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Stress Experienced by Respite Care Workers and Family Caregivers When Caring for Alzheimer's Patients

Monica D. Minewiser
University of the Incarnate Word

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**STRESS EXPERIENCED BY RESPITE CARE WORKERS AND FAMILY
CAREGIVERS WHEN CARING FOR ALZHEIMER'S PATIENTS**

BY

MONICA D. MINEWISER

THESIS

Presented to the Graduate Faculty of the University of the Incarnate Word
in Partial Fulfillment of the Requirements for the Degree of

MASTER OF SCIENCE IN NURSING

UNIVERSITY OF THE INCARNATE WORD

December 1999

APPROVED:

Sandra Strickland, Dr.P.H., R.N.
Sandra Strickland, PhD, RN, Chairperson

Dianna Tison Ph.D., R.N.
Dianna Tison, PhD, RN, Member

Barbara Aranda-Naranjo Ph.D., RN, FAAN
Barbara Aranda Naranjo, PhD, RN, FAAN, Member

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DEDICATION

This work is dedicated to my husband Tom Minewiser who has more wisdom, talent, and understanding than all of my years of schooling could provide to me.

I also dedicate this to our children Pamela, Teresa, Noel, Miriam and Marina who watched me grow in the role of professional and student.

Above all, I dedicate this work to God, who in His mercy gave me the tools that I needed to complete this task.

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ABSTRACT

Stress Experienced by Respite Care Workers and Family Caregivers When Caring for Alzheimer's Disease Patients.

Monica D. Minewiser, BSN, RN University of the Incarnate Word

Changing demographics and cost containment in health care in caring for the Alzheimer's Disease (AD) patient has given birth to a growing need for respite care workers. The purpose of the study was to determine whether the stress level of a respite care worker who works with an AD patient in a non-institutionalized setting on a daily basis will be significantly less than that of a family caregiver when caring for an AD patient. The Revised Memory and Behavior Problem Checklist (RMBPC) was the instrument used to measure stress. This is a questionnaire consisting of 24 questions and allows 5 levels of responses for both the frequencies of behaviors of AD patients and the reactions of the caregivers. A total of 25 respite care workers and 25 family caregivers responded to the same questionnaire. The results of the study determined that overall, the stress levels of respite care workers was less than that of family caregivers. However, averaging of the responses to certain questions showed surprising results. The findings of this study conclude that since there is a dearth of research in this area, additional research will be needed to determine what interventions could be instituted to reduce respite care workers' stress in certain areas of AD patient behaviors.

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CHAPTER 1

INTRODUCTION

Background

Conservative estimates place the number of Alzheimer's Disease (AD) cases between one and two million in the United States among people ages 65 and older. At least 200,000 to 400,000 of these are severely demented (White, 1997). The criteria for diagnosis of AD include insidious onset and more or less continuous progression. Because the prevalence of the disease increases dramatically with each succeeding decade of life, estimates are that AD afflicts 25 to 45 percent of people ages 85 and older (Leon, Cheng & Neumann, 1998).

Alzheimer's Disease causes substantial functional impairment, including cognitive impairment, focal symptoms, hallucinations, delusions, and psychosocial incompetence. These symptoms change as the disease progresses. This places AD patients' caregivers in a position of stress.

An AD patient is usually better cared for at home than in an institution as there is a better caregiver-to-patient ratio in the home and this may be the only choice financially. Caregiving for AD patients is an all day, twenty four hour, every day responsibility. Caregivers in institutions work a shift and then go home and have days off every week. Family caregivers can do the same if families share in the responsibility of caring for the family member with AD. Some families do not, or can not. In this case, the responsibility sometimes falls on a

single person, such as a son, a daughter, or more often, a spouse who may be close to the same age as the AD patient. With no respite from this continuous stress, family caregivers can be affected physically and emotionally until they reach a point of burnout. Organizations have emerged that provide respite care for the family caregivers. These organizations refer to their workers as respite care workers. These respite care workers usually provide caregiving services to AD patients for several hours per day, and provide this service for multiple patients.

Respite care workers caring for AD patients are subjected to some stress levels as would a family caregiver of an AD patient, and may also be subjected to additional stress since they have to work with multiple patients. Each AD patient can present different stressors to the respite care workers, a factor that is not present with family caregivers when caring for their loved ones with AD.

Problem Statement

Is there a difference in the stress level of a respite care worker who works with Alzheimer's Disease patients in a non-institutionalized setting on a daily basis, 5 days a week, and a family caregiver who works with an individual AD family member on a daily basis with respite care workers as the primary source of respite?

Need for and Significance of Study to Nursing

Many research articles have been written about the stress experienced by AD patient caregivers, however despite exhaustive searching, research articles regarding respite care worker stress seem to be non-existent. As life expectancies increase, the percentage of older adults increases. This creates an increasingly demanding role for family caregivers resulting in an increasingly demanding need for respite care workers.

According to Hayes (1999), the present trend in health care is quality and cost-efficiency. For this reason, care systems for AD has been under study. It has been projected that by 2040, seven million Americans will be diagnosed with AD. Caring for these patients has been traditionally done by family, relatives, and friends. Demographics are changing with more women entering the workforce, a decrease in birth rates, and a greater mobility of the population in this country. The results are a smaller number of children remaining to care for their aging parents. Without these informal caregivers, the estimated cost of caring for AD patients is \$54 billion per year. Changing demographics and cost containment in health care in caring for the AD client population has become a very real political, economic, and social issue. Therefore, respite care services have been identified as an effective strategy in managing AD clients in the community.

Hayes (1999) also states that health care in the United States is leaning towards taking root in the community with a focus on in-home care. Therefore, attention should be directed to health promotion and disease prevention among patients and those caring for them. Stress-

related illnesses have been identified in family caregivers of AD clients by Hayes who also shows that respite programs can help to ease some of the stress and burden of the caregiving task of family caregivers.

The literature reviewed has shown that family caregivers of AD patients exhibit negative reactions to the task of caregiving resulting in the use of respite care workers. Since there is a dearth of literature on stress and respite care workers when caring for AD patients, it seems necessary to health care to study the subject. Since AD is the fourth leading cause of adult death in the United States (Nadler-Moodie & Wilson, 1998), it presents a public health issue and is therefore significant to nursing.

Spier & Yurick (1998) propose that undergraduate students in baccalaureate nursing programs should be given clinical experience in the homes where people with AD receive care. This would provide nurses with a sensitivity to the needs of AD patients, and the needs of the caregivers.

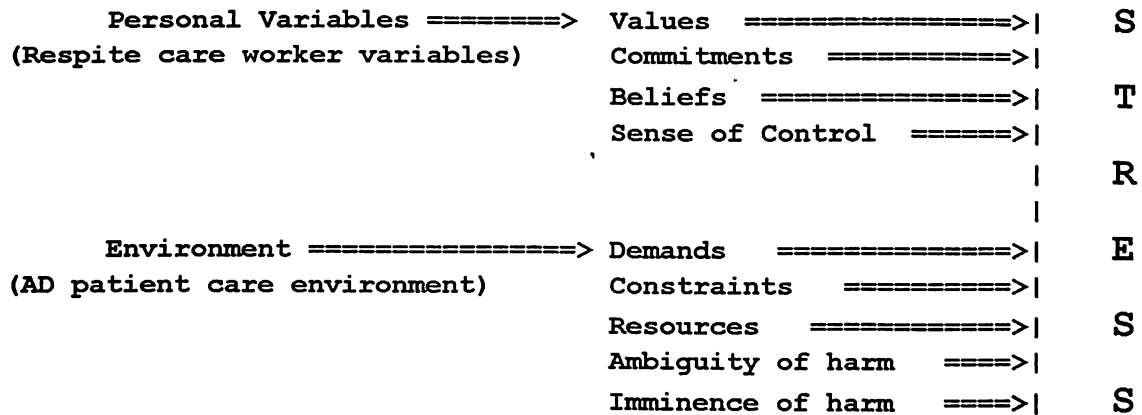
Although the article mentions the needs of the AD patient, it primarily deals with the needs of the caregivers and the value of the clinical experience to the student nurses. They are taught to recognize stress experienced by the caregivers, especially as AD progresses and the patient's functional level diminishes. These students could also provide support and respite for the caregivers. Caregivers benefit by having respite time and the students benefit by gaining an awareness of the special requirements of AD patients, including assessment skills, and communication skills.

The literature describes stress and burden experienced by family caregivers and identifies respite care as being an intervention used to ease the stress and burden related to the caregiving task. In the interest of primary prevention, it is beneficial for nurses to study stress, if any, that may be experienced by respite care workers when caring for AD patients.

Theoretical Framework

Psychological stress among family caregivers of AD patients has been adequately documented. It is no wonder that family caregivers of AD patients have been associated with symptoms of depression. Since this study involves the description of stress among respite care workers, Lazarus' Stress, Coping and Adaptation Model (Lazarus & Folkman, 1984) has been used. For the purpose of this study, only the stress element of the framework has been tested. According to Lazarus & Folkman (1984), stress is a product of two factors: personal variables and the environment. This stress could be evaluated by the person as being related to his or her well-being. During this process, the person's resources may be strained or surpassed. The personal variables are the factors by which each person is affected by stressful situations. The environment changes from one moment to the next producing the other factor that causes stress. This concept is schematized in Figure 1.

Figure 1. A Theoretical Schematization of Stress in Respite Care Workers.



(Adapted from Lazarus & Folkman (1984, pg.305))

Stress, as defined here, pertains to the relationship between the individual and the environment. This takes into account the characteristics of the individual and the nature of the environmental event to provide a reference to the amount of stress perceived by the individual. In this way it can be determined if the level of stress is taxing or exceeding the individual's resources and endangering his or her well-being (Lazarus & Folkman, 1984).

This researcher has tested the following theoretical proposition from the framework: The greater the exposure to stressful situations, the greater the impact on the individual.

Operational Definitions

The operational definitions for this study include:

1. **AD patients:** Those individuals that are diagnosed as having “A form of presenile dementia due to atrophy of frontal and occipital lobes....Involves progressive, irreversible loss of memory, deterioration of intellectual function, apathy, speech and gait disturbances, and disorientation.” Thomas (1985 p.64).
2. **Respite care workers:** Non-professional, non-family, paid caregivers of AD patients who are employed by a respite care agency.
3. **Stress is defined by Lazarus & Folkman (1984, p.21) as “a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well being”.**
4. **A Family Caregiver:** The spouse, son, daughter, brother, sister or other relative or close friend that cares for an AD patient without pay in a family setting.
5. **A non-institutionalized setting:** The private home of an AD patient or family.
6. **Daily basis:** Defined as any day of the week between and including Sunday and Saturday.

Hypothesis

The stress level of a respite care worker who works with an Alzheimer's Disease patient in a non-institutionalized setting on a daily basis will be significantly less than that of a family caregiver when caring for an AD patient.

Assumptions

The assumptions made by this researcher were that:

- 1. Respite care workers caring for AD patients would experience some level of stress.**
- 2. The respite care workers and family caregivers can read, write, and understand the English language.**
- 3. Sufficient responses would be obtained from the questionnaire to determine level of stress among the respite care workers.**

Limitations

The limitations to the research were:

- 1. The use of convenience sampling.**
- 2. All subjects may not interpret the wording of the questions in the same way.**
- 3. Personal beliefs, feelings, and past experiences may impact how subjects respond to the items of the questionnaire.**
- 4. The size of the sample may not be sufficient for generalization of the results.**

CHAPTER 2

REVIEW OF THE LITERATURE

According to Thomas (1985) in Taber's Cyclopedic Medical Dictionary (p. 1639), stress is defined as "The physical and psychological forces experienced by individuals". This dictionary also states that all organisms require some degree of stress in order to maintain health. Consistent or repeated high levels of negative stress, however, can do mental and physical harm to humans.

No literature could be found that deals with stress related to respite care workers when caring for AD patients. One source of literature available that describes stress among caregivers of AD patients is related only to that experienced by family caregivers. Family caregiver stress can negatively impact the AD patient. An abundance of articles are available in support of caregiver stress. When respite care workers are providing their services, they are, for that period of time, the AD caregiver, subject to the same stress that the family caregiver would be subjected to. For this reason, literature pertaining to stress that family caregivers of AD patients are subjected to was used as an example in this paper.

In the article by Eisdorfer, Rabins, & Reisberg (1991), family caregivers of AD patients are referred to as "the hidden victims" because of the stresses and burdens placed upon them. This is substantiated by Hayes (1999). According to her, caring for an AD patient is an all day task that requires the caregiver to be very alert. Therefore the task becomes burdensome.

Caregivers of AD patients admit to being burdened by social

isolation and the lack of time for themselves. Spier & Yurick (1998) have mentioned that the caregiver of an AD patient is a “Prisoner in his or her own home” since it is as though the caregiver has forfeited all rights to freedom as a result of being tied down to the caregiving task. Some caregivers accept the responsibility as a duty, and to avoid a guilt feeling associated with institutionalization of their loved ones. All this causes caregivers to tend to neglect their own health care needs.

Bourgeois, Schulz, & Burgio (1996) refer to “Undesirable social role changes, the development of depression and anxiety, strained relations with other family members, and general feelings that life is uncontrollable and overwhelming” as resulting from caregiving for AD patients. The authors recognize that caregiving of any disabled person is burdensome. However, according to them, the range, frequency, and severity of deficits in cognition and behaviors that are a problem and that are associated with dementia can result in demanding stresses.

Eisdofer et al. (1991) state that some of the medical, physical, and psychological problems associated with caring for AD patients are:

1. Clinical depression.
2. Alcohol abuse.
3. Sleep deprivation.
4. Anxiety.
5. Fatigue.
6. Irritability.
7. Frustration.
8. Poor morale.
9. Loneliness.

10. Isolation.
11. Anger.
12. Violence.
13. High stress levels.
14. Increase in morbidity.

Hayes (1999) believes that caregiving takes a toll on the caregiver, not only physically and emotionally, but also financially and socially. Hayes notes that caregivers of patients with dementia experience stress and depression which is significantly higher than that experienced by caregivers of non-dementia clients. Caregivers of dementia patients experience increased role strain as cognitive functioning of the patient declines. Bourgeois et al. (1996) state that although caregiving for any disabled individual is burdensome and stressful, the type, frequency, and severity of cognitive deficits and problem behaviors found in AD patients can produce stresses that are physically demanding and persistent. These deficits and behaviors range from wandering, hallucinations, embarrassing behavior, dangerous behavior, and agitation, to emotional distress and problems with activities of daily living. Some behavioral problems that are less predictable such as aggressive outbursts, repetitive verbal statements, wandering, and losing things can produce additional stress factors.

According to Acton (1997), caregiving is stressful and burdensome. Acton portrays stress as the reaction of the caregiver to memory and behavior problems, which are problems exhibited by demented people. Burden is portrayed as the negative impact of the task of caregiving related to the sense of loss, isolation, loneliness, and

despair felt by the caregiver. This in turn results in caregivers' long-term consequences impacting them mentally, emotionally, psychosocially, physically, and financially.

Acton also states that the stress and burden of caregiving can adversely affect the immune system. Poor health and well-being evolves. It is also noted that caregivers are most often afraid to leave the AD patient, and that they are even afraid to sleep. Caregivers fear that if left unattended, the AD patient may harm himself or herself. Repeating questions, misplacing things, verbal and physical violence by the AD patients are some of the stressors for caregivers. According to Spier & Yurik (1998), isolation is a result of caregivers not having adequate support.

Eisdorfer et al. (1991) cite that depression in caregivers results from changes in the demented patient's personality and from lack of control over the patient's condition. Insomnia and loss of appetite and weight are related to the depression. The same authors place caregivers of AD patients at risk of abusing alcohol while also being more apt to use tranquilizers. They state that a third of family caregivers use psychotropic medication with no diagnosis for the use of such drugs. Alcohol combined with these drugs cause those using them to be tired and depressed. Habitual use could lead to decreased alertness resulting in minimal or no watchfulness over the AD patient and his or her activities. Alcohol could also cause the caregiver to be irresponsible and resort to verbal and physical abuse.

Lachs, Williams, O'Brien, Hurst & Horwitz (1997) state that caring for AD patients is so stressful that patient abuse occurs. These authors

performed a study on the risk factors for elder abuse and neglect that have been reported and verified. The cohort consisted of 2,812 Community-dwelling older adults. The cohort was followed over a 9 year period. The stratified probability sampling method used in this study is a preferred method of obtaining samples. At the inception, the median age was 75 years. Men (1,643) were oversampled against women (1,169). The results show that the elderly were most abused by their adult children, and somewhat abused by their spouses according to this study. It may be possible to head off problems with various interventions.

A theoretical concept, affiliated-individuation (AI), was studied by Acton (1997) for its ability to mediate the effects of stress and burden on caregivers. "AI is defined as the inherent need to be affiliated with others while remaining independent from these same people, yet feeling comfortable and confident in both situations" (Acton, 1997, p. 337). Acton states that stress and burden have been correlated to ill health. An example of this is heightened symptoms of depression and demoralization.

The purpose of Acton's article was to test a model based on the Modeling and Role-Modeling Theory. Measures of stress, burden, affiliation, individuation, and life satisfaction were performed on a sample of family caregivers of AD patients. In this study AI was found to be effective in reducing effects of stress and burden on family caregivers. In addition to the results of the direct research that Acton performed, the author used references from a large number of accredited sources. No published research that would confirm AI's

ability to reduce the effects of stress and burden on family caregivers was presented, as none were found by the author. While research on similar concepts can provide some insight, conflicting research indicates that more study is needed. Acton also points out that AI is in the early stages of being tested and needs replication in order to evaluate its true potential.

Bourgeois et al. (1996) reviewed and analyzed the content and process of interventions for caregivers of patients with AD. The authors reviewed caregiver intervention studies. The identified types of interventions included support groups, individual/family counseling, respite care, skills training interventions, and comprehensive, multi-component interventions. Since most of the data obtained in the studies reviewed are from self-report, the accuracy of outcomes is questionable. The beliefs of those involved in the interventions have an impact on the outcome. In this review, the authors are recommending that the strength, integrity, and effectiveness of interventions be improved.

Literature reviewed by Bourgeois et al. (1996) shows, among other things, that individual psychosocial interventions and respite programs are moderately effective, though psychosocial interventions with groups are less effective. This is with regard to interventions aimed at alleviating caregiver distress, according to these authors.

Bourgeois et al. (1996) state that belonging to support groups helped caregivers of AD patients by providing opportunity to discuss common problems and fears with other caregivers in an equal situation. This enables them to be better readied to face challenges related to the

caregiving task. According to the investigator and participants in these authors' studies, support group meetings were designed to "increase understanding of AD" (p. 70), share common feelings, and to provide better problem solving techniques through discussions with others.

Caregivers of AD patients need to know how to obtain respite services in their community (Eisdofer et al., 1991). The authors refer to the necessity of AD patient caregivers to take some time for themselves for their own well-being as well as that of the patient.

Eisdofer et al. (1991) cite research as suggesting that caregiving for AD patients is so burdensome that it leads to increased morbidity among caregivers since AD is a long process. Therefore the authors suggest that caregivers of AD patients be given respite for at least 2 hours a day. They are of the opinion that caregivers would collapse because of exhaustion at some point. If this should happen, the AD patient would have to be entirely cared for by non-family caregivers. Montgomery (1989) states that family caregivers give up the role of caregiver and institutionalize their loved ones mostly because of caregiver health problems rather than the recipient's condition.

Hayes (1999) points out that with demographics changing in the United States and the recent emphasis on cost containment in health care, new approaches need to be resorted to in order to accommodate the needs of AD clients and their caregivers. The author identifies respite services as an effective approach in the ongoing management of AD clients. She describes the need for such services as well as the barriers to such services. However, methods of overcoming barriers to respite services, and a cost-effective and sensitive way of providing

respite services are discussed.

Cox (1997) cited studies that questioned the value of respite services, and conflicting studies that indicated that these services are beneficial. Cox compared respite care users with those who stopped or never began using respite care to determine the benefits of respite care programs. The findings of her study point out the impact of the need variables on the use of respite services. The greater the cognitive decline of the relative, and the greater the caregiver burden, the more potential exists for the use of respite services. Relief of caregiver burden as a result of using respite services was also a result of the findings. Cox cited literature that identified the factors related to utilization of respite care programs as:

- 1. Workers being matched with clients.**
- 2. Worker training.**
- 3. Service flexibility.**
- 4. The amount of respite care offered.**

Cox stated that the use of respite services increased when the caregiver was female and married to the participant, when the ages of the caregivers and care recipient were greater, and when caregiver burden increased. The study focused on identifying the factors associated with the use of respite care. It compared respite care users with those stopping respite care use, and those who did not use respite care, factors that can predict respite use, and effects of respite care on users of the service. Caregivers were accepted into the program on the basis of their annual income. This income was adjusted to family size. The program was not free, but allowed some financial reimbursement.

A medical certification that the relative had AD or a related disorder was required. This sampling method is not representative of all caregivers of AD patients. The author mentions only Whites and Blacks in the study, making no mention of other races.

Among the reasons given for stopping the use of respite care services were that the care recipient died, was placed in a nursing home, changed caregivers, or that the program did not meet the needs of the AD patient or those of the caregivers. No mention was made regarding possible financial considerations, excessive paperwork, or some of the other factors for not using the service in the first place. The author suggests that since many of the participants in the program stopped using the respite care services because the recipient was institutionalized, a failure of the program is indicated. In the advanced stages of AD, institutionalization may be the only option for family caregivers. The data analysis shows significant improvement in the behavior of the AD patient and a significant decrease in the burden scores of the caregiver with the use of respite care. Rosenheimer and Francis' article (as cited in Hayes, 1999) states that caregiving being physically, emotionally, financially, and socially over-whelming results in clients with AD being inappropriately institutionalized very often, or abused and neglected by caregivers when there is no support. Some barriers to the use of respite services are lack of knowledge of the availability of respite services, and the lack of guidance of caregivers to respond to the needs of the AD client and their own need for respite.

Respite care workers are with their AD clients for several hours each day, 5 days a week. A respite care worker is replacing the family

caregiver for some period of time. This respite care worker in essence, becomes the surrogate family caregiver. Literature does not document stress as experienced by respite care workers when caring for AD patients, thus leaving a gap in information pertaining to stress experienced by AD patient caregivers in general.

CHAPTER 3 METHODOLOGY

Research Design

The research design for this study was a non-experimental, exploratory ex post facto design. The purpose of the study was to determine the phenomenon of stress experienced by respite care workers and actual client caregivers when caring for AD patients in the patients' own home environment. The data obtained with the frequency of occurrence was documented. However, no interventions were introduced.

Design for data collection

Setting

The data for the study was collected at a respite care agency, a non-profit organization, and at private homes of family caregivers affiliated with the respite care agency in a major city in the Southwestern part of the United States. The subjects consisted of respite care workers and family caregivers of AD patients. The agency informed the family caregivers and respite care workers of the study by letter. The respite care workers volunteered and were given the questionnaire at the respite agency on a payday. A room was utilized at the agency to provide a quiet place and one free from the hierarchy. The family caregivers who volunteered to participate were given the same questionnaire in their own homes. The questionnaire was given at a time when the respite care worker was available and the family

caregiver had an opportunity to answer it without interruption as much as possible.

Sampling and Sample

A convenience sample of 25 respite care workers and 25 family caregivers was recruited on a voluntary basis as participants in the study. Participants were notified by mail through the respite agency that a questionnaire of 24 questions would be given to those who wished to volunteer as participants in a research study. In order to participate in the study the subjects had to be:

1. Over 18 years of age.
2. Able to read, write, speak and understand the English language.
3. Employed by and/or affiliated with the designated respite care agency.
4. A family member/respite care worker caring for an AD patient presently and in the recent past.

The desired number of respite care worker volunteers were not available on one payday, therefore the procedure was repeated on two consecutive paydays until the desired number of respite care workers had voluntarily participated.

Protection of Human Subjects

To protect the human rights of the participants, permission was obtained from the Institutional Review Board of the University of the Incarnate Word (IRB of UIW) and the IRB of the agency in which the study was done. Involvement in this study did not represent any appreciable risks to the physical or psychological safety of the participants and did not affect the employment of the respite care workers with the agency. All participants were notified that they may withdraw from the study at any point. An Informed Consent document was provided to each participant (See Appendix 5).

On the top of the questionnaire, there was a statement included which states that "Completion of this questionnaire is deemed consent to participate in the study." Participation in the study was known only to the participants and this researcher. Two ballot box type containers with locks, one for respite care worker questionnaires and one for family caregiver questionnaires were used to collect the questionnaires upon completion.

This researcher was in possession of the only keys to the boxes. The ballot box for the family caregiver questionnaires was carried to each participant, and both boxes were opened only after all the questionnaires had been collected. Participants were notified that upon

request, they would be provided a summary of the study after completion.

Instrumentation

The Revised Memory and Behavior Problems Checklist (RMBPC) by Teri, Traux, Logsdon, Uomoto, Zarit, and Vitaliano (1992) is the instrument that was used to measure levels of stress among respite care workers and family caregivers of AD patients. This researcher has obtained written permission from one of the authors to use the RMBPC (See Appendix 2). These authors used the RMBPC to obtain data from 201 geriatric patients with dementia and their caregivers. This checklist consists of 24 items. It is a “caregiver-report measure of observable behavioral problems in dementia patients.” Refer to Appendix 1 for the RMBPC. The behaviors cited in the items in the questionnaire relate to the environment. The frequency refers to the number of times that the behaviors are exhibited. The reaction responses were the effect that the environment has on the individual as determined by personal variables. The reliability of the scale of patients’ behavior was .84, and that of caregiver reaction was .90. The subscale reliability ranged from .67 to .89. The validity of this instrument was confirmed through comparison of its scores with well established indexes of depression, cognitive impairment, and caregiver burden.

The RMBPC is a paper and pencil questionnaire that is easy to use and is self-administered. It requires less than 15 minutes to complete.

The RMBPC gives one total score and 3 subscale scores. The subscales are related to patient problems such as memory-related, depression, and disruptive behaviors. Scores for caregiver reaction to AD patient problems are also given. Behaviors (frequency ratings) are rated from 0 to 4 with 0 being "Never occurred", and 4 being "Daily or more often". A rating of 9 is also included, with 9 being "Don't know/not applicable". This instrument also evaluates the caregiver's reaction to individual behaviors, providing a guide of the effect of each behavior on the caregiver. Reaction ratings are from 0 to 4 with 0 being "Not at all", and 4 being "Extremely". A rating of 9 is also included, with 9 being "Don't know/not applicable". The RMBPC was designed to assess behavioral problems in patients with dementia and caregivers' reactions to those behaviors.

This researcher included all responses, 0 thru 4 and 9. The responses of frequency and reaction scores of each group i.e., respite care workers and family caregivers, were averaged and standard deviations were calculated using a *t* value from a standard table since the total number of responses was greater than 40. An ANOVA test was performed to test for a possible difference in variances. Hypothesis tests of means were done. Because there was a significant difference in the frequency in which characteristics were observed, this researcher did a one tailed test to determine if respite care workers working with AD patients are less stressed than family caregivers of AD patients. A hypothesis test was then done to determine if the stress level of respite care workers was less than the stress of family caregivers.

Data-Collection Protocol

The subjects consisted of respite care workers and family caregivers of AD patients. The respite care workers were those working for the same respite care agency. The family caregivers were those using services of the same agency by which the respite care workers are employed. A description of the characteristics of the sample was done only to show data, not to test any correlation.

When the respite care workers came to pick up their pay checks, this researcher met each of them and asked them if they received the letter from the agency about the study. Each respite care worker who stated that he/she received the letter about the study and was volunteering to participate was shown to the quiet room designated for the answering of the questionnaire. He/she was shown the “ballot box” type secured box in the room and instructed to drop the completed questionnaire into it. This researcher then handed out the questionnaire, asked the participant to read the instructions and asked him/her if there were any questions before responding to the questionnaire. The researcher then left the room. The participants were told where the researcher was (in the building in close proximity) in case any participant needed clarification of a question.

Family caregivers who volunteered to participate were given the questionnaire in their own homes. This researcher went to the home of the family caregiver with prior notification, and at a time that the respite care worker was with the AD patient. The family caregiver was asked to pick a quiet room in the home where he/she could be comfortable to respond to the questionnaire. This researcher went to that quiet room

with the family caregiver and showed him/her the secured box and set it down in the room. The purpose of the secured box was then explained and the participant was instructed to drop the completed questionnaire into it. This researcher then handed out the questionnaire, asked the participant to read the instructions and asked him/her if there were any questions before responding to the questionnaire. The researcher asked the family caregiver to begin working on the questionnaire, and then the researcher left the room.

CHAPTER 4

ANALYSIS OF DATA

In order to determine whether stress experienced by respite care workers caring for AD patients in a non-institutionalized setting is less than the stress experienced by family care givers when caring for AD patients in the same setting, a nonexperimental exploratory ex post facto study was conducted. This study was conducted in a major city in the Southwestern part of the United States. This investigator conducted a survey using a 24 question questionnaire as an assessment tool to measure stress which is the independent variable. The data obtained with the frequency of occurrence was documented. However, no interventions were introduced. The research data were analyzed by first describing the sample. A *t*-test was used to test the research hypothesis, and statistical results were delineated in tabular form. This chapter concludes with a condensed and summarized presentation of the statistical findings.

Demographics and Description of Sample

All 25 respite care workers and 25 family caregiver participants provided demographic data. The responses to the characteristics of the sample included:

1. Males and females.
2. Ages 31-40, 41-50, 51-60, 61-70 and greater than 70.
3. Race included Caucasian, Black, and Hispanic.
4. Number of months caring for AD patient(s) ranged from 1 month to 84 months.

5. There were no participants less than 31 years of age, and none were of *Asian* or *Other* races.

The demographics data is shown in the following table 1.

Table 1 - Demographics

<u>GENDER</u>	<u>RESPITE CARE WORKERS</u>	<u>FAMILY CAREGIVERS</u>
Male.....	2 (8%)	11 (44%)
Female.....	23 (92%)	14 (56%)

<u>RACE</u>	<u>RESPITE CARE WORKERS</u>	<u>FAMILY CAREGIVERS</u>
Caucasian.....	20 (80%)	25 (100%)
Black.....	3 (12%)	
Hispanic.....	2 (8%)	

<u>AGE</u>	<u>RESPITE CARE WORKERS</u>	<u>FAMILY CAREGIVERS</u>
31-40 years....	3 (12%)	1 (4%)
41-50 years....	4 (16%)	10 (40%)
51-60 years....	3 (12%)	6 (24%)
61-70 years....	4 (16%)	6 (24%)
>70 years.....	11 (44%)	2 (8%)

<u>MONTHS*</u>	<u>RESPITE CARE WORKERS</u>	<u>FAMILY CAREGIVERS</u>
1 to 6	14 (56%)	1 (4%)
7 to 12	5 (20%)	5 (20%)
13 to 24	2 (8%)	13 (52%)
25 to 36	2 (8%)	4 (16%)
37 or More....	2 (8%)	2 (8%)

* Number of months caring for AD patient(s).

The noteworthy data from the demographics report are as follows:

- Most of the respite care workers were female, Caucasian, over 70 years of age, and had worked less than six months caring for AD patients.
- The gender of the family caregivers were close to evenly split, with 44% males and 56% females, all were Caucasian, and most were between 41 and 70 years of age, and had been caring for an AD patient from 13 to 84 months.

Findings

For the purpose of measuring stress experienced by respite care workers and family caregivers when caring for Alzheimer's patients, the questionnaire the Revised Memory and Behavior Problems Checklist was utilized. Scores of this instrument were used to determine the levels of stress experienced by each of the two groups of caregivers.

Responses marked as "9" were blocked out in the mean and standard deviations. This response indicated that the frequency of the behavior or the reaction to that behavior was not known or was not applicable. Responses marked as "9" were included in the questionnaire because this response could be useful in additional research. The statistical data is shown in Table 2.

 Table 2 - Statistics

	Standard Deviation for "Frequency" Responses	
	Respite Care Worker	Family Caregiver
Response Frequency	562	585
Response Sum	730	863
Standard Deviation	1.49	1.53

$$F = 1.04$$

$$\text{Difference of Means} = .2366$$

	Standard Deviation for "Reaction" Responses	
	Respite Care Worker	Family Caregiver
Response Frequency	567	468
Response Sum	296	652
Standard Deviation	0.939	1.21

$$F = 1.67$$

$$\text{Difference of Means} = -.60$$

Standard deviation for "Frequency" responses was done and the F value was 1.04. To be significant, F would have had to be 1.93. At .01 significance level, 1.04 is not greater than 1.93 therefore no claim can be made that it is the variances that make the difference.

Is there a significant difference in the means of the "Frequency" responses? The critical difference is 6.2296. The difference of the sample means was .2366 which is greater than .2296, so the data support a significant difference in the frequency in which characteristics are observed.

Standard deviation for “Reaction” responses was done and the F value was 1.67. At .01 significance level, 1.67 is not greater than 1.93 therefore no claim can be made that it is the variances that make the difference.

D.R. Reject H_0 if $m_1 - m_2 < -.16$

dm. $.49 - 1.09 = -.60$

D: $-.60 < -.16$ therefore Reject H_0

C: Respite care workers are statistically less stressed than family caregivers.

The two mean hypothesis test used .01 as a significant level. The scores were 62.5.

A one-tailed test was performed to determine whether Respite Care Workers were less stressed than Family Caregivers at .01 significance level. The critical value was established at -.16. Since the difference of the sample means was -.6, which is smaller than -.16, one can conclude that Respite Care Workers are less stressed than Family Caregivers. Therefore, the H_0 was rejected, allowing one to conclude that respite care workers are statistically less stressed than family caregivers.

Additional Findings

Despite the overall scores to the questions in the questionnaire, average scores to specific questions showed “Frequency” and “Reaction” responses by the respite care workers to be equal to or higher than those of the family caregivers. A brief list of these questions and responses follows:

<u>Question</u>	<u>*RCW Average</u>		<u>**FC Average</u>	
	<u>Freq.</u>	<u>React.</u>	<u>Freq.</u>	<u>React.</u>
8. Destroying Property.	0.52	0.40	0.28	0.28
11. Talking loudly and rapidly.	0.28	0.28	0.12	0.16
12. Appears anxious or worried.	1.68	0.72	1.00	0.64
13. Threats to hurt oneself.	0.24	0.20	0.08	0.08
14. Threats to hurt others.	0.24	0.24	0.04	0.08
17. Appears sad or depressed.	1.88	1.04	0.80	0.88
18. Expressing feelings of hopelessness or sadness.	1.48	0.76	0.72	0.72
19. Commenting about death of self or others.	1.08	0.48	0.48	0.48

***RCW = Respite care workers**

****FC = Family caregivers**

To this researcher, this implies that either AD patients behave differently to caregiving from family members than to caregiving from respite care workers or that respite care workers are more observant of these behaviors than are family caregivers.

Summary of Findings

The findings of this study indicated that there was a significant difference ($D: -.60 < -.16$ at .01 significance level) found between the scores obtained on the questionnaire, the Revised Memory and Behavior Problems Checklist. The responses to the questionnaire therefore indicates that respite care workers experience less stress than family caregivers when working with AD patients in a non-institutionalized setting.

CHAPTER 5

SUMMARY OF THE STUDY

This study was conducted to determine if there is a difference in the stress level of a respite care worker who works with Alzheimer's Disease patients in a non-institutionalized setting on a daily basis, 5 days a week, and a family caregiver who works with an individual AD family member on a daily basis with respite care workers as the primary source of respite. This chapter summarizes the previous chapters, discusses the findings, and delineates conclusions from this study. Recommendations for further study conclude this summary.

Summary

This non-experimental exploratory ex post facto study was based on the stress element of the Stress, Coping and Adaptation Model by Lazarus & Folkman (1984). According to this model, stress is a product of two factors, personal variables and the environment.

Studies on the topic of respite care worker stress could not be found. The only literature found regarding AD caregiver stress was related to stress experienced by family caregivers, hence this literature was used as a basis for the exploration of stress experienced by respite care workers.

According to Eisdorfer, et al. (1991), family caregivers of AD patients are referred to as "The hidden victims" because of the stresses and burdens that the caregiving experience places upon them. Acton (1997) states that caregiving is stressful and burdensome. Acton used the Memory and Behavior Problems Checklist by Zarit & Zarit (1990) to

measure stress in family caregivers of adults with Dementia to test a midrange model based on Modeling and Role-Modeling Theory. This researcher wrote to Steven H. Zarit, Ph.D., to obtain permission to use the Memory and Behavior Problems Checklist as the instrument for her study. He gave permission to do so but suggested that the revised version be used, and provided a copy of this version along with reliability and validity information. The reliability of the scale of patients' behaviors was .84 and that of the caregivers' reactions was .90. The validity of this instrument was confirmed through comparison of its scores with well established indexes of depression, cognitive impairment, and caregiver burden. When used by the authors, the participants consisted of 201 geriatric patients and their caregivers.

For this research study, the Revised Memory and Behavior Problems Checklist was used to measure stress experienced by both groups of caregivers i.e. respite care workers and family caregivers. The questionnaire consisted of 24 questions related to behavioral problems in AD patients and the responses indicated the frequency of occurrence and the reactions of the caregivers to these behavioral problems.

The sample consisted of 25 respite care workers and 25 family caregivers affiliated with the same agency. These participants were voluntary, male and female, whose ages ranged from 31 to greater than 70. Only Caucasians, Blacks, and Hispanics participated in the study. The number of months of caring for AD patient(s) by the participants ranged from 1 month to 84 months. The data were collected over a period of one month. A convenience sampling method was used.

The questionnaire was given to respite care workers on two paydays at the respite care agency and collected in a ballot box type container for the purpose of anonymity. The questionnaire was given to family caregivers in their own homes by appointment and also collected in a ballot box type container for the purpose of anonymity.

The questionnaires were scored, and mean scores for the two groups were calculated to be .49 for respite care worker responses and 1.09 for family caregiver responses. The data were analyzed using a *t*-test. The level of significance in the difference of the scores was set at .01. An ANOVA test was done and showed that it was not the variances that made the difference.

The findings of this study were consistent with the theoretical framework on which this study was based to test levels of stress. Data analysis demonstrated that there was a significant difference ($p = .01$) between the levels of stress experienced by respite care workers and family caregivers when caring for AD patients in a non-institutionalized setting.

Discussion of the Findings

The findings of this study help to confirm that caring for an AD patient in a non-institutionalized setting is stressful. This is a sentiment expressed by Eisdorfer et al. (1991) when they recommend that caregivers of AD patients be given at least two hours of respite each day. Spier & Yurick (1998) refer to the caregiver of the AD patient as a "Prisoner in his or her own home" because they recognize that caregiving is stressful. Bourgeois et al. (1996) cite frequency and

severity of cognitive deficits and problem behaviors of AD patients as stress producing. Acton (1997) portrays stress as the reaction of the caregiver to memory and behavior problems, which are problems exhibited by demented people.

The instrument, the Revised Memory and Behavior Problems Checklist, used to measure stress in this study included frequency and reactions to cognitive deficits such as asking the same question over and over, losing or misplacing things, and difficulty concentrating on a task, as some of the cognitive deficits. The findings of this study produces the following results for these specific behaviors:

“Asking the same question over and over.”

Family Care Givers: Frequency = 91 Reaction = 66

“Losing or misplacing things.”

Family Care Givers: Frequency = 55 Reaction = 30

“Difficulty concentrating on a task.”

Family Care Givers: Frequency = 75 Reaction = 32

The highest possible scores for this instrument is 96 for both frequency and reaction. This corresponds to findings in the literature regarding stress that caregivers experience when caring for an AD patient. Since there was no literature found that can be used to compare this study's results regarding respite care worker stress, a direct comparison cannot be made in regard to respite care worker stress, however this study did find that respite care workers are subjected to some levels of stress. For example, respite care worker responses to the same questions asked above are as follows:

“Asking the same question over and over.”

Respite Care Workers: Frequency = 64 Reaction = 19

“Losing or misplacing things.”

Respite Care Workers: Frequency = 49 Reaction = 16

“Difficulty concentrating on a task.”

Respite Care Workers: Frequency = 43 Reaction = 6

Conclusions

Based on the significant statistical findings of this study, the following conclusions were derived. The research hypothesis that the stress levels of respite care workers who work with an Alzheimer’s disease patient in a non-institutionalized setting on a daily basis will be significantly less than that of a family caregiver when caring for an AD patient provides support for the theoretical framework.

It can also be concluded that all caregivers of AD patients experience some level of stress and the greater the exposure to stressful situations the greater the impact on the individual. Eisdorfer et al. (1991) cite research that suggests that caregiving of AD patients is burdensome and leads to high morbidity and other problems such as drug and alcohol abuse.

These conclusions indicate the need for primary prevention in the way of education for all caregivers of AD patients to understand the disease process of AD. Education should also include information regarding the stress related to the caregiving task. Based on the findings of this study, this researcher concludes that respite care workers need formal training on care for the caregiver.

Recommendations are for a training course for respite care workers on:

- 1. Coping strategies.**
- 2. Social outlets in the form of support groups.**
- 3. Therapeutic relationships between caregivers and clients regarding transference and countertransference.**
- 4. Infection control.**
- 5. Safety.**

Implications for Further Nursing Research

The findings of the study suggest that although the overall level of stress was greater for family caregivers than for respite care workers when caring for AD patients, an averaging of the frequency and reaction responses for each question as shown in Appendix 3, Family Caregivers' Responses and Appendix 4, Respite Care Workers' Responses, has provided an unexpected result. In the responses to questions 8, 11, 12, 14, 15, 17, 18, and 20, respite care workers indicated an equal or higher frequency and reaction rating than did family caregivers. This could point to a need for further nursing research on respite care workers. Are respite care workers, by virtue of experiencing some of the stress related to the caregiving task, alleviating the burden of family caregivers thereby being a support system to them or are the respite care workers a support system to the AD patient? Almost all areas of respite care still remain to be studied (Montgomery, 1989).

Another area that implies the need for additional research studies

would be the demographics of this study. All family caregiver subjects were Caucasian. Could ethnicity, age, length of time caring for an AD patient, or other factors have had an impact on the responses?

Recommendations for Further Study

Based on the conclusions of this study, the following recommendations are made:

1. A replica study be conducted using a larger sample to determine if the results can be duplicated.
2. A replica study be conducted in another environment, including respite care workers and family caregivers affiliated with several agencies to ensure replication success.
3. A similar study be conducted using an experimental research design which could control for intervening variables.

APPENDIX 1
QUESTIONNAIRE

Completion of the questionnaire is deemed consent
to participate in the study.

Revised Memory and Behavior Problems Checklist

PLEASE CHECK ONE OF THE FOLLOWING:

- A. _____ Respite Care Worker
 - B. _____ Primary Family Caregiver
-

INSTRUCTIONS

The following is a list of problems patients sometimes have. Please indicate if any of these problems have occurred during the past week. If so, how much has this bothered or upset you when it happened? Use the following scales for the frequency of the problem and your reaction to it. Please read the description of the ratings carefully.

FREQUENCY RATINGS:

- 0 = never occurred
- 1 = not in the past week
- 2 = 1 to 2 times in the past week
- 3 = 3 to 6 times in the past week
- 4 = daily or more often
- 9 = don't know/not applicable

REACTION RATINGS:

- 0 = not at all
- 1 = a little
- 2 = moderately
- 3 = very much
- 4 = extremely
- 9 = don't know/not applicable

Please answer all the questions below. Please circle a number from 0 - 9 for both *frequency* and *reaction*.

	Frequency	Reaction
1. Asking the same question over and over.	0 1 2 3 4 9	0 1 2 3 4 9
2. Trouble remembering recent events (e.g., items in the newspaper or on TV).	0 1 2 3 4 9	0 1 2 3 4 9
3. Trouble remembering significant past events.	0 1 2 3 4 9	0 1 2 3 4 9
4. Losing or misplacing things.	0 1 2 3 4 9	0 1 2 3 4 9
5. Forgetting what day it is.	0 1 2 3 4 9	0 1 2 3 4 9
6. Starting, but not finishing, things.	0 1 2 3 4 9	0 1 2 3 4 9
7. Difficulty concentrating on a task.	0 1 2 3 4 9	0 1 2 3 4 9
8. Destroying property.	0 1 2 3 4 9	0 1 2 3 4 9
9. Doing things that embarrass you.	0 1 2 3 4 9	0 1 2 3 4 9
10. Waking you or other family members up at night	0 1 2 3 4 9	0 1 2 3 4 9
11. Talking loudly and rapidly.	0 1 2 3 4 9	0 1 2 3 4 9
12. Appears anxious or worried.	0 1 2 3 4 9	0 1 2 3 4 9

FREQUENCY RATINGS:

- 0 = never occurred
- 1 = not in the past week
- 2 = 1 to 2 times in the past week
- 3 = 3 to 6 times in the past week
- 4 = daily or more often
- 9 = don't know/not applicable

REACTION RATINGS:

- 0 = not at all
- 1 = a little
- 2 = moderately
- 3 = very much
- 4 = extremely
- 9 = don't know/not applicable

	Frequency	Reaction
13. Engaging in behavior that is potentially dangerous to self or others.	0 1 2 3 4 9	0 1 2 3 4 9
14. Threats to hurt oneself.	0 1 2 3 4 9	0 1 2 3 4 9
15. Threats to hurt others.	0 1 2 3 4 9	0 1 2 3 4 9
16. Aggressive to others verbally.	0 1 2 3 4 9	0 1 2 3 4 9
17. Appears sad or depressed.	0 1 2 3 4 9	0 1 2 3 4 9
18. Expressing feelings of hopelessness or sadness about the future (e.g., "Nothing worthwhile ever happens," "I never do anything right").	0 1 2 3 4 9	0 1 2 3 4 9
19. Crying and tearfulness.	0 1 2 3 4 9	0 1 2 3 4 9
20. Commenting about death of self or others (e.g., "Life isn't worth living," "I'd be better off dead").	0 1 2 3 4 9	0 1 2 3 4 9
21. Talking about feeling lonely.	0 1 2 3 4 9	0 1 2 3 4 9
22. Comments about feeling worthless or being a burden to others.	0 1 2 3 4 9	0 1 2 3 4 9
23. Comments about feeling like a failure or about not having any worthwhile accomplishments in life.	0 1 2 3 4 9	0 1 2 3 4 9
24. Arguing, irritability, and/or complaining.	1 2 3 4 9	0 1 2 3 4 9

APPENDIX 2
Permission to use the
Revised Memory and Behavior Problems Checklist



June 29, 1999

Monica D. Minewiser, RN, BSN
1105 Brookside Cove
Cedar Park, Texas 78613

Dear Ms. Minewiser:

You may use the Memory and Behavior Problems Checklist in your research. I would, however, encourage you to use the revised version, which is enclosed.

Good luck with your study.

Sincerely,

A handwritten signature in black ink, appearing to read "Steven H. Zarit".

Steven H. Zarit, Ph.D.
Professor of Human Development

APPENDIX 3
Respite Care Workers' Responses to the Questionnaire

RESPIRE CARE WORKERS' RESPONSES

Key: F= Frequency, R= Reaction

Subj. #	Respite Care Workers																									Average Frequency	Average Reaction																										
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25																												
	F	R	F	R	F	R	F	R	F	R	F	R	F	R	F	R	F	R	F	R	F	R	F	R	F	R																											
Q1	2	0	3	1	4	1	4	1	2	0	4	2	1	1	0	0	4	1	4	1	3	0	4	0	3	3	4	0	0	0	4	1	2	0	0	0	4	1	2	1	0	0	2	1	4	4	3	0	1	0	2.56	0.76	
Q2	4	0	2	0	2	1	2	1	9	9	4	2	4	4	4	1	3	1	4	1	2	1	4	0	4	2	4	0	3	2	4	1	1	0	4	0	2	0	1	1	0	0	2	0	3	3	4	0	1	0	2.72	0.84	
Q3	4	0	2	0	2	0	2	1	9	9	2	2	4	4	4	1	1	0	9	9	2	1	4	0	2	1	4	0	4	3	3	2	1	0	4	1	9	9	1	1	0	0	2	0	2	2	2	0	1	0	2.12	0.76	
Q4	2	0	1	0	0	0	1	0	0	0	3	2	0	0	9	9	3	0	2	2	1	0	4	1	0	0	4	0	2	3	2	4	0	4	1	4	1	0	0	2	1	1	0	4	4	3	0	1	0	1.96	0.64		
Q5	2	0	3	0	2	1	2	0	9	9	4	2	9	0	4	1	2	0	9	9	4	0	4	1	3	2	4	0	3	2	4	1	2	0	4	0	1	0	1	1	0	0	2	0	2	2	4	0	1	0	2.32	0.52	
Q6	2	0	1	0	1	0	1	0	9	0	4	2	0	0	9	9	3	1	2	0	1	0	4	0	0	0	4	0	1	0	2	2	2	0	4	0	0	0	2	1	0	0	1	0	0	3	0	1	0	1.56	0.24		
Q7	3	0	2	0	1	0	2	0	9	0	3	2	4	0	9	9	3	0	9	9	2	0	4	0	0	0	4	0	1	0	3	3	1	0	4	1	0	0	0	0	0	0	1	0	0	4	0	1	0	1.72	0.24		
Q8	0	0	0	0	0	9	0	0	9	0	1	3	3	3	9	9	0	0	9	9	0	0	4	0	0	0	0	0	0	0	3	9	0	4	1	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0.52	0.40		
Q9	0	0	0	0	1	0	1	0	9	0	1	3	0	0	2	1	0	0	0	0	1	0	4	0	0	0	0	0	0	1	2	1	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0.56	0.24	
Q10	0	0	9	9	9	9	0	0	9	0	3	3	0	0	9	9	0	0	9	9	0	0	4	1	9	9	3	0	9	9	2	2	1	0	0	0	9	9	0	0	0	0	0	0	0	0	0	9	9	1	0	0.56	0.24
Q11	0	0	0	0	0	0	0	0	9	0	2	3	0	0	9	9	0	0	0	0	2	1	0	0	0	0	0	0	0	1	3	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0.28	0.28
Q12	4	0	0	0	0	0	0	0	9	0	4	3	3	3	2	0	1	0	2	3	1	0	0	1	1	4	0	1	1	2	2	9	0	3	1	2	1	4	2	2	1	1	0	0	4	0	1	0	1.68	0.72			
Q13	0	0	1	1	1	0	0	0	0	0	2	0	0	0	0	0	0	9	9	1	0	0	0	0	9	0	0	0	0	3	4	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0.28	0.32	
Q14	2	0	0	0	0	0	0	0	0	0	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	3	3	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0.24	0.20	
Q15	0	0	0	0	0	0	0	0	9	9	0	3	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	9	0	0	1	1	3	2	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0.24	0.24	
Q16	0	0	0	0	1	0	0	0	9	9	2	2	0	0	0	0	1	1	2	3	0	0	4	2	0	9	3	0	1	1	2	2	2	0	2	1	0	0	2	1	0	0	1	1	0	0	0	0	0	0	0.92	0.56	
Q17	4	2	1	1	0	0	0	0	9	9	4	2	3	3	2	1	2	1	2	1	1	0	4	2	1	1	4	0	1	0	1	3	3	0	4	3	2	2	2	2	2	1	0	0	1	1	3	0	0	1.88	1.04		
Q18	3	1	0	0	0	0	1	0	9	9	4	3	1	1	0	0	1	0	0	0	1	1	4	2	9	9	4	0	1	0	2	3	0	0	4	3	1	1	4	2	0	0	1	1	1	1	4	0	0	1.48	0.76		
Q19	2	1	1	1	0	0	1	0	0	0	4	2	4	4	1	1	0	0	0	0	1	0	4	2	0	0	4	0	0	0	1	3	0	0	4	2	0	0	3	2	2	1	1	1	0	0	0	0	0	1.32	0.80		
Q20	2	1	0	0	0	0	0	0	0	0	3	2	0	0	0	0	1	1	0	0	3	0	0	0	0	0	4	0	0	0	2	2	0	0	4	3	9	9	4	3	0	0	0	0	0	0	4	0	0	1.08	0.48		
Q21	0	0	1	0	1	1	1	0	0	0	1	3	0	0	0	0	3	1	0	0	1	0	0	0	0	0	4	0	0	0	1	2	3	0	0	0	0	0	4	3	0	0	0	0	3	3	0	0	1	0	0.96	0.52	
Q22	2	1	0	0	0	0	0	0	0	0	2	0	0	2	1	2	0	0	0	1	0	0	0	2	2	4	0	0	0	2	3	0	0	4	1	1	1	4	3	0	0	0	0	0	0	4	0	0	0	1.12	0.56		
Q23	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	1	0	0	0	1	0	0	0	0	4	0	0	0	2	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0.36	0.12	
Q24	0	0	0	0	0	0	0	0	0	0	3	2	0	0	0	0	0	0	2	2	1	1	0	0	0	0	3	0	0	0	2	3	2	0	3	0	0	0	3	1	0	0	0	0	0	0	0	0	0	0	0	0.76	0.36

Note: For the purpose of averaging, a response of 9 ("Don't know, not applicable") was scored as a non-response .

Average all questions: 1.22 0.49

APPENDIX 4
Family Caregivers' Responses to the Questionnaire

FAMILY CARE GIVERS' RESPONSES

Key: F= Frequency, R= Reaction

Family Caregivers

Subj. #	1		2		3		4		5		6		7		8		9		10		11		12		13		14		15		16		17		18		19		20		21		22		23		24		25		Average Frequency	Average Reaction		
	F	R	F	R	F	R	F	R	F	R	F	R	F	R	F	R	F	R	F	R	F	R	F	R	F	R	F	R	F	R	F	R	F	R	F	R	F	R	F	R	F	R	F	R	F	R								
Q1	4	1	4	3	4	4	4	3	4	3	4	3	4	3	4	3	4	3	4	4	3	3	4	3	4	4	3	2	4	3	4	4	3	3	3	3	2	0	0	4	3	4	0	3	3	4	2	4	1	4	3	3.64	2.64	
Q2	4	1	4	3	4	3	4	3	3	2	3	2	3	2	4	3	3	2	3	2	3	3	4	3	3	3	2	3	2	4	4	3	3	3	2	4	3	4	1	9	9	4	2	4	1	4	1	4	1	3.40	2.16			
Q3	4	0	4	3	4	3	3	2	3	2	3	2	3	2	4	3	3	2	3	2	3	2	4	3	3	3	3	2	3	2	4	3	3	3	3	2	4	4	4	4	9	9	3	2	2	1	4	1	2	1	3.16	2.16		
Q4	2	0	3	2	2	2	3	2	2	2	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	0	3	2	2	2	1	0	1	0	4	2	4	2	1	0	4	2	1	2	1	0	4	1	2.20	1.20	
Q5	4	0	4	3	4	3	4	3	4	2	4	2	4	2	4	3	4	3	4	2	4	2	4	3	3	2	3	1	3	1	3	2	1	1	3	2	4	3	4	2	9	9	4	2	9	0	4	0	4	0	3.36	1.76		
Q6	2	0	4	3	3	2	3	1	2	1	3	1	2	1	2	1	2	2	2	1	2	1	2	1	1	0	1	1	2	1	2	1	2	0	1	0	2	2	4	2	4	0	4	2	4	2	1	0	4	0	2.44	1.04		
Q7	3	0	4	3	4	3	3	1	2	1	3	1	3	2	4	2	4	2	2	1	2	1	4	1	3	0	2	1	3	1	2	1	2	0	2	1	3	3	4	3	2	0	4	2	4	2	2	0	4	0	3.00	1.28		
Q8	0	9	0	9	0	9	1	0	0	9	0	9	1	2	0	9	1	1	0	0	1	1	1	1	0	0	0	0	0	1	1	0	9	0	0	1	1	0	0	0	9	0	0	0	0	0	0	0	0	0	9	0.28	0.28	
Q9	2	3	1	1	2	3	2	3	1	2	2	2	2	3	2	3	1	2	1	2	1	1	3	3	3	2	2	1	1	2	2	0	0	2	0	0	0	9	0	9	9	2	2	0	0	1	0	0	9	1.32	1.52			
Q10	2	1	3	2	3	3	3	3	2	2	3	3	3	2	2	3	3	4	3	3	2	4	3	4	4	3	3	2	1	3	3	2	1	3	2	3	4	4	3	1	0	3	3	0	0	2	1	1	1	2.64	2.20			
Q11	0	9	0	9	1	2	0	9	0	9	0	9	0	9	1	1	1	1	0	9	0	9	0	9	0	9	0	9	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	9	0.12	0.16		
Q12	0	9	0	9	1	1	1	2	0	9	0	9	0	9	0	9	0	0	1	1	0	9	0	9	0	9	1	1	0	0	9	0	0	0	0	4	4	4	4	3	2	0	0	0	3	2	4	1	4	1	1	1.00	0.64	
Q13	1	1	1	2	2	3	2	3	1	2	2	3	1	2	1	1	1	1	3	4	2	2	2	2	2	2	1	1	1	2	2	2	2	2	2	4	4	9	0	0	0	0	0	0	0	1	0	0	1	3	1.36	1.76		
Q14	0	9	0	9	0	9	0	0	0	9	0	9	0	9	0	0	0	0	9	0	9	0	9	0	9	0	0	0	0	0	0	0	0	0	0	0	0	2	2	0	0	0	0	0	0	0	0	0	0	9	0.08	0.08		
Q15	0	9	0	9	0	9	0	0	0	9	0	9	0	9	0	0	0	0	9	1	2	0	9	0	9	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	9	0.04	0.08		
Q16	0	9	0	9	1	1	1	2	1	2	1	2	1	2	1	1	1	1	1	1	1	1	1	1	0	9	1	1	0	0	0	0	1	0	0	9	0	9	3	3	3	3	0	0	0	0	0	0	0	9	0.68	0.80		
Q17	1	2	1	2	1	2	9	9	0	9	0	0	9	0	9	0	9	0	9	0	9	0	9	0	9	0	0	0	0	0	9	9	0	0	9	4	4	4	4	0	0	0	0	4	3	1	1	4	4	0.80	0.88			
Q18	0	9	0	9	0	9	0	9	1	1	0	9	0	9	0	9	1	1	0	9	0	9	0	0	0	9	1	1	1	1	0	0	0	9	1	1	4	4	2	2	0	0	0	0	2	2	1	1	4	4	0.72	0.72		
Q19	1	1	1	2	1	1	1	1	9	9	1	2	0	9	0	9	1	1	0	9	0	0	0	9	9	1	1	1	1	1	1	0	9	1	1	1	1	4	3	0	0	0	0	1	1	0	0	3	4	0.76	0.84			
Q20	0	9	0	9	0	9	0	9	0	9	1	2	0	9	0	9	0	9	0	9	0	9	0	9	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1	1	2	4	3	0.48	0.48		
Q21	1	2	1	2	1	1	1	1	1	2	9	9	1	1	1	1	1	1	1	0	0	1	1	1	2	1	1	0	0	2	2	2	0	0	1	1	9	9	0	0	0	0	4	3	0	0	1	3	0.88	1.08				
Q22	0	9	0	9	0	9	0	9	0	9	0	9	0	9	9	9	0	9	0	0	9	9	1	1	1	2	0	0	0	0	2	2	1	2	0	0	1	1	4	3	0	0	0	0	4	4	1	1	2	4	0.68	0.80		
Q23	0	9	0	9	0	9	0	9	0	9	0	9	0	9	0	9	0	9	0	0	9	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	4	3	0	0	0	0	0	0	1	1	1	3	0.24	0.28				
Q24	1	1	0	9	1	1	1	1	1	2	1	2	1	1	0	9	1	2	1	1	1	1	1	1	1	1	1	1	0	0	0	0	1	1	2	2	0	0	4	4	4	4	0	0	0	0	4	4	4	1	1	1	1.24	1.24

Note: For the purpose of averaging, a response of 9 ("Don't know, not applicable") was scored as a non-response .

Average all questions: **1.44** **1.09**

APPENDIX 5
Informed Consent Document

LETTER TO POTENTIAL SUBJECTS AND INFORMED CONSENT

Dear Prospective Participant,

I am a graduate nursing student attending University of the Incarnate Word, in San Antonio, Texas working towards a master's degree in Adult health Nursing. I am conducting a study to explore whether there is a difference in the stress level of a respite care worker who works with Alzheimer's Disease patients in a noninstitutionalized setting on a daily basis and a family caregiver who works with an individual Alzheimer's Disease family member on a daily basis. The information from this study may help you and others with similar problems and conditions.

The study procedures involve no potential risks or harm to you. The procedures include: 1) Responding to a questionnaire consisting of 24 questions referring to behaviors of Alzheimer's Disease patients and the reactions of the caregivers to those behaviors, 2) providing some demographic information on the sheet provided, and 3) dropping the completed questionnaire into a ballot box type container. Participation in this study will involve taking approximately 15 minutes to complete the questionnaire.

Your compliance with this request is voluntary and you will remain anonymous. There is the possibility the results of my study could be published in a nursing journal. However, the results of your participation would be grouped into statistical data and could not be traced to you as an individual.

Completing and returning these questionnaires constitutes consent to participate in this study. You may choose not to participate in this study, or to withdraw from the study at any time.

The instructions for the questionnaire are on the first page of the questionnaire and can be easily understood. If you have any questions pertaining to the study or about being a participant, please feel free to call me at (512) 331-1724.

Sincerely,

Monica D. Minewiser 10/9/99

Monica D. Minewiser, BSN, RN

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