (Robinson, 1986).

Another contributing factor associated with depression is the duration of caregiving role. A study found this marker to be associated with chronicity of stressors experienced by the caregiver (Pearlin, Mullan, Semple & Skaff, 1990). In general, husband and wife caregivers were older and had been caregivers longer than daughters, therefore, may be more prone to depression. This finding, however, is not consistent across studies. The duration of care was found in one study to be related to depression (Baumgarten et al., 1994) but unrelated to depression in two others (Draper et al., 1992; Kielcolt-Glaser et al., 1991).

Caregiving demands is another factor influencing depression levels in dementia caregivers. It is important to control for this variable since different caregiver groups take care of patients requiring varying amounts of care. Jones and Peters (1992) reported

higher rates of stress for carers of older dependents (particularly 85 years and over), carers of more dependent and more disabled elderly persons; carers of close relatives (spouses but especially children) and, independently of relationship, female carers. These factors were found to have deleterious effects on the social and family life of the caregivers and are associated with great amounts of stress as reported by the carers. Those caregivers caring for the very frail dependent are most likely to be daughters, since they almost always take on the role after their parent's death or when the parent is no longer able to function in the caregiver role.

Hypothesis

The primary focus of this study is to identify the difference in mean levels of depression among husband, wife and daughter caregivers. Based on the literature review, it is hypothesized that: wives will be at highest risk for depression, followed second by daughters and finally husbands having the least risk. This hypothesis will be tested in a two-step process: first, the degree of depression will be tested using the revised CES-D scale and followed by regression analysis of the independent variables (age, health, duration of care, care demands and caregiver relation to patient). The mean CES-D scores of wife, husband and daughter caregivers will be compared using Chi-square.

THEORETICAL FRAMEWORK

Lazarus and Folkman (1984) conceptualized adaptation to stress as an interaction of personal and environmental factors--the nature of the stressor, the individual's interpretation of the stressor, personal resources, and coping efforts (Figure 1). This theory suggests that adaptation efforts are process-oriented with the expectation that there will be change in the ways of coping as stressful situations unfold (Pruchno & Resch, 1989). Lazarus and Folkman (1984) define coping as all efforts to manage a stressful situation. According to this definition, methods of coping may be more or less effective in alleviating stress, thus reducing depression risk. However, even those behaviors which do not directly reduce stress are considered coping efforts to help minimize depressive episodes. The definition avoids equating coping, or adaptation, with mastery but does seem to encompass efforts to minimize, avoid, tolerate, accept and overcome the situation as part of the process (Lazarus & Folkman, 1984).

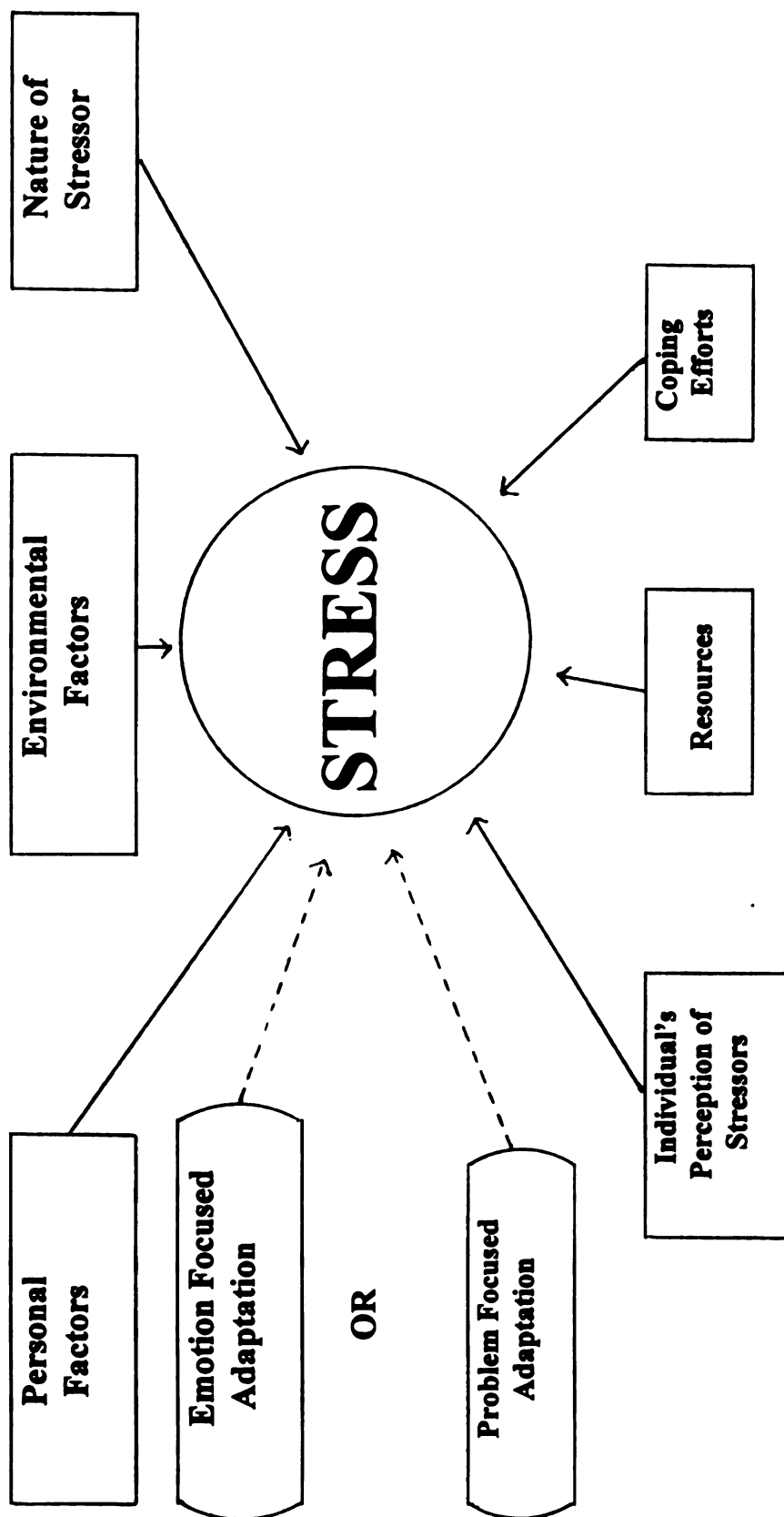


Figure 1: Lazarus & Folkman's Model of Stress Adaptation (1984)

In an attempt to manage depressive symptomatology in caregivers, two coping efforts are identified: 1) problem focused, and 2) emotion focused (Folkman & Lazarus, 1980). Problem-focused efforts to adapt refer to methods aimed at managing or altering the problem causing the stress. Emotion-focused efforts are aimed toward regulating the individual's emotional response to the problem when an appraisal reveals that nothing can be done to modify harmful, threatening or challenging conditions (Folkman & Lazarus, 1980). This suggests that the stresses common in dementia which are not controllable by the caregiver, will be most successfully dealt with by combining both strategies (Figure 2) which focus on organizing an effective support and service network ("problem focused") and on managing the emotional stress aroused by the illness ("emotion focused").

Study Model

In this study, the factors contributing to caregiver depression are assumed to be first and foremost the caregiver's relationship to the care recipient as well as increased care demands, poor health, increased duration of care and age of the caregiver. These factors particularly focus attention on the chronic, long term nature of dementia with progressive patient deterioration, lack of support and available resources. While some caregivers manage well, others experience a host of simultaneous stressors which add to the heavy weight of caregiving. Among these are personal crisis (newly diagnosed illness, lack of insurance, finances, marriage problems, job insecurity, etc.), environmental stressors (housing difficulty, lack of transportation, etc.) and developmental stressors (Medicaid/Medicare limitations, retirement, decreased social

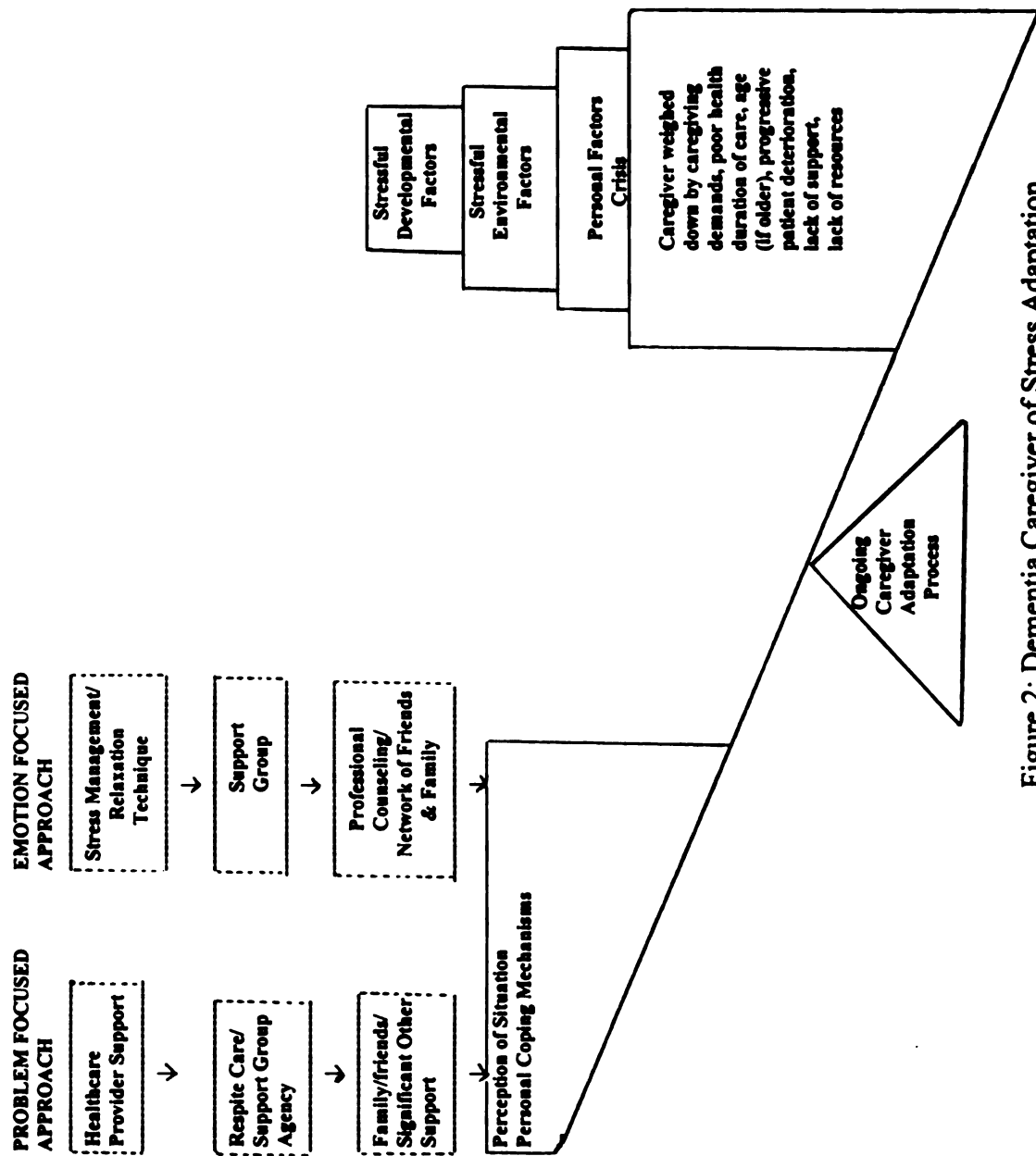


Figure 2: Dementia Caregiver of Stress Adaptation
Developed by Juliet Alfonso-Santos, 1998

security benefits, menopause, etc.). The accumulation of these stressors without adequate adaptation mechanisms have been known to contribute to a multitude of mental health symptoms such as depression, nervousness, anxiety, sleeplessness, frustration and lowered morale (Brody, 1990).

Two important factors are vital in the caregiver process of adaptation:

1) perception of the situation (severity of the problem), and 2) personal coping mechanisms (attitude, outlook, source of spiritual strength, etc.). These factors provide the base for the ongoing process of adaptation to the arduous demands of caregiving. Two adaptation pathways may be implemented together or one at a time to balance the "teeter-totter" effect of providing care (Figure 2): 1) problem focused, and 2) emotion focused.

The problem focused pathway seeks the support of family, friends and significant others in an effort to adapt to caregiving tasks and responsibilities. For example, respite care, agency service and health care provider support are activated to address the physical and medical needs of the patient, thereby, helping to reduce the strain on the primary caregiver. The second pathway, emotion focused adaptation, seeks to adapt via the emotional assistance of counselors, network of friends, and support groups. In the language of adaptation, men can be expected to use more problem-focused efforts and women more emotion-focused efforts (Folkman & Lazarus, 1980). However, both genders may benefit by implementing both approaches to adaptation. In addition, stress management and relaxation techniques may also be utilized to help the caregiver adapt to the stress of round-the-clock surveillance required due to disruptive, even dangerous, behaviors such as wandering, night time wakefulness, turning on the stove or water faucet

and leaving them unattended (Brody, 1990).

NEED FOR STUDY

The results of previous research imply the need for reducing the impact of caregiver burden and the prevention and treatment of depression among the high risk caregiver population. (Pruchno & Resch, 1989).

It is crucial to identify those caregiver groups that are at high risk for depression in order to provide adequate support and community services (Collins, King, Given & Given, 1994a). Without such support, caregivers frequently become frustrated and overwhelmed thus leading to heightened risk of substandard care and earlier admission to a long term care facility.

METHODOLOGY

Original Studies: Two studies were used as the basis for this secondary analysis:

- 1) **Family Homecare - A Community Based Model** (Barbara A. Given, Principal Investigator, 1987-1991). National Center for Nursing Research, Grant#1 R01 NR01915-01 (N=307).
- 2) **Impact of Alzheimer's Disease on Family Caregivers** (Clare E. Collins, Principal Investigator - 1989-1991). National Institute of Mental Health, Grant #2 R01 MH41766-03 (N=226).

Both longitudinal panel studies (repeated interview process involving the same subjects spaced several months apart consisted of convenience samples of self selected caregiver-patient dyads. The samples were located with the assistance of 145 community agencies including local chapters of the Alzheimer's Association, the Michigan Association of Adult Day Care Centers and various health agencies in southwest Michigan. These groups were instrumental in contacting possible subjects via mailings and were efficient in identifying the caregivers of dependent elderly relatives being cared for at home (Collins, Stommel, Wang & Given, 1994b). Eligibility criteria for inclusion in both studies were: a) patients had to be at least 64 years of age; b) dependent in at least two activities of daily living or instrumental activities of daily living, and c) had to have a primary caregiver. Caregivers were considered eligible to participate in the study if they were: a) family members, b) considered to be the primary caregivers, and c) the dependent relative was residing in the home at the time of entry into the study. For the dementia study, the additional eligibility criterion required that the patient had diagnosis of Alzheimer's disease or other progressive dementia. All data collection were conducted in their own home to assure that the caregiver was the exclusive source for all information.

Sample for Current Analysis:

A few caregivers who were neither spouse or daughter of the care- recipient were excluded. Thus, a total of 246 caregiver-dementia patient dyads were included in the current analysis, of which 36 are from the Family Home Care Study and 210 from the Alzheimer's Disease Study. Since this is a secondary analysis, the procedure for the protection of human subject was submitted by the original researchers and was approved.

A second request for permission to perform secondary analysis and guarantee the anonymity of the subjects was submitted to and approved by the University Committee on Research Involving Human Subjects (UCRIHS).

Operational Definitions and Instrumentation

Depression. To measure depressive symptomatology, the current analysis employs a shortened version of the Center for Epidemiologic Studies Depression Scale (CES-D). The revised 15 Question CES-D Scale has been shown to produce bias-free responses with respect to gender, thus, proving to be an equally good measure of depressive symptomatology among men and women. The revision was the result of discussions in the literature regarding the original CES-D Scale (Radloff, 1977) which focused on possible age bias. The process resulted in identification of two CES-D items which showed "gender specific" response patterns ("talked less than usual", and "had crying spells") among men and women (Stommel, et al., 1990).

In addition, three other CES-D items were excluded due to their poor psychometric qualities ("thought life a failure", "people were unfriendly", and "people dislike me"). Four of the 15 remaining items were reverse coded since these were worded positively in the questionnaire: 1) just as good as others, 2) hopeful about future, 3) happy, and 4) enjoyed life. The revised 15 item scale correlated very highly with the original 20 item scale (0.98). The shortened version barely affected its overall reliability as evidenced by Chronbach's alpha of 0.89 for the 20 item scale versus 0.88 for the 15 item scale (Stommel, et al., 1993).

In the CES-D instrument, subjects are asked to respond to the items detailing depressive symptoms by indicating how often they experienced these symptoms during the past month: "rarely or none of the time" (=0), "some or a little of the time" (=1), "occasionally or a moderate amount of time" (=2), "most or all of the time" (=3). For the original 20 -item scale, summated scale scores can range from 0 to 60. To preserve the same range, the mean score for the 15 item version is multiplied by 20.

Caregiver health was measured in two ways: 1) by having the caregiver rate his or her own health on a scale ranging from excellent health (=1), to poor health (=4); and 2) by a count of 14 commonly occurring morbidities such as arthritis, glaucoma, high blood pressure, emphysema, heart trouble, effects of stroke, diabetes, kidney/urinary tract disease, cancer/leukemia, nervous disorders, stomach/intestinal problems, prostate problems, and broken hip.

Care demands. The first measure of care demands include caregiver involvement in tangible (objective) care task based on the concept of frequency of assistance (Stommel, et. al., 1995). The caregivers were asked to indicate how often the patient required assistance for any activity with confirmed dependency. The caregivers were also asked to report the frequency of assistance for the same activity rendered by informal and formal care providers in a typical week. Answers ranged from no involvement (0), once a week (1), several (two to six) times a week (3.5), once a day (7), and several times a day (14). This coding scheme provides an approximate interval level of measurement of the weekly frequency of care rendered by the caregivers. The frequency of assistance scores for individual activities were then summated (the IADLs and ADLs combined) reflecting all instances of assistance that patients received in a 7

day period (Stommel, et. al, 1995).

The second measure of care demands utilized the cognitive deficit questionnaire (intangible or subjective measure) comprised of 6 questions reflecting the caregiver's perception of the patient's cognitive deficit (Appendix C). Subjects were asked how frequently their relative displayed the following behaviors: seem confused, forgets what day it is, gets the present mixed up with the past, forgets where he/she is, forgets important or recent events and repeats self or asks the same question over and over. A Likert-type scale was used to identify answer categories: "not at all" (=0), "sometimes" (=1), "most of the time" (=2), "always" (=3). The scale's internal consistency was found to be Cronbach's alpha = .77 (Stommel et al., 1990).

Duration of care was measured by asking the caregiver to estimate how long they have been providing assistance in terms of years and months. For the current analysis, the duration of care measure was rounded off to the nearest year.

Caregiver age was measured by asking the caregiver to indicate their exact birthdate. Age in years was obtained by subtracting the birthdate from the interview date.

Gender was measured by having the caregiver indicate sex: female (=0), and male (=1). **Family relationship** was measured by indicating whether the caregiver was a wife (=1), husband (=2), or daughter (=3).

ANALYSIS

The data for this analysis come from longitudinal, non-experimental panel studies. Thus, even with the use of multivariate statistical analysis models, the influence

of unmeasured extraneous variables cannot be ruled out.

The main research questions/hypotheses focused on a comparison of depression levels among 3 groups of caregivers: wives, husbands, and daughters. Depression was measured on a continuous, standardized scale (the CES-D) with a potential range from 0-60 (higher scores reflect greater depressive symptomatology). Thus, analysis of variance (ANOVA) which is used to test for differences in mean scores across comparison groups, is an appropriate statistical procedure. Further complications arise from the need to take into account the effects of other variables on depression, such as care demands, duration of care, age, and health of the caregiver. Using an analysis of covariance (ANCOVA) approach, it is possible to account for the simultaneous effects of these other variables and to adjust the mean differences among the four groups of interest accounting for these variables. The F-test is used to determine if the independent variables (both the relationship factor and the covariables) explain systematic variations. A statistically significant F value results in rejection of the Null Hypothesis (the independent variables have no effect on depression). To test for pairwise differences among the three pairs of caregivers (wife-husband, wife-daughter, husband-daughter), Tukey's post hoc comparison test was used to control for Type I error.

RESULTS

Table 1 and 2 shows the socio-demographic characteristics of the sample respondents. Among the 246 dementia caregivers, 48% were wives, 25% were husbands, and 27% were daughters (Table 1). 73% were spouse caregivers compared to only 27% of daughter caregivers. The patient profile comprised a fairly equal distribution of males (51%) and females (49%). Only 5% of the caregivers lived apart from their relative while the other 95% lived together with the patient. As expected, the majority of caregivers (75%) were female and 25% were male. 98% (N=241) of the caregivers were Caucasian and 2%(N=5) were African-Americans. The mean caregiver age was 63 years while the patient's mean age was almost 73 years. The average duration of care was almost 4 1/2 years.

TABLE 1
Socio- Demographic Characteristics
of Caregivers
(N=246)

	Mean	SD	Range
Caregiver age	62.6 yrs.	10.99	27-86 yrs.
Years of caregiving	4.4 yrs.	3.13	≤ 1 yr ≥22yrs.
		N	Percentage
<u>Living arrangement</u>			
Caregiver & patient		235	95.5
Caregiver & patient in different household		11	4.5
<u>Gender</u>			
Female		185	75.2
Male		61	24.8
<u>Relation to patient</u>			
Wife		119	48.4
Husband		61	24.8
Daughter		66	26.8
<u>Marital status</u>			
Single		11	4.5
Married		222	90.2
Widowed		8	3.3
Divorced/separated		5	2.0
<u>Employment status</u>			
Full-time		49	19.9
Part-time		25	10.2
Not employed		172	69.9
<u>Education</u>			
Some high school or less		40	16.2
High School graduate		59	24.0
Some college		93	37.8
College graduate/graduate degree		54	22.0
<u>Race/Ethnicity</u>			
White/Caucasian		240	97.6
African-American		5	2.0
Other		1	.4

TABLE 2
Socio- Demographic Characteristics
of Care Recipients

	Mean	SD	Range
Patient Age	72.5 yrs.	8.48	54-99 yrs.
Household Income	\$21,500.00 (median)	\$18,320.62	\$1,000-\$152,503
	N		Percentage
<u>Gender sex</u>			
Female	121		49.2
Male	125		50.8
<u>Patient marital status</u>			
Married	186		76%
Widowed	60		24%

The actual minimum score on the 15 item CES-D Scale was zero (least depressed) and the observed maximum score was 49 (most depressed). Using accepted cut-offs (Weissman, 1987) 26% were not likely to be clinically depressed (CES-D \leq 16) while 60% scored \geq 16 and can be considered at high risk for depression (Table 3). Having 60% of these caregivers in this danger zone is quite impressive since the non-caregiver general population scores have been found to be in the lower ranges and mean scale scores not exceeding 10 on the 20 item CES-D Scale (Stommel, et al. 1993). This finding is consistent with Shields' study (1992) in which 50% of all caregivers experienced depression. It is important to emphasize that the CES-D Scale has been found to have an 80% accuracy rate in screening for clinical depression (Weissman, 1987).

TABLE 3
CES-D Scale Caregiver Depression Scores

	N	Percentages
<16 ^b	98	39.8
≥16 ^c	148	60.2

- a. Mean=18.96, median= 19.0, SD= 9.69, minimum= 0, maximum= 49.
- b. Less likelihood of clinical depression.
- c. 80% likelihood of clinical depression.

Table 3 shows that approximately one-third of all caregivers reported experiencing mild levels of emotional distress. However, there are proportionately more caregivers who have CES-D scores of 16 or higher (60%) compared to the number of caregivers who have scores of less than 16. This finding implies that there is significant clinical depression among the caregivers. This is consistent with the findings of Anthony-Bergstone, et al. (1988), in which common responses to the stress of dementia included depression.

Caregiver health. 25% of the caregivers reported having excellent health while 56% reported good health (Table 5). Only 2% claimed they currently experience poor health. Several caregivers (N=73) reported being in perfect health as reflected by zero illness count. However, the average illness count reported was 1.5 across the caregiver groups.

The first measure of **care demands** is based on tangible or objective care tasks performed by the caregiver per week (Table 4). The mean involvement per week is 30.5 (SD=15.3). The scores ranged from one (minimal care demand) to sixty-seven

(extremely heavy care demand). The high caregiving demand score have been found to be directly correlated to the level of depression experienced by 60% of the caregivers. The caregivers with the highest score can be anticipated to be at most risk for depression.

The second measure of **care demands** employed here is the patient's cognitive disability score (intangible or subjective care demand) (Table 5). The sample mean score for this scale was 1.7 (SD=.72). The scores ranged from zero (no deficit) to 3 (total deficits) on the cognitive disability scale. As expected, older patients showed more cognitive deficits ($r=.184$). The implications of the cognitive deficit care demands are uncertain. Since the cognitive deficit scale is constructed by the rater (caregiver self-report), it is naturally assumed that some responses have been colored by the rater's "mood". It is difficult to ascertain if the responses reported are due to the stress of care demands or merely the negative outlook of the caregiver towards life in general.

TABLE 4
Weekly Involvement In Tangible Care Tasks by Caregiver
(Care Demands)(N=246)

	N	%
Frequency of involvement ^{a,b}		
1-12	28	11.2
13-24	69	27.8
25-36	59	23.8
37-48	54	21.8
49-60	33	12.4
61-67	3	1.2

- a. Frequency of involvement includes ADLs such as: bathing, dressing, grooming, toileting, eating, stool & urine incontinence, etc.; and IADLs such as: shopping, cooking, laundry, housework, managing money, transportation, etc.
- b. Mean = 30.54, median = 30.0, SD = 15.33, minimum = 1.00, maximum = 67.0

A key issue to address is the difference in the level of depression between spouse and daughter caregivers of the elderly dementia patient. Tables 5 and 6 show the main results from the ANCOVA which addresses the research hypotheses. The model contained 7 covariates (Table 5) and 1 relationship factor (Table 6). The model as a whole accounted for 21.4% of the variation in caregiver depression scores (overall $F=7.79$, $p<.001$). However, among the covariates, only two were statistically significant: self-rated health ($p<.0001$) and frequency of care involvement ($p<.007$). Caregiver self rated health may be significant secondary to an already depressed caregiver reporting personal well being through "negative lenses", thus rating themselves as more ill than others.

Caregiver relation to patient was not found to be statistically significant ($F=1.22$, $p= .297$). This may be due to dementia's overwhelming intensity as the condition

worsens, thus overshadowing this variable. As the disease progresses, caregiver relation (wife, husband, or daughter) to the patient does not seem to matter since the dementia care demand is so great and frequently results in difficult role adaptation.

TABLE 5
Depression Scores Regressed on 7 Covariates
Representing 6 issues

		Mean Square	F	Sig.
1.	Caregiver Age (in yrs)	170.2	2.21	.138
2.	Duration of Care (in yrs)	50.72	.659	.418
3a.	Caregiver Self rated Health (subjective)	2,141.52	27.81	.000
3b.	Count of Caregiver Illness far less likely that this objective measure is affected by depression (objective)	70.94	.921	.338
4a.	Frequency of caregiver Involvement per week (care demand)	562.08	7.30	.007
4b.	Patient Cognitive Deficit Score	254.08	3.30	.071
5.	Caregiver Relation to Patient	93.86	1.22	.297

a. Model Goodness of Fit: $R = .462$, $R^2 = .214$

A key issue to address is the difference in the level of depression between spouse and daughter caregivers of the elderly dementia patient. Table 6 shows the remaining results of the ANCOVA focusing on the main question of interest: are there differences in mean depression scores of wife, husband, and daughter caregivers? While the unadjusted depression means in the sample were found to be highest among wives (19.61), husbands (18.87), and daughters (17.89), none of the observed mean difference among the 3 groups were statistically significant ($F\text{-test}=.664$; $p=.516$). After adjusting the observed means

for the influence of all the covariates, group differences became even smaller: 19.6 (wives), 18.9 (husbands), and 18.9 (daughters). These findings remained insignificant ($p=.297$).

TABLE 6
Caregiver Unadjusted and Adjusted Mean Depression Scores

	N	Unadjusted Group Mean ^a	SD	Adjusted Group Mean ^b
Wives	119	19.61	9.42	19.40
Husbands	61	18.87	9.54	18.86
Daughters	66	17.89	10.35	18.91

- a. Group mean before covariates (age, health, duration of care and care demands) are accounted for using ANOVA.
- b. Group mean after covariates are accounted for using ANCOVA.
- c. $F = .664$, $p = .516$ (oneway), $F = 1.219$, $p = .297$ (multivariate)

In addition, post hoc, pairwise comparisons between wife, husband and daughter groups were conducted using Tukey's difference test (Tukey HSD). The results revealed that no pairwise comparison is statistically significant (with all CIs containing the value of 0). Thus, the main hypothesis was not supported; there was no statistically significant difference in the mean depression scores of the three caregiver groups.

DISCUSSION

This paper reports an examination of data for three caregiver groups (husbands, wives, or daughters) at risk for depression. It was hypothesized that wives were at highest risk followed by husbands and daughters. The results of analyses performed to

test this hypothesis did not support differences in mean levels of depression among the groups.

A review of the literature revealed that four variables were frequently associated with depression: caregiver age, health, duration of care and care demands. It was found that only two of these variables had significant effects on the level of depression: caregiver health and care demands. The main finding, however, is that, in the care of the dementia patient, caregiver relationship to patient does not seem to be an important factor. This finding came as a surprise, because previous studies involving mostly non-dementia patients had shown differences in depression by caregiver relation. A possible explanation is that dementia is so overwhelming that perhaps other variables become less important in their impact on depression with the exception of care demands and caregiver health. Such findings strongly suggest that perhaps caregiver depression levels may be decreased if respite care or other community resources are utilized to assist the primary caregiver with delivery of care thus minimizing care demands.

No significant relationship was found between duration of care and depression scores despite its central place in the theoretical model of caregiver adaptation. This finding is consistent with the studies of Draper, et al. (1992) and Kielcolt-Glaser, et al. (1991). This may be attributed partly to measurement error which is affected by the vague onset of dementia symptomatology and the subjective, self reported length of care in years. Since dementia is an insidious, progressive illness, one may have difficulty identifying the start of caregiving due to the ambiguity of the disease onset. Another contributing factor is the mis-specification of the relationship between duration of care and depression. Although the statistical model assumed a linear relationship, it is likely

that any relationship between duration of care and depression (if it exists) is non-linear. Depression does not necessarily worsen as duration of care increases. It may, in fact, be that depression level is highest at the initial caregiving period, in the middle, or at the end when the patient is in the terminal phase of the illness and the caregiver has exhausted all resources as well as physical and emotional strength.

The DSM-IV criteria for depression have been listed in this study. However, in comparing the DSM-IV, a diagnostic tool, with the revised 15 item CES-D Scale, a screening tool, it is particularly interesting to note that all items in the DSM-IV have been addressed by the 15 item CES-D except for "suicidal" intent. This may have purposely been omitted by the original author of the CES-D Scale due to the ethical and legal implications to the health care professional. The CES-D Scale was developed to focus on the assessment of depressive "mood". However, individuals with high CES-D scores may not always be suicidal. Higher CES-D scores may correlate with higher depression risk but it is not an accurate indicator for the severity index of depression.

A key concept which may explain the null finding in levels of depressive symptomatology among wife, husband and daughter caregivers is the fact that husbands have more external support when in a caregiving situation. Society does not generally view men as care takers, thus when they do take on the role, more sympathy from relatives and other support systems result in greater assistance. Without this increased support in comparison to wife and daughter caregivers, it is conceivable that husbands may actually experience even higher depression levels. In contrast, the female caregiver may not be viewed as needing assistance since the role "comes naturally" to them and society expects the wife to care for her husband. If the wife is unable to assume this

"duty", the daughter is usually the next expected caregiver. In this study, the majority of female caregivers are at high risk for depressive symptomatology.

In conclusion, while there were no statistically significant differences in the levels of depression among wife, husband, or daughter caregivers, two significant findings remain:

- 1) the average depression scores among all of these dementia caregivers is high compared to the general population and points to clinical depression (CES-D=18 in daughters, 19 in spouses)
- 2) high care demands explain part of the reason for increased depressive symptomatology

Implications for Advanced Nursing Practice & Primary Care

Caregiving for the dementia patient is not something most people typically are socialized to desire or seek. However, confronted with the need for care, family members most often rise to the occasion due to various reasons. Some become caregivers by default: they are female or unemployed outside the home (Aneshensel, et al., 1993). Some are initially reluctant or resentful but later become dedicated to the role. However, there are those who are committed initially, but wanes eventually, due to tremendous stress. Regardless of how caregivers are channeled into the role, the data in this study suggest that more than half succumb to depression.

In any population in which CES-D scores are at 60% greater than or equal to 16, the recognized cut off point for clinical depression risk, APNs in primary care must be

vigilant in identifying caregivers at risk. As an assessor, the APN should utilize the 15 item CES-D Scale in screening for depression risk, evaluate the family's perception of the situation, coping mechanisms and care demands, as well as identify which types of supportive care must be implemented to assist the caregiver. It is important for the APN to provide ongoing, supportive treatment for both patient and caregiver with regular monitoring and periodic reassessment of the caregiving situation (Barnes, et al., 1992).

As the coordinator of care, the APN must respond promptly to all caregivers presenting with specific or nonspecific somatic complaints through medical intervention, psychotherapy and referral to support groups. Another option is to encourage the caregiver to utilize respite care, a short term, intermittent care to provide rest from the burden of sustained caregiving. Regular and planned rest should be provided in order to maintain a fulfilling social and family life thus helping maintain their own identity. Expedient intervention for these individuals is of utmost importance in order to preserve emotional equilibrium within the home, therefore, enhancing caregiver adaptation and quality of care provision for the elderly dementia patient.

It may also be beneficial to begin the intervention process using the emotion focused approach first (stress management, relaxation techniques professional counseling, support from family and friends). The data in this study suggests that although care demands in the dementia case contained hands on tasks, the cognitive deficit portion is subjective and is not amenable to problem focused approach. The dual nature of this variable cannot be properly addressed without utilizing the emotion focused approach. In general, most caregivers may benefit from stress management, relaxation technique, referral to support groups, professional counseling and a supportive network of friends

and relatives which is the goal of the emotion focused approach. Using both approaches in concert may prove to be effective in the APN management of the depressed caregiver. The ultimate goal for the caregiver is to maintain emotional wellness, therefore, decreasing the rate of early extended care facility placement of the elderly.

Limitations of Research

There are several limitations to the current study that should be noted. First, the samples were part of a convenient sampling process from support group agencies. These individuals were seeking external assistance and have already acknowledged a degree of psychological distress with their mere presence in the support group. The sample does not include isolated caregivers (those not seeking outside support), who for the most part, may need help the most or may have a much lower true prevalence of depression.

A second limitation of this study is its ethnically homogeneous, small sample. Results may be quite different if the sample included better representation from other ethnic groups such as Asians, Hispanics and African-Americans whose response to stressful situations varies markedly.

Thirdly, it can not be known with certainty the degree to which the sample respondents experienced depression prior to the caregiving role. It is very likely that rates reported are inflated by their “distress factor”. This distress factor pushes people to seek help and makes it more likely that the phenomena of interest (depression) will be present in a detectable way (Gallagher, et al., 1989).

Future Studies

Future studies should focus on which resources are most beneficial to caregivers and the effective implementation of such programs while involving representation from the general population. Studies of APN interventions leading to successful care provision in the home without nursing home placement would be of interest.

Care demands also deserve a deeper exploration. A search involving caregivers with regular respite care and other agency or family support while measuring depression may be of value. Future researchers should further investigate the total CES-D Scale score while looking at "mood" and the somatic subscale to determine what percentage of CES-D scores is correlated with the somatic complaints while comparing caregiver and non-caregiver groups. Considerable research is needed on the factors that may predispose family caregivers in the development of depression.

APPENDIX A

APPENDIX A

Items from the Center for Epidemiologic Studies Depression Scale (CES-D)

1. I was bothered by things that usually don't bother me.
2. I did not feel like eating; my appetite was poor.
3. I felt that I could not shake off the blues even with help from my family or friends.
4. I felt that I was just as good as other people.
5. I had trouble keeping my mind on what I was doing.
6. I felt depressed.
7. I felt that everything I did was an effort.
8. I felt hopeful about the future.
9. I thought my life had been a failure.
10. I felt fearful.
11. My sleep was restless.
12. I was happy.
13. I talked less than usual.
14. I felt lonely.
15. People were unfriendly.
16. I enjoyed life.
17. I had crying spells.
18. I felt sad.
19. I felt that people dislike me.
20. I could not get "going."

Radloff, L.S., (1977)

APPENDIX B

APPENDIX B

Revised 15 Items CES-D Scale

1. I was bothered by things that usually don't bother me.
2. I did not feel like eating; my appetite was poor.
3. I felt that I could not shake off the blues even with help from my family or friends.
4. I felt that I was just as good as other people.
5. I had trouble keeping my mind on what I was doing.
6. I felt depressed.
7. I felt that everything I did was an effort.
8. I felt hopeful about the future.
9. I felt fearful.
10. My sleep was restless.
11. I was happy.
12. I felt lonely.
13. I enjoyed life.
14. I felt sad.
15. I could not get "going."

Radloff, L.S. (1977)

Revised by Stommel, Given, C., Given B.,

Schultz, & McCorkle (1993)

APPENDIX C

APPENDIX C

Cognitive Deficit Scale

List of items that constitute the patient's cognitive deficit scale. The subjects were asked: "How frequently has your relative displayed the following behaviors?" Answer categories included "not at all" (=0), "sometimes" (=1), "most of the time" (=2), "always " (=3). The scale includes the following 6 items: (Stommel, et al, 1990)

Does your relative seem confused?

Does your relative forget what day it is?

Does your relative get the present mixed up with the past?

Does your relative ever forget where he/she is?

Does your relative ever forget important or recent events?

Does your relative repeat himself/herself or ask the same question over and over again?

Chronbach's Alpha: 0.77 (present sample of N=246)

**MICHIGAN STATE
UNIVERSITY**

April 10, 1998

TO: Manfred Stommel
A-230 Life Sciences Building

RE: IRB#: 98-188
TITLE: DIFFERENCES IN THE LEVEL OF DEPRESSION BETWEEN
SPOUSE AND DAUGHTER CAREGIVERS OF ELDERLY
DEMENTIA PATIENTS
REVISION REQUESTED: N/A
CATEGORY: 1-E
APPROVAL DATE: 04/07/98

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project and any revisions listed above.

RENEWAL: UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must use the green renewal form (enclosed with the original approval letter or when a project is renewed) to seek updated certification. There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB # and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.



OFFICE OF
RESEARCH
AND
GRADUATE
STUDIES

**PROBLEMS/
CHANGES:**

Should either of the following arise during the course of the work, investigators must notify UCRIHS promptly: (1) problems (unexpected side effects, complaints, etc.) involving human subjects or (2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of any future help, please do not hesitate to contact us at (517)355-2180 or FAX (517)432-1171.

University Committee on
Research Involving
Human Subjects
(UCRIHS)

Michigan State University
246 Administration Building
East Lansing, Michigan
48824-1046

517/355-2180
FAX 517/432-1171

Sincerely,

David E. Wright, Ph.D.
UCRIHS Chair

DEW:bed

cc: Juliet Santos

The Michigan State University
IDEA is Institutional Diversity
Excellence in Action

MSU is an affirmative action,
equal opportunity institution

REFERENCES

REFERENCES

American Psychiatric Association (1994). Diagnostic & statistical manual of mental disorders. (4 ed.). Washington, DC: American Psychiatric Association.

American Psychiatric Association (1997). Practice guideline for the treatment of patients with alzheimer's disease and other dementias of late life. American Journal of Psychiatry, May Supplement.

Aneshensel, C.S., Pearlin, L.I. & Schuler, R.H. (1993). Stress, role captivity, and the cessation of caregiving. Journal of Health and Social Behavior, 34, 54-70.

Anthony-Bergstone, C.R., Zarit, S.H. & Gatz, M. (1988). Symptoms of psychological distress among caregivers of dementia patients. Psychology and Aging, 3(3), 245-248.

Barnes, C.L., Given, B.A. & Given, C.W. (1992). Caregivers of elderly relatives: spouses and adult children. Health & Social Work, 17(4), 282-288.

Baumgarten, M., Hanley, J.A., Infante-Rivard, C., Battista, R.N., Becker, R. & Gauthier, S. (1994). Health of family members caring for elderly persons with dementia. Annals of Internal Medicine, 120(2), 126-132.

Boss, B.J. (1994). Concepts of neurologic dysfunction. In McCance, K.L. & Huether, S.E., eds. Pathophysiology: the biologic basis for disease in adults & children, 2nd ed. St. Louis: Mosby.

Brody, E.M. (1990). Women in the middle: their parent-care years. New York: Springer.

Burgeois, M.S., Beach, S., Schulz, R. & Burgio, L.D. (1996). When primary and secondary caregivers disagree: predictors & psychosocial consequences. Psychology & Aging,

11(3), 527-537.

Cohen, D., Luchins, D., Eisdorfer, C., Pareza, G., Ashford, J.W., Gorelick, P., Hirschman, R., Freels, S., Levy, P., Semla, T. & Shaw, H. (1990). Caring for relatives with alzheimer's disease: the mental health risks to spouses, adult children & other family caregivers. Behavior, Health & Aging, 1, 171-182.

Collins, C., King, S., Given, C.W. & Given, B. (1994a). Stress effects on family caregivers of alzheimer's patients. Springer Publishing Company.

Collins, C., Stommel, M., Wang, S. & Given, C.W. (1994b). Caregiving transitions: changes in depression among family caregivers of relatives with dementia. Nursing Research, 43(4), 220-225.

Draper, B.M., Poulos, C.J., Cole, A.D., Poulos, R.G. & Ehrlich, F. (1992). A comparison of caregivers for elderly stroke and dementia victims. Journal of the American Geriatrics Society, 40, 896-901.

Folkman, S. & Lazarus, R.S. (1980). An analysis of coping in a middle aged community sample. Journal of Health and Social Behavior, 21, 219-225.

Franks, M.M. & Parris Stephens, M.A. (1996). Social support in the context of caregiving: husbands' provision of support to wives involved in parent care. The Gerontological Society of America, 51B(1), 43-52.

Fujimoto, D. & Shimomura, S.K. (1996). Alzheimer's disease. In Herfindal, E.T., & Gourley, D.R., eds. Textbook of therapeutics: drug and disease management, 6th ed. Baltimore: Williams & Wilkins.

Fuller, Jonap, F. & Haley, W.E. (1995). Mental and physical health of male caregivers of a spouse with alzheimer's disease. Journal of Aging & Health, 7(1), 99-118.

Gallagher, D., Rose, J., Rivera, P., Lovett & Thompson, L.W. (1989). Prevalence of depression in family caregivers. The Gerontologist, 29(4), 449-456.

George, L. & Gwyther, L. (1986). Caregiver well-being: a multidimensional examination of family caregivers of demented adults. The Gerontologist, 26(3), 253-259.

Haley, W.E. & Pardo, K.M. (1989). Relationship of severity of dementia to caregiving stressors. Psychology & Aging, 4 (4), 389-392.

Hooker, K., Monahan, D., Shifren, K. & Hutchinson, C. (1992). Mental and physical health of spouse caregivers: the role of personality. Psychology & Aging, 7 (3), 367-375.

Horowitz, A. & Shindelman, L.W. (1983). Reciprocity and affection: past influences on current caregiving. Journal of Gerontological Social Work, 5, 5-20.

Jones, D.A. & Peters, T.J. (1992). Caring for elderly dependents: effects on the carer's quality of life. Age and Aging, 21, 421-428.

Kielcolt-Glaser, J.K., Dura, J.R., Speicher, C. E., Trask, O. J. & Glaser, R. (1991). Spousal caregivers of dementia victims: longitudinal changes in immunity & health. Psychosomatic Medicine, 53, 345-362.

Lazarus, R.S. & Folkman, S. (1984). Stress, appraisal, & coping. New York: Springer Publishing.

Pearlin, L.I., Mullan, J.T., Semple, S.J. & Skaff, M.M. (1990). Caregiving and the stress process: an overview of concepts and their measures. The Gerontologist, 30(5), 583-591.

Pruchno, R.A. & Resch, N.L. (1989). Mental health of caregiving spouses: coping as mediator, moderator, or main effect. Psychology and Aging, 4(4), 454-463.

Radloff, L.S. (1977). The CES-D scale: a self-report depression scale for research

in the general population. Applied Psychological Measurement, 1(3), 385-401.

Robinson, K.M. (1989). Predictors of depression among wife caregivers. Nursing Research, 38(6), 359-363.

Schulz, R. & Williamson, G.M. (1991). A 2 year longitudinal study of depression among alzheimer's caregivers. Psychology & Aging, 569-578.

Shields, C.G. (1992). Family interaction and caregivers of alzheimer's disease patients: correlates of depression. Family Practice, 31, 19-33.

Stommel, M., Given, C.W. & Given, B. (1990). Depression as an overriding variable explaining caregiver burdens. Journal of Aging & Health, 2(1), 81-102.

Stommel, M., Given, B.A., Given, C.W., Kalaian, H.A., Schultz, R. & McCorkle, R. (1993). Gender bias in the measurement properties of the center for epidemiologic studies depression scale (CES-D). Psychiatry Research, 49, 239-250.

Stommel, M., Given, B.A. & Given, C.W. (1995). The impact of the frequency of care activities on the division of labor between primary caregivers and other care providers. Research on Aging, 17(4), 412-433.

Stone, R., Cafferata, G.L. & Sange, J. (1987). Caregivers of the frail elderly: a rational profile. The Gerontologist, 27, 616-626.

Weissman, M.M. (1987). Advances in psychiatric epidemiology: rates and risks for major depression. American Journal of Public Health, 77 (4), 445-451.

MICHIGAN STATE UNIV. LIBRARIES



31293017188479