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**The physiological impact of stress on caregivers of Alzheimer's  
disease victims**

**Brown, Sharon Danielle, M.S.**

**The University of Arizona, 1987**

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THE PHYSIOLOGICAL IMPACT OF STRESS ON CAREGIVERS  
OF ALZHEIMER'S DISEASE VICTIMS

by

Sharon Danielle Brown

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A Thesis Submitted to the Faculty of the  
COLLEGE OF NURSING  
In Partial Fulfillment of the Requirements  
For the Degree of  
MASTER OF SCIENCE  
In the Graduate College  
THE UNIVERSITY OF ARIZONA

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Associate Professor of Nursing

June, 17, 1987  
Date



## DEDICATION

To Mom and Dad -

For your support, your friendship, your guidance, but most  
of all . . . . .

Your love.

## ACKNOWLEDGMENTS

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## ABSTRACT

This thesis focused on the physiological impact of uncertainty on caregivers of Alzheimer's disease victims. A convenience sample of 30 subjects was used. The uncertainty level was assessed using Parent's Perception of Uncertainty in Illness Scale. Physiological arousal was determined by assaying urinary cortisol and catecholamine levels.

The results of the study showed that uncertainty and physiological stress were inversely related. This lead to the conclusion that uncertainty was beneficial in that it offered a degree of hope. Knowledge of the disease process increased the stress perceived due to the devastation of Alzheimer's disease and its incurable state.

Younger individuals had higher physiological stress than older individuals for comparable amounts of uncertainty. Multiple reasons for this finding are postulated. They include the thought that the younger caregivers may fear developing the disease. It also may be that younger individuals need certainty about the future.

## CHAPTER I

### INTRODUCTION

Alzheimer's disease is a degenerative disorder of the cerebral cortex that affects over 1.5 million adults in the United States (Gwyther, 1983) and is the most prevalent cause of severe intellectual impairment in adults over 65 years old (Burnside, 1979). There is presently no known cause and no cure. The disorder is progressive, but there is great variation in the rate of change from person to person. It is characterized by varying patterns in the type, severity, and sequence of changes in mental and neurological functioning (Whitehouse, 1986).

Alzheimer's disease is characterized by progressive mental deterioration and therefore much of the burden of care and the psychological stress is shouldered by the primary caregiver, most commonly a spouse or child. Farkas (1980) cites that the spouse of a chronically ill individual experiences any of a wide range of emotions and the illness state of one family member can cause many anxieties and fears in other family members. Mailick (1979) noted that the family of a chronically ill individual, especially the primary caregiver, must attempt to balance the demands and stresses placed upon them so they can care for the afflicted person.

Illness in any family disrupts the pattern of that family's daily living. When the illness is a chronic disability, the problems



that emerge for both the individual and his family can be devastating (Bonner, 1974). Abram (1972) states that the environment created by a chronic illness is characterized by a variety of stressors and uncertainties. These stressors and uncertainties can adversely affect the family, as well as the ill member (Bonner, 1974; Klein, Dean & Bogdonoff, 1967).

Alzheimer's disease has an insidious onset and a gradual, progressive course that eventually leads to death. It is not the outcome of this chronic illness that causes a multitude of stresses for the family, but rather the ambiguity that surrounds the day-to-day living with an Alzheimer's disease victim because of the unpredictability of the affected person's everyday behavior. The inconsistent rate of deterioration of the patient forces the family to keep trying to adjust to new problems and to increasing levels of impairment (Barnes, Rasking, Scott & Murphy, 1981). Gwyther (1983) states that spouses of the Alzheimer's victim describe feelings of being in limbo and regard their living situation as being similar to a funeral that never ends as they wait for the eventual death to come.

Westbrook & Viney (1982) state that patients and families describe feelings of uncertainty when the symptoms of the illness have a gradual and ambiguous onset, which are followed by a feeling of relief when a diagnosis is made. The diagnosis removes some of the ambiguity surrounding the meaning of the symptoms. The lack of medical knowledge concerning the cause, treatment and cure of Alzheimer's disease causes the stress and uncertainty experienced prior to diagnosis to continue on throughout the course of the disease. Mishel

(1983) states that uncertainty prevails when it is unclear to the individual or his family which course the disease will follow. This lack of clarity exists in Alzheimer's disease.

The uncertainty and stress experienced by the primary caregiver can have adverse effects. Klein, et al. (1967) cite that as symptoms of illness increase in the ill individual, so does the psychophysiological impact on the caregiver. As the symptomatic distress of the ill individual increases, the spouse experiences an increase in emotional tension. This emotional tension causes an electrocortical arousal state, and the amount of arousal is related to the uncertainty of the stimulus input (Warburton, 1979). Warburton (1979) states that new and unpredictable information represents an increase in uncertainty, and this increases arousal. Electrocortical arousal is related to the physiological stress response. There is an intimate link between electrocortical arousal and stress hormone release (Warbuton, 1979).

Psychological stress leads to physiological responses (Selye, 1976; Frankenhaeuser, 1975). Two known physiological responses to stress are activation of the sympathomedullary system and adrenocortical system. This activation causes increases in catecholamine and glucocorticoid levels, respectively (Pollock, 1984; Selye, 1976). The changes in these hormonal levels induce physiological mechanisms which are conducive to survival during the period of stress. Chronic activation of these systems, however, can be detrimental (Ganong, 1981). Henry (1982) explains that repeated or chronic stimulation of neuroendocrine systems causes alterations in the normal homeostatic

feedback mechanisms and pathophysiological adaptations ensue. These adaptations result in organ failure and disease (Henry, 1982). Accumulation of a scientific data base which addresses the impact of chronic illness upon family members, especially the primary caregiver, is imperative in light of the knowledge that the psychological stress experienced by the caregiver is a potential health threat (Klein, et al., 1967).

### Statement of the Problem

Alzheimer's disease is a chronic illness that produces an environment characterized by uncertainty. The primary caregivers of those afflicted with Alzheimer's disease must live day to day with lack of information and stresses. The burden of the disease may cause physiological changes which can predispose the caregiver to disease development. The intent of this study is to investigate the following questions:

1. What is the degree of uncertainty experienced by an individual who is the primary caregiver of someone with Alzheimer's disease?
2. Is the degree of uncertainty in caregivers of individuals with Alzheimer's disease related to the caregiver's excretion rate of catecholamines and cortisol?

### Purpose of the Study

The purpose of the study is to investigate the uncertainty experienced by caregivers of individuals with Alzheimer's disease,

and to determine if the experience of uncertainty is associated with a physiological stress response as measured by hormonal excretion.

### Significance of the Problem

There is an increasing prevalence of dementia in the United States and it is rapidly becoming a major public health problem (Rabins, Mace & Lucas, 1982). The majority of demented individuals are cared for at home by family members (Rabins, et al., 1982). This living situation predisposes the primary caregiver to a variety of stressors associated with dealing with chronic illness. These stressors are manifested in physiological changes, which are adaptive, but if allowed to continue, could become pathological.

Lazarus (1974, p. 321) states, "anything we can learn about the physiological processes concerned with emotion, especially the stress emotions, contributes to and is in some measure necessary to an understanding of illness". It is important for nurses to accumulate a scientific data base which will allow recognition of potential health problems. If it can be substantiated that being a primary caregiver to an individual with Alzheimer's disease is a stressful situation, by measuring the perceived uncertainty, then nursing interventions can be planned at a primary level. It is also important for health care workers to recognize and attempt to quantify the burden felt by family caregivers (Klein, et al., 1967). Reduction of this burden may allow the caregiver to continue to care for the afflicted at home by reducing the stress that may lead to illness in the caregiver. An ill caregiver may not be able to give the care needed by the victim

of Alzheimer's disease. The care provided by a family member often increases the afflicted's ability to continue to live in the community and not be institutionalized (Bergmann, Foster, Justice & Matthews, 1978). Elliott (1979) states that although the stress of caring for a victim of Alzheimer's disease may be destructive to a family, only the family can provide the quality care that these people deserve. Health care intervention planned at maintaining a healthy caregiver and, therefore, a home environment with personal resources capable of caring for the victim of Alzheimer's disease will achieve savings not only in terms of health care dollars, but also in terms of human pain and suffering (Aronson & Lipkowitz, 1981).

#### Summary

This chapter discusses the introduction to the study, the statement of the problem, and the research questions. The purpose of the study and the significance of the problem were also discussed.

## CHAPTER II

### CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW

The conceptual framework for this study, as illustrated in Figure 1, is based on a review of the literature concerning the variables of uncertainty and physiological stress response. The conceptual framework depicts that at the construct level there is a relationship between cognition and stress. The concept level shows that uncertainty is a cognitive process and that a physiological response is a manifestation of stress. The relationships at the construct and concept levels will be discussed early in this chapter. The operational level will be discussed with the operational definition.

#### Conceptual Links

##### Cognition and Stress

Cognition is the act or process of assimilating stimuli, resulting in the formation of a cognition structure or schema as the end product of information processing. Characteristics of the stimuli as well as characteristics of the individual influence the perception of stimuli. An individual does not respond to reality, but rather to his mediated rendition of it (Mishel, 1984a). The person chooses from among stimuli that which will be focused upon and assimilated into the cognitive process. The formation of a cognitive structure is the end product of information processing. It is necessary for decision-making and a resulting performance. When all of the

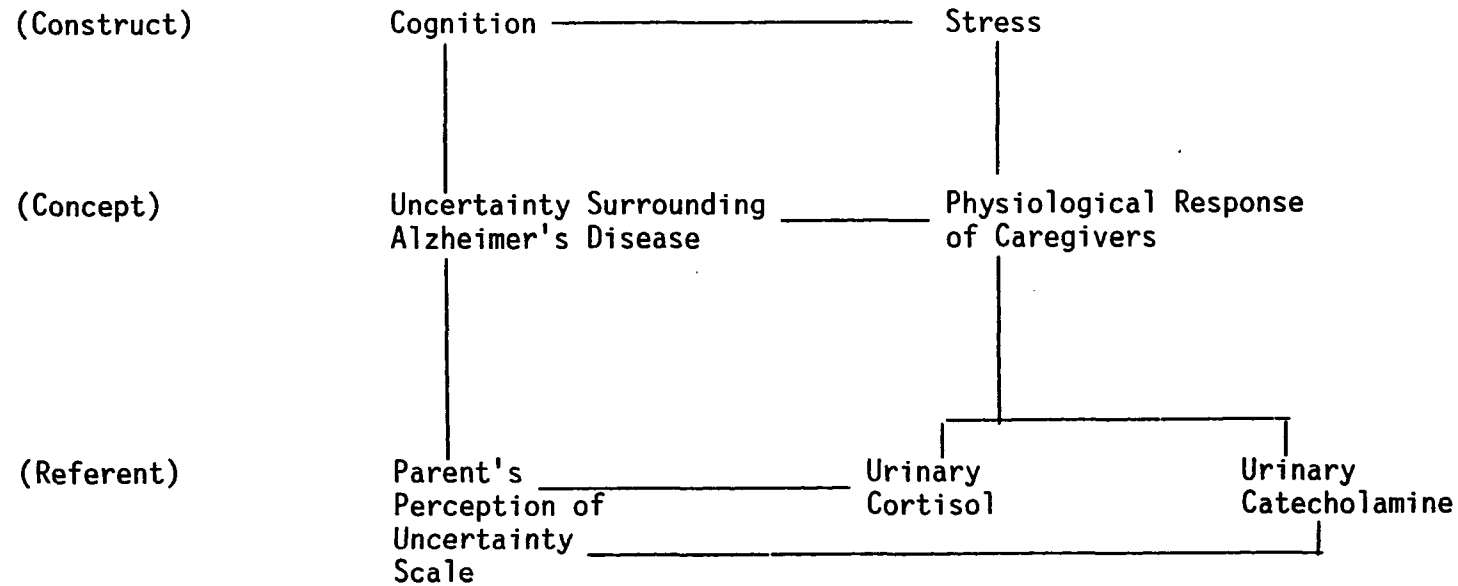


Figure 1. Conceptual framework describing the relationship between stress and physiological arousal.

information necessary to classify an event are not known, the perceiver may not be completely certain how to categorize and structure the event (Mishel, 1984a).

Stress results from cognition of an event or groups of events which are appraised as structurally complex and/or whose available information is incomplete to meet the needs of the individual (Shalit, 1977). It is the perception of the situation by the individual that elicits the stress response. Stress comes from the inability to complete the appraisal process, which is necessary for deciding upon a coping response (Shalit, 1977). An appraisal process involves a cognitive process (Lazarus, 1974). This process is a psychological analysis of the data available and in certain conditions of cognition which will be explored later, results in a stressful emotional state (Lazarus, 1974).

#### Cognition and Uncertainty

Uncertainty is conceptualized as a cognitive process. Mishel (1981, p. 258) states that "a situation is judged as uncertain when it cannot be adequately structured or categorized because sufficient cues are lacking". When the cognitive process of categorizing stimuli is structurally complex, or information is deficit, or the stimuli is perceived as unpredictable, then uncertainty results (Mishel, 1984a). Perception of uncertainty leads to information seeking in an attempt to decrease the uncertainty (Lanzetta, 1971). The perceived uncertainty will remain when the information seeking is unsuccessful, as in Alzheimer's disease, where information to reduce unpredictability



and uncertainty does not exist (Barnes, et al., 1981). Berlyne (1977) cites that motivational processes, such as those that occur in the cognitive process labeled uncertain, have three conceptual phases. Those phases are drive, arousal, and stress. These states are induced or intensified by deviations from the normal equilibrium of the individual. Drive is conceptualized as a state in which new behavior patterns are sought since the existing behavior is seen as inadequate. Drive is measured through observable characteristics of behavior (Berlyne, 1977).

Arousal is conceptualized as the efficiency with which information is gathered and processed. It is measured through psychophysiological changes such as changes found in the electrical activity of the brain as measured through an electroencephalogram (Berlyne, 1977).

Stress results when drive and arousal fail to re-establish normal equilibrium and is conceptualized as a transient or prolonged breakdown in adaptive function. It is measured through biochemical and pathological phenomena (Berlyne, 1977). Berlyne (1977) also states that uncertainty can be a source of stress when, as a perceived state, the drive and arousal conditions that occur fail to relieve or reduce the uncertain state.

#### Uncertainty Surrounding Alzheimer's Disease

Individuals with Alzheimer's disease exhibit a gradual decline in intellectual, emotional, and motor function (Adolfsson, 1978). The downward trajectory of the disorder progresses steadily without remission. In contrast, however, the day-to-day functioning of the

afflicted individual has a wide range of variability and is both uncertain and unpredictable (Hayter, 1974).

Alzheimer's disease is generally described in three stages (Burnside, 1979; Charles, Truesdell & Wood, 1982; Gwyther, 1983; Hayter, 1974). The changes that occur during the first stage are subtle. Memory loss is the primary symptom during this stage. The individual is often aware of his deficit and for some time may be able to disguise it (Charles, 1982). Hayter (1974) states that an individual's ability to think logically is superior to his memory and this enables him to conceal his memory loss. Most patients are not diagnosed during the first stage and are therefore often labeled as apathetic, careless, unmotivated and/or inattentive (Hayter, 1974). Gwyther (1983) cites that toward the end of the first stage the victim of Alzheimer's disease is usually performing poorly at work. He may be unable to add or subtract, or may have difficulty organizing time and dates. He may be fired and the family suffers the emotional and the economical trauma that ensues. This early stage usually lasts two to four years (Gwyther, 1983).

The second stage characteristically extends over many years (Hayter, 1974) and begins when the diagnosis of Alzheimer's disease is made (Gwyther, 1983). The symptoms of this stage are progressive memory loss, aphasia, agnosia, apraxia, and wandering, commonly at night (Hayter, 1974; Gwyther, 1983). Charles, et al. (1982) state that during the second stage, greater neuronal loss is seen in the frontal and temporal lobes and the victim begins to forget learned socially accepted behaviors. This forgetfulness is usually

demonstrated by neglected grooming and/or inappropriate eating habits and toileting. When cortical cells are destroyed, as in Alzheimer's disease, learned socially acceptable behaviors are replaced by more primitive behaviors. The victim has the motor ability to carry out activities, but he lacks the mental skills to use those motor skills appropriately (Hayter, 1974).

Home management is a major problem during the second stage (Gwyther, 1983). The night wandering, increasing confusion and inability to carry out personal care are the primary reasons why family members must provide constant care, attention and supervision (Gwyther, 1983). Barnes, et al. (1981) cite that most patients with Alzheimer's are not institutionalized, but rather reside at home until late in the illness and this places a stressful and demanding burden of care upon family members. Aronson & Lipkowitz (1981) state that the family members are subjected to witnessing the slow extinction of a personality, usually within an outwardly healthy body. They state that this may be more emotionally traumatic and stressful than the death itself.

Mackey (1983) states that during the second stage an array of cognitive disturbances becomes apparent and behavior and personality are affected more obviously. The victim experiencing the steady decline will often show signs of depression, restlessness, agitation, and/or irritability. Paranoid tendencies are also seen. These severe emotional sequelae can drastically affect family dynamics (Aronson & Lipkowitz, 1981).

The third and final stage is usually short (Gwyther, 1983). It involves progression of all the generalized and focal symptoms and the patient often becomes mute and unresponsive (Charles, et al., 1982). The victim is emaciated despite voracious eating habits (Burnside, 1979; Hayter, 1974). Grand mal seizures are common during this stage. The cause of death is most commonly pneumonia (Charles, et al., 1982; Gwyther, 1983; Hayter, 1974). Victims are often institutionalized during this stage.

Alzheimer's disease is devastating to the victim, but families may suffer even more, since for them there is the terrible haunting loss of a family member who is still with them (Wallis, 1983). The caregiver must be constantly vigilant because the actions of the victim of Alzheimer's disease are unpredictable and inconsistent. The meaning of their actions are vague and lack clarity. Anticipation of action can be exhausting because the uncertainty releases stress hormones, and mental work can be as tiring as physical work because it causes electrocortical arousal and the consequent stress response (Warburton, 1979).

### Stress and Physiological Response

Psychological stress represents one component of a larger category of biological stress phenomena that involve common integrative mechanisms and are organized according to common principles (Mason, 1975). Mason (1975) also states that emotional stimuli are a very potent and natural stimuli capable of increasing the activity of the pituitary-adrenocortical axis. Cannon (1914) pioneered the area of

physiological responses to emotion and came to the conclusion that during times of great emotion there is increased secretion of catecholamines from the adrenal medulla and increased discharges along sympathetic pathways.

Stress is a concept with many meanings. It has been extensively discussed in the literature. Selye (1976) conceptualized stress as the rate at which one lives moment to moment and anything that speeds up the intensity of life, pleasant or unpleasant. Stress, he cites, causes wear and tear on the body because stress elicits a process he terms a general adaptation syndrome which can be measured by certain characteristic changes in the structural and chemical compositions of the body.

Warburton (1979) addresses the physiological aspect of stress and information processing with respect to degree of electrocortical arousal achieved. The process of arousal is the link to stress hormone release. He found that corticosteroid and adrenal catecholamines release occurred in the same uncertain, high information situations as electrocortical arousal. The hormones mobilize substrate for fuel necessary for activity, both mental and physical. It is essential to note that sustained stress will result in a depletion of fuel reserves leading to fatigue, even though stress hormone levels may still be elevated (Warburton, 1979).

Stress in this study was far less broad in definition and was conceptualized as a physical state resulting from a condition which is perceived by an individual as threatening or harmful. Other types of stress conceptualizations; i.e., emotional stress, environmental

stress, are not discussed. There is present in the literature a wealth of studies which have investigated acute stress and the physiological responses. There is little in the literature pertaining to investigations of chronic long-term stress and the resultant physiological changes.

### Uncertainty, Cognition, Stress, and Physiological Response

The linkage between uncertainty as a cognitive state and stress measured in physiological terms has not been extensively investigated in the literature. The literature addressing the linkage between a chronic uncertain state and the physiological changes that occur are even scarcer. Studies of acute stress are more prevalent.

Clinical studies on the relationship between uncertainty and stress have found that medical patients show a strong correlation between uncertainty about hospital events and stress (Mishel, 1983). In this study, stress was measured as a psychosocial phenomena due to the experience of hospitalization. In another study Mishel (1984b) investigated uncertainty and psycho-social adjustment in patients with gynecological cancer. The results of that study showed that uncertainty is related to maladjustment. This study also looked at stress (maladjustment) as a psycho-social phenomena (Mishel, 1984b).

Laboratory studies have shown that uncertainty is a stressful cognitive state and creates a drive within the individual which is aimed at modifying or eliminating the aversive state. Lanzetta (1971) found that more than a moderate degree of uncertainty is aversive.

He states that when faced with uncertainty, an individual behaves in such a manner as to attempt to reduce the uncertainty.

In a study not supportive of the relationship proposed in this study, Monat, Averill & Lazarus (1972) investigated the effects of uncertainty on stress reactions using unpredictable electric shock as the uncertain stimulus. They studied various conditions of uncertainty; temporal uncertainty and event uncertainty. They measured heart rate as the physiological parameter indicative of stress; i.e., stressful states cause increase in heart rate. Monat, et al., concluded that the degree of stress experienced did not vary with uncertain events and that the cognitive appraisal and coping process in stress reaction patterns are of utmost importance.

Other laboratory studies are more supportive of the relationship proposed in this study. Pervin (1963), in a laboratory study which varied the amount of control a subject had over conditions of threat; i.e., shock application, found that control, associated with feelings of certainty and predictability, as opposed to lack of control which was associated with uncertainty and unpredictability, reduced conflict, optimized psychological and physical preparation and allowed for avoidance of surprises.

In more recent work, Frankenhaeuser (1980) has conducted a series of experimental studies concerned with psychophysiological response patterns in acute stress situations. She used catecholamines and cortisol excretion, as physiological arousal indices, and had subjects perform choice-reaction tasks requiring maintenance of controllability. She found that acute stress perception increased

catecholamine excretion which she interpreted as important for mobilization of effort induced by the stress. The decrease in cortisol excretion was related to the subject's high level of personal control of each task. High control decreases the perception of uncertainty.

Two recent field studies have also demonstrated support for the relationship between uncertainty and physiological response, one in an acute situation and one studying a chronic state. In the acute stressful state, Lundberg (1981) investigated changes in catecholamine and cortisol excretion in parents and their three year old child. He compared control levels, those obtained while the family was at home and levels obtained under uncertain diverse conditions produced by hospitalizing the family for testing as part of a larger longitudinal study of family interactions. The results showed that the stay in the hospital induced a pronounced elevation in epinephrine excretion and a moderate elevation in norepinephrine excretion. Cortisol excretion was elevated only in fathers. This study demonstrated that catecholamines and cortisol are sensitive indicators of psychological arousal.

In a study of chronic uncertainty, Fleming, Baum, Gisriel & Ratchel (1982) investigated the psychological stress induced by the uncertain conditions of living near the Three Mile Island nuclear plant after the devastating accident. They used measurement of urinary catecholamines and found them effective measurements of the biochemical aspects of stress. They found that living near the damaged reactor was stressful because of the threat and uncertainty perceived and



that this resulted in the elevated excretion of catecholamines. They did not, however, directly measure the amount of perceived uncertainty, but assumed its existence.

### Conceptual Definitions

Uncertainty -- a cognitive state which is created when an event cannot be adequately structured or categorized because sufficient cues are lacking. It occurs in situations where the event is not recognized; recognized but not categorized; or categorized incorrectly (Mishel, 1981).

Physiological Stress -- a physical state that is induced by perceived harmful or threatening stimuli and is characterized by activation of neuroendocrine systems and fluctuations in physiological homeostasis.

### Operational Definitions

Uncertainty -- total scale score on the 31-item Parents Perception of Uncertainty Scale (PPUS). The PPUS was modified to measure the uncertainty a primary caregiver experiences related to the care receivers illness state.

Physiological Stress -- the measure of urinary excretion of free cortisol and catecholamines, collected over a continuous 24 hour period.

### Summary

A review of the literature concerning physiological stress responses to uncertainty produces findings which do not support the

linkages proposed in this study. Recent studies show strong support for the relationship between uncertainty and physiological stress response. Most of these studies involve acute stress; i.e., produced over a short period of time and are not related to health-illness situations. Fewer studies have looked at the physiological stress response produced as a result of a chronic uncertain illness state.

## CHAPTER III

### METHODOLOGY

This chapter will present the research questions followed by the measurement tools that were used to operationalize each concept. The study design including the setting, sample, data collection procedure, data analysis, and limitations of the study will also be discussed.

#### Research Questions

This study addressed the relationship between uncertainty and physiological stress response in the caregivers of victims of Alzheimer's disease. The research questions were:

1. What is the degree of uncertainty experienced by an individual who is the primary caregiver of someone with Alzheimer's disease?
2. Is the degree of uncertainty in caregivers of individuals with Alzheimer's disease related to the caregiver's excretion rate of catecholamines and cortisol?

#### Instruments

##### Parent's Perception of Uncertainty Scale

The variable of uncertainty was measured by the Parent's Perception of Uncertainty Scale (PPUS) (Mishel, 1983). This scale was developed to measure the uncertainty one experiences concerning

another's illness. The PPUS addresses the uncertainty experienced by a parent concerning his/her child's illness. For this study the scale was modified by addressing the primary caregiver's experience of uncertainty about his/her significant other's illness. The PPUS is a 31-item Likert scale. A total of eight items were deleted because they did not pertain to the situation being investigated. Five of the eight were deleted because they were related to a person who is hospitalized and not applicable to the subjects in this study caring for a significant other at home. Three other items relating to treatment given the afflicted individual were deleted because presently there is no treatment for Alzheimer's disease. No new items were added.

There are five possible responses to each statement, ranging from strongly agree to strongly disagree. Each participant was to mark the one response that best described his/her feeling regarding the statement. The responses are weighed one to five, with five showing the most uncertainty and one showing the least uncertainty. The statements are both negatively and positively stated to prevent bias by the participant.

Mishel (1983) reports that the original PPUS total scale has a standardized alpha of .91. The scale is composed of four subscales. The ambiguity subscale, possessing 13 items has an alpha of .87 with all item subscale correlations being substantial in the .40 to .70 range. The lack of clarity subscale, a nine item subscale, has a standardized alpha of .81 and item subscale correlations in the .46 to .65 range. The lack of information subscale, a five item subscale,

has a standardized alpha of .73 and subscale correlations in the .41 to .56 range. The last subscale, unpredictability, is a four item subscale with a standardized alpha of .72 and item subscale correlations in the .41 to .62 range.

Coefficient theta was estimated for the overall scale and each subscale. A comparison of theta and alpha displayed no differences among the reliability estimates. This implies that the items are homogenous since the two estimates were highly similar (Mishel, 1983).

#### Validity

The PPUS underwent several measures to establish validity. Construct validity was supported by findings from factor analysis. Four factors emerged from the data, each measuring a characteristic of the construct of uncertainty (Mishel, 1983).

Further support for validity was established by investigating if the scale, PPUS, did indeed distinguish between known groups as predicted. A one way analysis of variance revealed that the scale did not perform as theoretically predicted. This was explained as a conceptual problem rather than the fault of the scale.

A third test to support the validity of the scale found support for the theoretical prediction that parent's uncertainty correlated positively with parent's judgments of the seriousness of their child's illness. Significant correlations were found between the total scale and judged seriousness of illness.

Mishel (1983) concluded that further testing was necessary in the area of construct validity. Further investigation is also necessary using different dyads such as spouse-spouse, child-parent.

This will be the third testing of the scale using primary caregivers as subjects.

#### Urinary Free Cortisol and Urinary Free Catecholamines

The determinants of the physiological stress response, urinary free cortisol and urinary free catecholamines, were measured using a fluorometric method of measurement. Urinary free cortisol was assayed using a fluorometric method described separately by Ratliff & Hall (1977) and evaluated separately by Culp, Frings, and Gilleland (Ratliff & Hall, 1977) to establish reliability. Validity was established with a recovery of cortisol added to normal urine of 90 to 106 percent with a mean of 99.5 percent. A standard deviation of  $\pm 10$  micrograms (ug) per 24 hours was obtained for analysis of a urine pool for which the mean value was 176 ug/24 hours. Precision of the method was evaluated by daily assay of duplicate aliquots of a frozen urine pool, giving a coefficient of variation of 5.1 percent. Stability of cortisol in frozen samples is presumed.

Urinary free catecholamines was assayed using a fluorometric method as described by Crout (1961) and evaluated separately by McKay & Dryer (1961) for reliability. Validity was established with a mean of 91 percent, and a recovery of epinephrine of 68 to 103 percent with a mean of 83 percent. Duplicate same day analyses show variation of mean no more  $\pm 10$  percent, but separate day analyses can show a mean deviation of duplicate samples as high as  $\pm 20$  percent.

Determinations were made for cortisol using excitation and emission wavelengths of 467-475 nanometers (nm) and 523-530 nm

respectively. Determinations for epinephrine were made with excitation and emission wavelengths of 410 nm and 520 nm respectively. Norepinephrine determinations were made with excitation and emission wavelengths of 395 nm and 505 nm respectively.

#### Demographic Data

Demographic data was obtained from the subject concerning his/her relationship to the afflicted family member, marital status, educational status, sex and age. Also obtained was the age, sex, and duration of symptoms of the Alzheimer victim, and the number of individuals living in the household. This data was used in compiling descriptive statistics for the sample group.

Each subject was asked one question at the termination of the urine collection time: "Has anything happened since I last saw you that is unusual or different in your daily life?" They were asked to list any such happening, positive and/or negative. This information was used to determine any contaminating acute stress that might have occurred.

#### Design

A descriptive design was used in this study to address the research questions.

### Procedure

#### Setting

This research was conducted in each subject's home. Subjects were informed of the study purpose and requirements for participation.

A disclaimer was read to the subjects prior to issuing the equipment and questionnaire (Appendix A). This research project was approved by the Human Subjects Committee of the University of Arizona College of Nursing (Appendix B).

### Sample

A convenience sample of 30 subjects was obtained from members of the Alzheimer's Disease and Related Disorders support group. The criteria for eligibility were that the subject must:

1. have a person with Alzheimer's disease living in his/her home;
2. have major responsibility for the patient with Alzheimer's disease who has required constant supervision with activities of daily living or wandering for at least three months;
3. read and write English;
4. agree to participate in the study;
5. be willing to refrain from coffee, tea, and alcohol during the urine collection period; and
6. not presently be taking any medication that will interfere with the hormone procedure; i.e., methyl dopa, isoproterenol, quinidine, chlorpromazine, quinine, epinephrine, tetracycline, digitoxin, reserpine, hydralazine, chlorothiazide, pentolinium, mecanylamine, phentolamine, phenoxybenzamine, prednisone, hydrocortisone, dexamethasone.



## Data Collection Procedure

The subject was contacted directly at a support group meeting. The purpose of the study, the collection procedure including approximate amount of time that the subject had to give, and the right to confidentiality were explained. A convenient time, place, and date was arranged in order for the subject to complete the questionnaire (Appendix C) and be given the equipment necessary for the urine collection. The procedure for the urine collection, the dietary restrictions, and the questionnaire were fully explained to the subject. The approximate time to complete the questionnaire was 20 minutes and the urine was collected continuously over a 24 hour period. The following is a detailed explanation of how the complete procedure was explained to the subjects.

The pieces of equipment provided were a glass jar to store the urine, a styrofoam box, a funnel and a commode pan. The subjects were told that the urine collection must be for a continuous 24 hour period and that all urine voids must be saved. If the subject was planning to be away from home during the 24 hour period and was therefore unable to maintain the continuous collection, then another time was arranged.

The commode pan set in the toilet and was used to collect each void. The urine was then immediately poured into the glass jar using the funnel for ease in pouring. The glass jar was kept at all times in the styrofoam box surrounded with ice. The subjects were asked to maintain ice in the box for the 24 hour period. The subjects were asked to keep the top on the jar at all times except when pouring

in urine. The jar and box were stored in a convenient location for the subject away from a floor heater or vent.

The time period for the 24 hour collection was determined by establishing the time of subject's last void prior to the investigator's visit and considering that the start time. Estimated times were accepted. The subjects were then told to save all urine voids as described above up until the same time the next day. The subjects were given a written detailed instruction including the time frame particular to each's collection and a phone number where they could locate the investigator if they had any questions or problems regarding the collection (Appendix D).

Finally, arrangements were made for the investigator to collect the urine samples the next day and they were transported on ice directly to the lab where aliquots were stored in the freezer until the analysis was performed. The investigator questioned the participant at the termination of the urine collection to determine if any unusual occurrences had altered the subject's daily routine during the previous 24 hours other than those associated with caring for the Alzheimer's victim.

## Data Analysis

Research Question 1. What is the degree of uncertainty experienced by an individual who is the primary caregiver of someone with Alzheimer's disease?

The mean and standard deviation for the total group were obtained on uncertainty.

Research Question 2. Is the degree of uncertainty in caregivers of individuals with Alzheimer's disease related to the caregiver's excretion rate of catecholamines and cortisol?

Pearson product moment correlations was calculated for the level of uncertainty, cortisol excretion, and catecholamine excretion. A significance level of 0.10 was accepted for this study.

### Summary

This chapter discussed the measurement tools to be utilized, the study design, the setting, and the sample. The data collection and data analysis were also discussed.

## CHAPTER IV

### PRESENTATION AND ANALYSIS OF THE DATA

This chapter will present: 1) characteristics of the sample; 2) a descriptive analysis of the uncertainty scale to address research question one; and 3) a correlation matrix displaying the relationship among the variables to address research question two. The characteristics of the sample are presented first.

#### Characteristics of the Sample

Descriptive statistics were employed to analyze the characteristics of the sample (n=29). Data were collected on 30 subjects but one subject (number one) was eliminated from the study when her urine output indicated impaired renal concentrating ability. Therefore, only the results from subjects two through 30 were analyzed. Information gathered on the subjects included the caregiver's age, sex, relationship to the family member with Alzheimer's disease, marital status, educational level, and number of people in the household. Data collected on the family member with Alzheimer's disease included the victim's age, sex, and the duration of symptoms.

The caregiver's age, sex, and educational level are shown in Table 1. The mean age of the sample was 58 years, with a range of 23 to 88 years, and a standard deviation of 15.9 years. Twenty-three of the subjects were female (79.3%) and six were male (20.7%). Fourteen subjects (48.2%) had a high school degree as the highest educational

Table 1. Caregiver's Age, Sex, and Educational Level

Characteristic	Category	Number	Percent
Age Range	22-35	4	13.7
	36-50	3	10.4
	51-69	15	51.7
	70-90	7	24.1
Sex	Female	23	79.3
	Male	6	20.7
Educational Level	High School	14	48.2
	High School Plus	6	20.8
	College	4	13.8
	College Plus	5	17.2

level obtained. Six subjects (21%) had formal education beyond high school, but not a college degree. Nine subjects (30%) had a college degree or more.

The demographic characteristics of marital status, relationship of the caregiver to the family member with Alzheimer's disease, and number of people in the household are shown in Table 2. Twenty-three of the subjects were married (79.3%). Fourteen subjects (48%) were related as a spouse to the victim of Alzheimer's disease. Eleven subjects (38%) were the children of the individual with Alzheimer's disease. Sixteen of the households (55.2%) had just the caregiver and the family member with Alzheimer's disease residing in the home.

The demographic characteristics of the family member with Alzheimer's disease are shown in Table 3. The mean age was 80 years, with a range of 59 to 90 years and a standard deviation of eight years. Twenty of the victims (69%) were female which fits the picture of Alzheimer's disease (Hickey, 1986). Twelve (41%) of the individuals with Alzheimer's disease had symptoms for one to four years, while 13 (45%) had symptoms for five to nine years. The mean duration of symptoms for this sample was a little over five years, with a standard deviation of 3.3 years.

#### Data Analysis Related to the Research Questions

The research questions explored in this study were:

1. What is the degree of uncertainty experienced by an individual who is a primary caregiver of someone with Alzheimer's disease?

Table 2. Caregivers' Marital Status, Relationship to the Family Member with Alzheimer's Disease, and Number of People in the Household

Characteristic	Category	Number	Percent
Marital Status	Married	23	79.3
	Single	3	10.3
	Divorced	2	6.9
	Widow	1	3.4
Relationship	Wife	9	31.0
	Husband	5	17.2
	Child	11	37.9
	Granddaughter	2	6.9
	Sister	2	6.9
Number of People in Household	2	16	55.2
	3	9	31.0
	4	2	6.9
	6	1	3.4
	7	1	3.4

Table 3. Alzheimer's Disease Victim's Age, Sex, and Duration of Symptoms

Characteristic	Category	Number	Percent
Age Range	58-68	5	17.2
	68-79	13	44.8
	80-90	11	37.9
Sex	Female	20	69.0
	Male	9	31.0
Duration of Symptoms (in years)	1-4	12	41.4
	5-9	13	44.8
	≥10	4	13.8



2. Is the degree of uncertainty in caregivers of individuals with Alzheimer's disease related to the caregiver's excretion rate of catecholamines and cortisol?

Question number one was addressed by use of the modified Parent's Perception of Uncertainty Scale (PPUS). The 21 statements used to evaluate the uncertainty experienced by the subjects, along with the mean score and the standard deviation for each statement are listed in Table 4. A total score on the uncertainty scale was also calculated for each subject.

The mean score of uncertainty for the 29 subjects was 64 with a standard deviation of 8.6. Some interesting information was obtained by taking a closer look at the responses to each item on the scale. Presented first will be a discussion of those items with low uncertainty scores (numbers 1, 3, 19, 20, 21; Table 4) followed by a discussion of those items with high uncertainty scores (numbers 2, 4, 6, 8, 10, 11, 12, 15, 18; Table 4). The score is based on a scale of one to five, with one being low uncertainty and five being high uncertainty. Items reversed scored are noted on Table 5.

Most subjects were aware of what was wrong with their family member as evidenced by the high percentage of people who disagreed or strongly disagreed with a statement addressing the issue (93%). The trajectory of the illness and the seriousness of the illness was understood by the family members also. Twenty-three subjects (73%) felt sure regarding the course of the illness and 21 (72%) felt that the seriousness of the family member's illness had been determined.

Table 4. Percentage of Subjects' Responses (N=29) to Each Statement on the Modified PPUS and Mean of the Uncertainty and Standard Deviation on Each Item

		Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Mean of the Uncertainty	Standard Deviation
1.	I don't know what is wrong with him/her.	3.4	0	3.4	51.7	41.4	1.7	.84
2.	I have a lot of questions without answers.	31.0	44.8	10.3	13.8	0	3.9	1.0
3.	I am unsure if his/her illness is getting better or worse	0	17.2	3.4	37.9	41.4	2.0	1.0
4.	It is unclear how bad his/her confusion will be.	24.1	44.8	6.9	10.3	13.8	3.6	1.4
5.	The explanations they give about him/her seem hazy to me.	10.3	24.1	10.3	41.4	13.8	2.7	1.3
6.	His/her symptoms continue to change unpredictably.	20.7	58.6	3.4	13.8	3.4	3.8	1.0
7.*	I understand everything explained to me.	13.8	55.2	10.3	17.2	3.4	2.4	1.0

\* Items positively scored

Table 4. Continued

		Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Mean of the Uncertainty	Standard Deviation
8.	The doctors say things to me that could have many meanings.	3.4	44.8	13.8	34.5	3.4	2.9	1.0
9.*	I can predict how long his/her illness will last.	3.4	3.4	3.4	55.2	34.5	4.1	.9
10.	Because of the unpredictability of his/her illness, I cannot plan for the future.	34.5	44.8	0	13.8	6.9	3.9	1.2
11.	The course of his/her illness keeps changing. He/she has good and bad days.	27.6	58.6	0	13.8	0	4.0	.9
12.	It is not clear what is going to happen to him/her.	13.8	58.6	3.4	13.8	10.3	3.5	1.2
13.*	I usually know if he/she is going to have a good day or bad day.	0	41.4	10.3	44.8	3.4	3.1	1.0

\* Items positively scored

Table 4. Continued

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Mean of the Uncertainty	Standard Deviation
14. The results of his/her tests are inconsistent.	0	17.2	20.7	37.9	6.9	2.5	.9
15.* I can generally predict the course of his/her illness.	0	20.7	6.9	48.3	24.1	3.8	1.1
16.* I'm certain they will not find anything else wrong with him/her.	6.9	20.7	6.9	55.2	10.3	3.4	1.2
17. They have not given him/her a specific diagnosis.	10.3	20.7	0	51.7	17.2	2.6	1.3
18.* His/her memory loss is predictable, I know when it is going to get better or worse.	3.4	6.9	6.9	58.6	24.1	3.9	1.0
19.* His/her diagnosis is definite and will not change.	17.2	58.6	6.9	17.2	0	2.2	1.0
20.* The seriousness of his/her illness has been determined.	20.7	51.7	13.8	13.8	0	2.2	.9
21.* The doctors and nurses use everyday language so I can understand what they are saying.	17.2	72.4	3.4	6.9	0	2.0	.7

\* Items positively scored

Table 5. The Caregivers' Age Subgroups and Mean Scores for Uncertainty, Cortisol and Catecholamines (N=29)

Age Group	N	Age Category	Uncertainty	Cortisol	Catecholamines
1	7	23-50	60.4	330.3	40.0
2	15	51-69	63.3	173.5	41.3
3	7	70-88	68.3	150.4	27.6

Twenty-two subjects (75%) felt that the diagnosis of Alzheimer's disease had been made and would not change.

Despite the certainty about the issues discussed above, many other issues remained less clear and/or predictable for the subjects. These dealt not with the broad diagnosis and course of the illness Alzheimer's disease, but rather more with the day-to-day functioning of the afflicted individual. Seventy-six percent of the subjects had a lot of questions without answers.

Twenty-three of the subjects (79%) felt that the family members with Alzheimer's disease had symptoms that changed unpredictably. The mean uncertainty score for the item addressing this issue was 3.9 with a standard deviation of 1.0. Two symptoms which are trademarks for Alzheimer's disease are confusion and memory loss. The subjects could not predict how bad the confusion would be on a day-to-day basis. The mean uncertainty score on the statement addressing the confusion issue was 3.6, with a standard deviation of 1.4. The mean uncertainty score with regard to the predictability of memory loss was 3.9, with a standard deviation of .96.

The devastation of Alzheimer's disease on the family structure is easier to understand when looking at the uncertainty that surrounds the future for that family. Twenty-six subjects (90%) could not predict how long the family member's illness would last. The mean uncertainty on a statement addressing this issue was 4.1, with a standard deviation of .92. Twenty-one of the subjects (72%) were unclear as to what would happen to the family member with Alzheimer's disease.

This unpredictability made it impossible for the subjects to plan for their own future.

The second research question addressed the relationship of uncertainty and physiological stress measurements; i.e., urinary cortisol and catecholamine levels. The mean of urinary cortisol excreted was 206 ug/24 hours with a range of 77 to 581 ug/24 hours. The expected range of normal for the test used was 90 to 264 ug/24 hours for males and 70 to 180 ug/24 hours for females. The mean excreted catecholamines was 38 ug/24 hours with a range of 10 to 94 ug/24 hours. The normal value for this test is less than 100 ug/24 hours. The correlation of total uncertainty to catecholamine levels was  $-.31$  with  $p=.10$ . The correlation of uncertainty to cortisol levels was  $-.32$  with  $p=.09$ .

Further exploratory analysis of the data was done to see if any change in dependent variable groupings would yield any other information regarding physiological stress responses and perceived uncertainty. Age was the first variable that was further analyzed. The group of subjects were divided into three groups of age. Age was chosen to see if uncertainty and/or physiological stress responses differ in young adults as compared to older adults. A one-way analysis of variance and a Scheffe' test, if indicated, were done on each of the subgroups and each of the following variables: Total uncertainty scores, the cortisol levels, and the catecholamine levels. The results are shown in Tables 5, 6, 7 and 8. The only significant finding ( $p=.10$ ) was that group number one (caregivers less than 50 years old) had a mean cortisol level considerably higher than groups two and three.

Table 6. Analysis of Variance of Catecholamine Levels and Age Subgroups (N=29)

Source	D.F.	Sum of Squares	Mean Square	F Ratio	F Probability
Between Groups	2	953.159	476.580	1.241	.306
Within Groups	26	9985.048	384.040		
Total	28	10938.207			



Table 7. Analysis of Variance of Cortisol Levels and Age Subgroups (N=29)

Source	D.F.	Sum of Squares	Mean Square	F Ratio	F Probability
Between Groups	2	145620.434	72810.217	6.547	.005
Within Groups	26	189148.876	11121.110		
Total	28	434769.310			

Table 8. Analysis of Variance of Total Uncertainty Score and Age Subgroup (N=29)

Source	D.F.	Sum of Squares	Mean Square	F Ratio	F Probability
Between Groups	2	224.682	112.341	1.599	.221
Within Groups	26	1826.076	70.234		
Total	28	2050.759			

The other subgrouping made was with the relationship of the caregiver to the victim of Alzheimer's disease (Table 9). Relationship was chosen to see if there was a difference between spouses and other relatives as to stress levels when caring for a loved one. A t-test was performed between the two groups (spouse and non-spouse) and each of the following variables: total uncertainty score, cortisol levels, and catecholamine levels. The results are shown in Table 10. There was no significant difference between the groups with respect to the perceived uncertainty. However, there were significant differences ( $p=.10$ ) between the groups with respect to both parameters of physiological stress, cortisol and catecholamine levels. Spouses had lower levels of both hormones.

### Summary

The chapter presented the characteristics of the sample and the statistical analysis of the data with regard to the research questions. Also presented were analysis of subgroups of the sample population by age and relationship.

Table 9. The Caregivers' Relationship Subgroups and Mean Scores for Uncertainty, Cortisol, and Catecholamines (N=29)

Relationship Group	N	Relationship Category	Uncertainty	Cortisol	Catecholamines
1	14	Spouse	64.8	154.5	28.7
2	15	Non-spouse	63.8	230.3	46.7

Table 10. t-test of Relationship Subgroups and Variables (N=29)

Variable	t-value	Degrees of Freedom	2-tail Probability
Catecholamine Levels	-2.61	26	.02
Cortisol Levels	-2.05	26	.05
Total Uncertainty	.32	26	.75

## CHAPTER V

### CONCLUSIONS AND IMPLICATIONS

This chapter will discuss conclusions based on the analysis of the data, implications for nursing practice and research, and limitations of the study. The conclusions will be presented first.

#### Conclusions

Since similar studies are not available for comparison with regard to caregivers' uncertainty level, the results must be compared to predicted outcomes based upon the literature search done. The literature supports the concept of uncertainty with respect to Alzheimer's disease. Victims of this disorder display an array of symptoms (i.e., confusion, wandering, memory loss, etc.), and these symptoms are unpredictable. The day-to-day caring for these individuals is stressful. These concepts were supported in this study also, as described in Chapter IV.

Cortisol and catecholamines are stress hormones whose regulation are due, in part, to the body's reaction to long-term stress. Elevations of these hormones is associated with an arousal state that can be from any number of stressors (physiological, psychological, emotional, etc.).

The inverse relationship found between uncertainty and both cortisol and catecholamines is of particular interest. Health care

providers have long held the concept that knowledge of the disease process is helpful and reduces stress. Research such as presented here, however, challenges that belief. Although both correlations are low ( $-.31$  and  $-.32$ ), they do show a trend that cannot be ignored. The present information available for family members about Alzheimer's disease is dismal. The medical profession can offer no cure for the disease. It runs its course and ends with a fatal outcome. A higher degree of knowledge about Alzheimer's disease, and therefore less uncertainty, may in fact be more stressful since the knowledge paints such a gloomy picture. A higher degree of uncertainty, indicating many unknowns, may also allow for hope, which decreases stress. Hope allows the caregiver to believe in a chance for a better future. Knowledge of the disease and the disease process dims and/or eliminates the prospect for a more positive future.

The relationship of age and stress response, as reported in this study showed that young individuals are more stressed than older individuals with the same amount of uncertainty. A similar finding could be interpreted from the results of the correlations between relationship to the victims of Alzheimer's disease and stress. Spouses had lower levels of cortisol and catecholamines than non-spouses for the same levels of uncertainty. The spouses were older than the non-spouses, who were primarily children or grandchildren of the victims. Therefore these two sets of findings will be discussed together.

Younger individuals may need certainty to cope. Uncertainty may be seen as aversive to younger individuals because future planning

is such an integral part of their life. Offspring of individuals with Alzheimer's disease are at risk for developing the disease later in life. This may add to the uncertainty and stress perceived by the younger subjects. Also the uncertainty of caring for a family member with Alzheimer's disease makes it difficult to plan for any future. The primary goal of a non-spouse may not be to have the individual with Alzheimer's disease with them. There is a high likelihood that a non-spouse has other support and/or significant people in his/her life. Spouses on the other hand may have less physiological arousal to the uncertainty because not knowing the future may not be appraised in the same manner as non-spouses. For the spouse, the individual with Alzheimer's disease is the significant other in their life. The spouse's focus is to have this person with them and the future is integrated with the victim of Alzheimer's disease, not a separate process from this individual's disease course.

Another interpretation of these results could be that older individuals have lower levels of circulating hormones because of any number of consequences of physiological aging. Among some of the possibilities would be: 1) decreased renal function, which would decrease the amount of hormone excreted; or 2) decreased adrenal function, cortex and/or medulla, which would decrease the amount of hormone secreted. Neither of these can be substantiated given the data obtained. Other physiological studies on the subjects would have had to have been performed (i.e., creatinine clearance, insulin tolerance test, etc.).



### Implications for Nursing Practice and Research

Although this research showed trends, further investigation of the research questions proposed is necessary using various populations to see if the same trends are supported. Change in health care to a more community focus, due to the escalating cost of institutional care, makes it imperative that nursing further describe and define the impact of caregiving on a family member. This information will help in the prescription of nursing care in the community.

For the present, the data from this study suggest that nursing take a close look at the practice of the type of knowledge given to clients. Perhaps nursing serves the client better by limiting the amount of knowledge of the disease process given to allow for retention of some degree of hope. How this balance of knowledge and hope is achieved is well beyond the limited scope of this study.

### Limitations of the Study

This study was limited from several aspects. The physical resources did not allow for the testing of renal function necessary to validate the excretion of cortisol and catecholamines. Normal renal function was assumed in all cases when total urine output was normal. Also, although the tests were conducted three times on each sample of urine, they were performed by an inexperienced individual and undetected errors could have occurred.

Sample size was a limitation in the study. A larger size sample may have yielded more conclusive statistical data. The study of chronic stress has limitations in and of itself. Just going into someone's

home and asking him to participate in a study evokes a stress response. Day to day frustrations not due to caring for a loved one with Alzheimer's disease are difficult to sort out. At the completion of the urine collection, all subjects were asked to describe any unusual occurrence not related to the care of the loved one in an attempt to monitor for such extraneous stresses, but none were found.

### Summary

The conclusions, based on the data analysis and the recommendations for nursing practice and future research investigating the problems addressed in this study were presented. Also described were the limitations of the study.

## APPENDIX A

## DISCLAIMER

## DISCLAIMER FORM

TITLE OF STUDY: THE PHYSIOLOGICAL IMPACT OF STRESS ON CAREGIVERS OF ALZHEIMER'S DISEASE VICTIMS

## PURPOSE:

THE PURPOSE OF THIS STUDY IS TO DETERMINE SOME OF THE SOURCES OF STRESS FOR CAREGIVERS OF ALZHEIMER'S DISEASE VICTIMS.

IF YOU AGREE TO PARTICIPATE, YOU WILL BE ASKED TO COMPLETE FOUR QUESTIONNAIRES. ONE QUESTIONNAIRE WILL ASK YOU ABOUT YOUR SOCIAL SUPPORT NETWORK. THE SECOND SCALE ASKS YOU ABOUT YOUR FAMILY MEMBERS ILLNESS. THE NEXT TWO SCALES DEAL WITH STRESS. ONE ASKS QUESTIONS ABOUT YOUR FEELINGS AND THE OTHER EVALUATES YOUR CONCENTRATION. AFTER COMPLETING THE FOUR SCALES, YOU WILL BE ASKED TO COLLECT YOUR URINE CONTINUOUSLY FOR THE FOLLOWING 24 HOUR PERIOD. YOU WILL BE PROVIDED WITH ALL THE EQUIPMENT NECESSARY. THE URINE SAMPLES WILL BE COLLECTED THE NEXT DAY. THE 24 HOUR URINE COLLECTION WILL BE OBTAINED TO ANALYZE FOR HORMONE LEVELS RELATED TO STRESS. A COMPARISON WILL THEN BE MADE BETWEEN THE QUESTIONNAIRES AND HORMONE EXCRETION.

YOU ARE BEING ASKED TO VOLUNTARILY PARTICIPATE AND GIVE YOUR OPINIONS ON THE QUESTIONNAIRES AND TO COLLECT YOUR URINE. BY RESPONDING TO THE QUESTIONNAIRES AND AGREEING TO COLLECT YOUR URINE, YOU WILL BE GIVING YOUR CONSENT TO PARTICIPATE IN THIS STUDY. YOUR NAME WILL NOT BE USED AT ANY TIME, AND YOU MAY CHOOSE NOT TO ANSWER SOME OR ALL OF THE QUESTIONS. YOUR QUESTIONS WILL BE ANSWERED AND YOU MAY WITHDRAW FROM THE STUDY AT ANY TIME. THERE ARE NO KNOWN RISKS. THE INFORMATION OBTAINED WILL ONLY BE USED IN THIS STUDY AND WILL BE SEEN ONLY BY THE INVESTIGATORS.

**APPENDIX B**

**HUMAN SUBJECTS APPROVAL FORM**

## THE UNIVERSITY OF ARIZONA COLLEGE OF NURSING

## MEMORANDUM

TO: S. Danielle Brown  
1402 E. Manlove Street #58  
Tucson, AZ 85719

FROM: Ada Sue Hinshaw, RN, PhD                      Katherine J. Young, RN, PhD  
Director of Research                      Chairman, Research Committee

DATE: December 20, 1983

RE: Human Subjects Review: The Physiological Impact of Stress  
on Caregivers of Alzheimer's Disease Victims

Your project has been reviewed and approved as exempt from University review by the College of Nursing Ethical Review Sub-committee of the Research Committee and the Director of Research. A consent form with subject signature is not required for projects exempt from full University review. Please use only a disclaimer format for subjects to read before giving their oral consent to the research. The Human Subjects Project Approval Form is filed in the office of the Director of Research if you need access to it.

We wish you a valuable and stimulating experience with your research.

ASH/fp

APPENDIX C

QUESTIONNAIRE

NO. \_\_\_\_\_

## MISHEL UNCERTAINTY IN ILLNESS SCALE

INSTRUCTIONS: PLEASE READ EACH STATEMENT. TAKE YOUR TIME AND THINK ABOUT WHAT EACH STATEMENT SAYS. THEN PLACE AN "X" UNDER THE COLUMN THAT MOST CLOSELY MEASURES HOW YOU ARE FEELING ABOUT YOUR FAMILY MEMBER TODAY. IF YOU AGREE WITH A STATEMENT, THEN YOU WOULD MARK UNDER EITHER "STRONGLY AGREE" OR "AGREE". IF YOU DISAGREE WITH A STATEMENT, THEN MARK UNDER EITHER "STRONGLY DISAGREE" OR "DISAGREE". IF YOU ARE UNDECIDED ABOUT HOW YOU FEEL ABOUT YOUR FAMILY MEMBER, THEN MARK UNDER "UNDECIDED" FOR THAT STATEMENT. PLEASE RESPOND TO EVERY STATEMENT.

1. I DON'T KNOW WHAT IS WRONG WITH HIM/HER.  
 STRONGLY AGREE      AGREE      UNDECIDED      DISAGREE      STRONGLY DISAGREE  
 \_\_\_\_\_
2. I HAVE A LOT OF QUESTIONS WITHOUT ANSWERS.  
 STRONGLY AGREE      AGREE      UNDECIDED      DISAGREE      STRONGLY DISAGREE  
 \_\_\_\_\_
3. I AM UNSURE IF HIS/HER ILLNESS IS GETTING BETTER OR WORSE.  
 STRONGLY AGREE      AGREE      UNDECIDED      DISAGREE      STRONGLY DISAGREE  
 \_\_\_\_\_
4. IT IS UNCLEAR HOW BAD HIS/HER CONFUSION WILL BE.  
 STRONGLY AGREE      AGREE      UNDECIDED      DISAGREE      STRONGLY DISAGREE  
 \_\_\_\_\_
5. THE EXPLANATIONS THEY GIVE ABOUT HIM/HER SEEM HAZY TO ME.  
 STRONGLY AGREE      AGREE      UNDECIDED      DISAGREE      STRONGLY DISAGREE  
 \_\_\_\_\_
6. HIS/HER SYMPTOMS CONTINUE TO CHANGE UNPREDICTABLY.  
 STRONGLY AGREE      AGREE      UNDECIDED      DISAGREE      STRONGLY DISAGREE  
 \_\_\_\_\_



7. I UNDERSTAND EVERYTHING EXPLAINED TO ME.

STRONGLY AGREE      AGREE      UNDECIDED      DISAGREE      STRONGLY DISAGREE

\_\_\_\_\_

8. THE DOCTORS SAY THINGS TO ME THAT COULD HAVE MANY MEANINGS.

STRONGLY AGREE      AGREE      UNDECIDED      DISAGREE      STRONGLY DISAGREE

\_\_\_\_\_

9. I CAN PREDICT HOW LONG HIS/HER ILLNESS WILL LAST.

STRONGLY AGREE      AGREE      UNDECIDED      DISAGREE      STRONGLY DISAGREE

\_\_\_\_\_

10. IT IS DIFFICULT TO KNOW IF THE TREATMENTS OR MEDICATIONS HE/SHE IS GETTING ARE HELPING.

STRONGLY AGREE      AGREE      UNDECIDED      DISAGREE      STRONGLY DISAGREE

\_\_\_\_\_

11. BECAUSE OF THE UNPREDICTABILITY OF HIS/HER ILLNESS, I CANNOT PLAN FOR THE FUTURE.

STRONGLY AGREE      AGREE      UNDECIDED      DISAGREE      STRONGLY DISAGREE

\_\_\_\_\_

12. THE COURSE OF HIS/HER ILLNESS KEEPS CHANGING. HE/SHE HAS GOOD AND BAD DAYS.

STRONGLY AGREE      AGREE      UNDECIDED      DISAGREE      STRONGLY DISAGREE

\_\_\_\_\_

13. IT IS NOT CLEAR WHAT IS GOING TO HAPPEN TO HIM/HER.

STRONGLY AGREE      AGREE      UNDECIDED      DISAGREE      STRONGLY DISAGREE

\_\_\_\_\_

14. I USUALLY KNOW IF HE/SHE IS GOING TO HAVE A GOOD DAY OR A BAD DAY.

STRONGLY AGREE      AGREE      UNDECIDED      DISAGREE      STRONGLY DISAGREE

\_\_\_\_\_

15. THE RESULTS OF HIS/HER TESTS ARE INCONSISTENT.

STRONGLY AGREE      AGREE      UNDECIDED      DISAGREE      STRONGLY DISAGREE

\_\_\_\_\_

16. THE EFFECTIVENESS OF THE MEDICINE IS UNDETERMINED.

STRONGLY AGREE      AGREE      UNDECIDED      DISAGREE      STRONGLY DISAGREE

\_\_\_\_\_

17. I CAN GENERALLY PREDICT THE COURSE OF HIS/HER ILLNESS.

STRONGLY AGREE      AGREE      UNDECIDED      DISAGREE      STRONGLY DISAGREE

\_\_\_\_\_

18. I'M CERTAIN THEY WILL NOT FIND ANYTHING ELSE WRONG WITH HIM/HER.

STRONGLY AGREE      AGREE      UNDECIDED      DISAGREE      STRONGLY DISAGREE

\_\_\_\_\_

19. THEY HAVE NOT GIVEN HIM/HER A SPECIFIC DIAGNOSIS.

STRONGLY AGREE      AGREE      UNDECIDED      DISAGREE      STRONGLY DISAGREE

\_\_\_\_\_

20. HIS/HER MEMORY LOSS IS PREDICTABLE, I KNOW WHEN IT IS GOING TO GET  
BETTER OR WORSE.

STRONGLY AGREE      AGREE      UNDECIDED      DISAGREE      STRONGLY DISAGREE

\_\_\_\_\_

21. HIS/HER DIAGNOSIS IS DEFINITE AND WILL NOT CHANGE.

STRONGLY AGREE      AGREE      UNDECIDED      DISAGREE      STRONGLY DISAGREE

\_\_\_\_\_

22. THE SERIOUSNESS OF HIS/HER ILLNESS HAS BEEN DETERMINED.

STRONGLY AGREE      AGREE      UNDECIDED      DISAGREE      STRONGLY DISAGREE

\_\_\_\_\_

23. THE DOCTORS AND NURSES USE EVERYDAY LANGUAGE SO I CAN UNDERSTAND WHAT  
THEY ARE SAYING.

STRONGLY AGREE      AGREE      UNDECIDED      DISAGREE      STRONGLY DISAGREE

\_\_\_\_\_

**APPENDIX D**

**INFORMATION SHEET**

## INSTRUCTIONS FOR 24-HOUR URINE COLLECTION

THE URINE MUST BE COLLECTED CONTINUOUSLY FOR A 24-HOUR PERIOD.  
ALL URINE VOIDS BETWEEN \_\_\_\_\_ AND  
\_\_\_\_\_ MUST BE SAVED IN THE JAR PROVIDED.

THE COMMODOE PAN SETS IN THE TOILET TO COLLECT EACH VOID. AFTER  
EACH VOID, IMMEDIATELY TRANSFER THE URINE INTO THE GLASS JAR, USING  
THE FUNNEL, IF NECESSARY, FOR EASE. PLEASE DO NOT PLACE TOILET PAPER  
IN COMMODOE PAN OR JAR.

THE GLASS JAR MUST BE KEPT IN THE STYROFOAM BOX SURROUNDED  
BY ICE AT ALL TIMES. THE TOP MUST BE KEPT ON THE JAR WHEN URINE IS  
NOT BEING ADDED TO THE COLLECTION. THE URINE COLLECTION MAY BE STORED  
IN A CONVENIENT LOCATION FOR YOU, AWAY FROM HEATER OR VENT.

THE INVESTIGATOR WILL RETURN TO COLLECT THE URINE SAMPLE AND  
THE EQUIPMENT AT \_\_\_\_\_ TOMORROW. IF YOU HAVE ANY  
QUESTIONS OR PROBLEMS THE INVESTIGATOR CAN BE REACHED AT \_\_\_\_\_  
FROM \_\_\_\_\_ TO \_\_\_\_\_ OR AT \_\_\_\_\_  
FROM \_\_\_\_\_ TO \_\_\_\_\_.

THANK YOU FOR YOUR TIME AND COOPERATION.

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