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The Reduction of Stress as Perceived by the Alzheimer Patient Caregivers Through the Use of Support Groups

Linda Blewer Swindle

THE REDUCTION OF STRESS AS PERCEIVED BY ALZHEIMER PATIENT CAREGIVERS THROUGH THE USE OF SUPPORT GROUPS

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A DIGEST PRESENTED TO THE FACULTY OF THE GRADUATE SCHOOL
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Digest

The following thesis is meant to provide the reader with a brief trip through the world of the caregiver of Alzheimer's patients.

The Introduction indicates the scope of the disease while Chapter One provides a look at normal aging and an indepth description of what to expect from the individual who has been diagnosed with Alzheimer's Disease. You will see what physical changes occur in the brain itself and how these changes eventually reduce the victim to someone who lies in a fetal position with no comprehension of their surroundings. The reader will also discover that 20th century medicine has never discovered a certain cause of Alzheimer's Disease nor a cure. The only certainty is the steady decline of the patient and in the end, the fact that this disease will claim the life of that patient.

Chapter One discusses stress; what it is, what it does and how it happens. It also addresses ways to defeat stress through the use of Rational Emotive Therapy. By the end of the chapter, you will have discovered that most researchers basically agree (regarding how stress is caused) and what happens when stress occurs. The thing psychologists and researchers disagree about is the best

method available to combat it once stress occurs.

Chapter One also discusses support groups and the value they posses for the Alzheimer's caregiver. The available literature agrees that support groups of any kind are valuable tools which are available to assist people with like problems.

Further on, in Chapter Two, the hypotheses of this thesis is touched upon briefly. This hypotheses is that support group attendance reduces the perceived level of stress in a caregiver of an Alzheimer's patient.

In Chapter Three, the method of gathering information and the population involved are discussed along with a copy of the survey instrument used and the results.

The reader will find Chapter Four consists of conclusions and recommendations followed by a list of references used to assist the author when gathering information for this thesis.

THE REDUCTION OF STRESS AS PERCEIVED BY ALZHEIMER PATIENT CAREGIVERS THROUGH THE USE OF SUPPORT GROUPS

Linda Blewer Swindle, R.N., B.S.

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1989

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No man is an island entire of itself
Everyman is a piece of the continent, a part of the main
Any man's death diminishes me, for I am involved in mankind
And therefore never send to know for whom the bell tolls,
It tolls for thee

John Donne

I am hungry for the life that is being taken away from me. I am a human being. I still exist. I have a family. I hunger for friendship, happiness, and the touch of a loved hand. What I ask for is that what is left of my life shall have some meaning. Give me something to die for! Help me to be strong and free until my self no longer exists. - J.T., an Alzheimer's victim

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Introduction

The purpose of this project is to show that one of the most valuable tools available to a caregiver of a patient with Alzheimer's Disease is a support group.

This tool provides a sounding board; a social outlet; a place to be fully understood; a look into the future for new members; a place to receive information regarding such things as what Medicare will really pay for, where a new affordable day care center is located, where financial and physical help is available; and maybe just an accepting shoulder to cry on.

A disease as devastating as Alzheimer's which affects 200,000 new people a year is a problem that everyone should be interested in since it is reported to affect one out of every three families in some way. There are an estimated 2.5 million victims living in the United States today (Oliver & Bock, 1987). For each of these people there are usually several family members and friends who share concern for that person. However, the vast majority of the time there is only that one person who is the caregiver, whose life is completely taken over and ruled by the illness. After a while when the disease has progressed to what is called stage three. The caregivers become prisoners within the confines of their own home, guardian for a person who rarely sleeps, must be watched constantly,

and who may not remember the identity of the caregiver much of the time. Unless relieved, the caregivers are unable to shop, take a walk, go out to dinner, or just relax. Many people do not have the financial resources to hire outside help and others who could afford to do so will not out of a sense of obligation and guilt. Some people are fortunate to have other family members or friends relieve them occasionally. However, often other people are afraid of the sometimes bizarre or aggressive behavior the patient may exhibit or they are simply "too busy."

In the years I have spent working in nursing homes, there seems to be a pattern of visitation to Alzheimer's patients. The family or a particular family member will visit very frequently, sometimes every day, or there will be no visitors at all except those visits made to assure quality of care. The main reason relatives use to explain why the do not visit is "what difference does it make if I come, the patient doesn't know me anyway." I think these visits also serve as a reminder that perhaps they may be stricken next if the disease has a history in the family. I am familiar with one family in which all four sisters died of Alzheimer's disease and the two brothers were spared. This would naturally cause concern in any family.

There is a trend toward more and more cities setting up brain banks, St. Louis included. Since

the only method medical science has to study Alzheimer's disease is through autopsys of the victim's brain, it is essential that family members participate in a brain bank project if one is available in their city. At this point in time, according to available literature, we are no nearer a cure, a positive cause, or preventive measures with regard to Alzheimer's than we were twenty-five years ago. The best science can do is positively identify the disease after death by looking at neurofibrillary tangles and neuritic plaques within the brain.

The only way a physician is able to diagnosis the disease, with a fair degree of certainly, is to run a battery of tests, ruling out other identifiable diseases and then rerun the tests again in six month to a year to see if cognitive impairment has increased.

When people talk about the subject of death, most people's reaction, according to the Harris survey, is that they would prefer to die quickly and painlessly. However, Alzheimer's victims are not allowed this easy exit. While the disease is physically painless without complications, the mental deterioration is devastating to both the patient and the people who love them.

The uniqueness of this disease lends itself to the need for support groups as these people who are care-givers can truly say "you can not imagine what it is like unless you have experienced it." They truly need

A comrade to commiserate with who is not required to use their imagination and to be able to say honestly "I know how you feel."

By interviewing caregivers who are members of Alzheimer's supports groups, I expect to show that the perceived level of stress caregiver's experience is reduced through their interaction with other members of their support group.

Chapter 1

Literature Review

Normal Aging

It is a common assumption that everyone who is elderly is senile, therefore the mental changes which occur with aging are often mistaken for dementia. The normal aging process, however, does not affect the individual's competency or ability to care for themselves. In fact, changes in memory and other intellectual abilities are relatively mild when there is no dementing illness. Often accumulated information and experience compensate for changes in memory function (Zarit et el., 1985).

The principle change occurring in memory with normal aging is a slowing in the time necessary for learning and recalling information. An older person may also be distracted more easily, which affects the capacity for learning and memory. These changes, however, do not indicate an inability to learn or remember. Rather, it indicates older people simply need more time and effort to remember (Zarit et el., 1985).

Typically learning is measured as a change in response from one experience or trial to another, whole memory is measured as change in relation to the time between experiences. The difference is simply whether it is the experiences that are noted, or whether it is the amount of time between experiences that are of concern. Normally it is referred to as

memory when long-time intervals are involved, however, with very short-time intervals the processes of both memory and learning are used. While the ability to recall appears to decline with age, the ability to recognize does not, or if so, it does to a much smaller degree (Botwinick & Storandt, 1974).

Some older people are frightened by moments of forgetfulness, fearing they are becoming senile. Sometimes other people may also assume that when an older person forgets something it is due to senility when the same incident occurring with a younger person will probably pass unnoticed. They fail to remember that occasional forgetfulness is common at any age.

Although the changes associated with normal aging are mild, many older people are treated as if they are in the process of becoming mentally incompetent. There is no reason to believe a healthy older person cannot manage their own affairs as they always have unless they themselves indicate some assistance would be welcome or something untoward happens suddenly.

There are times when even previously healthy people can become temporarily disturbed. Very likely this confusion is reversible if diagnosised and treated promptly. The terms delirium and reversible dementia refer to syndromes involving cognitive impairment that resemble senile dementia, but which may be brought

about by conditions which are treatable. Delirium may present such symptoms as hallucinations, delusions, disorientation, increased or decreased alertness, attention deficits, and disturbed sleep patterns. The symptoms, as well as the severity, may fluctuate rapidly. On the other hand, reversible dementia may involve symptoms of memory loss which are virtually indistinguishable from irreversible dementia (Zarit et el., 1985).

The main causes of delirium and reversible dementia, according to the National Institute of Aging Task Force in 1980, are toxic effects of medications or interactions between drugs, brain tumors, infections, electrolyte imbalances, malnutrition, and metabolic and indocrine disorders. Symptoms may occur following surgeries, fractures, head injuries, strokes, or environmental changes, such as moving to a nursing home or the loss of a spouse.

Brain damage such as occurs from head traumas strokes, and aneurysms are nonprogressive and usually selective rather than global. Because the symptoms which are apparent in cases of brain damage are often similar to those shown by dementia, such as memory impairment, lack of attention, and poor judgement, the possibility of nonprogressive brain damage as a cause is often overlooked. It's very important to the family and the patient that the difference

between a progressive and nonprogressive disease be ascertained. This allows the patient to compensate for cognitive problems caused by the brain damage by using abilities which have not been affected. It is also important that the patient and family know the brain damage is not going to progress (Zarit et el., 1985).

Depression is also often difficult to distinguish from irreversible dementia in the elderly. Many symptoms are present in both. Depressed persons may resemble dementia patients because they are often mentally and physically slow in their responses, show little or no interest in their surrounding and have withdrawn from their usual activities. In addition, many depressed people also complain of memory loss. In contrast to dementia, however, memory changes brought about by depression are mild. The importance of distingushing between dementia and depression is that depressed older people can improve with treatment (Zarit et el., 1985).

At this time, there are general criteria for the diagnosis of dementia, delirium and depression. Reputable clinicians diagnose irreversible dementia when there is unequivocal evidence and when other treatable causes have been ruled out. An inaccurate diagnosis of irreversible dementia can be devastating to both the patient and the family
1985).

A Clinical Description of Alzheimer's Disease

Alzheimer's disease is a chronic, progressive, irreversible neurological disorder that destroys memory, language, judgement, and all cognitive functioning, and in the process, changes behavior and personality. It has no certain cause, cure, or treatment. Alzheimer's is a disease of adult onset that can affect people in their forties and fifties, but by far the largest number of those afflicted are 60 years of age and older. The author is aware of several cases which show clinical evidence of early onset. Although probably not a disease caused by age as just illustrated, according to available literature, it appears to be age-related, with the risk of contracting Alzheimer's greatly increasing as one advances in age.

Upwards of 150,000 people die of Alzheimer's each year. It is the fourth largest killer of older Americans (Oliver & Bock, 1987). Two facts concerning this fatal illness exert enormous impact upon family members who care for relatives afflicted with Alzheimer's disease. One, it unfolds slowly and progressively with a gradual but certain deterioration. Individuals may live twenty years or more from the time of onset, however ten years is considered an average, and secondly if nothing else afflicts the Alzheimer victum they will remain physically well for many of those years. Physical frailty occurs in the late stages of the disease, long after the mind and personality have undergone drastic change. Due to this

fact, family members usually end up caring for persons with Alzheimer's disease at home significantly longer than do those who care for the physically frail. Eventually, however, most victims of Alzheimer's disease end their lives in nursing homes, not because their families reject them but because caregivers ultimately can no longer cope with the demands placed on them due to the numerous symptoms of this disease.

Alzheimer's disease is not likely to affect any two people in exactly the same way. Some people will become very passive and quiet while others become angry and agitated and in some cases physically and/or verbally abusive. Others may go through a sequence of behavior patterns over time, however, most victims of Alzheimer's disease have characteristics which are typical of the disease. When symptoms of the disease are discussed at a support group, rarely will someone bring up a problem that hasn't been encountered by the rest of the group if their relatives have had the disease long enough.

There are four stages of the illness which one can expect to occur over a period of time (Harnett,1984).

1. The first stage is very subtle and it is likely that neither the victim nor the family will realize what is happening. The victim experiences incidences of forgetfulness which are perhaps familiar to all of us: They forget a word or a thought, misplace

keys or glasses, forget a friend's name while introducing them. In the beginning these symptoms may be attributed to fatigue, anxiety, a cold, or a sensory overload. They may be attributed to the fact that "mom" is just getting old. As stage one begins to move into stage two something out of the ordinary may happen which alerts the family and maybe the victim that something is wrong. For example: A normally well groomed woman will dress for church, wearing two different color and type shoes; a person will go back to the kitchen for lunch 15 minutes after they have eaten to have the lunch they have forgotten they ate; a man is returned home after wandering around a mall for several hours, not knowing where he is and why he was there.

2. In stage two, the disease becomes more obvious. The victim begins to forget recent events. They seem to be relating to an earlier time in their life when they were younger and they may want to "go home" even though they have lived all of their adult life in the house they are in now. They begin to have problems with language, perhaps their vocabulary is reduced to 30 or 40 words. They may begin to babble nonsense sentences most of the time. They are no longer able to make simple calculations such as 4+4+2.

3. In the third stage, the more physical aspects of the disease begin to present. The affected person begins to pace almost continuously, perhaps interrupting

at times to dress and undress over and over again. The Alzheimer's sufferer rarely sleeps all night but wanders about the house sometimes only needing three or four hours sleep per 24 hours. They no longer remember what eating utensils are for or how to use them and require complete assistance with bathing and toileting. Incontinence develops. The individual will eventually forget how to walk and require a wheelchair. Strong negative reactions may occur stemming from a minor incident which will send the patient into a tirade. Toward the end of stage three the person will forget how to swallow and it will become necessary to introduce a nasogastric tube to prevent starvation and dehydration.

4. Stage four is the terminal stage of Alzheimer's disease but it may last for months or years. The victim will lie in a fetal position and probably not be aware of their surroundings or who is in the room with them. They may cry out continuously or be completely silent, however, unless they are affected by another disease, they will not be in any physical pain.

Physically speaking, sometime during the course of this disease, the nerve cells in the part of the brain that controls memory, thinking, and judgement are damaged, interrupting the passage of messages between cells. Messages are passed between nerve cells by chemicals called neurotransmitters. One specific neurotransmitter is lacking in patients with Alzheimer's

disease and it is believed to be related to the cause of the disease. Choline acetyltransferase is an enzyme located almost exclusively in cholinergic neurons. A significant decrease of choline acetyltransferase activity in the hippocampus and cortex, areas of the brain associated with learning and memory, is found in the brain of Alzheimer's victims. Also, the thinking center of the brain atrophies, making less surface area which plays a part in how well a person can think and function. The spaces in the center of the brain become enlarged. The nerve cells themselves develop special changes that are the hallmark of the disease as seen after death in an autopsy (Harnett, 1984).

Alzheimer's disease is not caused by hardening of the arteries, most Alzheimer's victims have normal blood vessels leading to the brain. Alzheimer's disease is not just the result of poisons in the environment. While there may be increased amounts of aluminum in the brains of persons who die with Alzheimer's, it is not known if that is a cause or effect of the disease (Harnett, 1984).

Alzheimer's disease may be the result of a slow-growing virus, a genetic abnormality or an immune problem, but the most reliable current theory is the missing neurotransmitter discussed earlier.

Stress

Hans Selye begins The Stress of Life with the

statement "In its medical sense, stress is essentially the rate of wear and tear in the body" (pg. 1). In this book he offers explanations of the biological and psychological processes which led to the discovery of G.A.S. or General Adaptation Syndrome. G.A.S. represents the three distinct stages of the manifestation of stress in the whole body as they develop in time. First there is the alarm reaction, second the stage of resistance, and third the stage of exhaustion.

Some in the medical community offered resistance to the use of the name stress in conjunction with quantifiable measurements. They noted that stress is an abstraction and does not occur as such in the pure state. Opponents felt it quite impossible to isolate stress for the objective, direct, scientific observation and measurements of its own effects, which would be indispensable for any scientific treatment of the problem. Doctor Selye agrees that stress is an abstraction but adds that so is life upon which the whole science of physiology is built.

In order to differentiate between cause and effect, Selye coined the word 'stressor;' stressor being the cause and stress the effect. Since the word stress has always been used so freely Doctor Selye felt it necessary to chronicle what stress is and what it is not.

It is not:

1. Simply nervous tension

2. An emergency discharge of hormones from the adrenal medulla.

3. Everything that causes a secretion by the adrenal cortex of its hormones, the corticoids.

4. Always the nonspecific result of damage.

5. The same as a deviation from homeostasis.

6. Anything that causes an alarm reaction.

7. Identical with the alarm reaction or the G.A.S. as a whole.

8. A nonspecific reaction.

10. Necessarily something bad.

11. Stress cannot, and should not, be avoided (pg. 62-63).

Stress is the state manifested by a specific syndrome which consists of all the nonspecifically-induced changes within a biologic system. Stress has its own characteristic form and composition but no particular cause. The elements of its form are the visible changes due to stress, whatever its cause. They are additive indicators which can express the sum of all the different adjustments that are going on in the body at any time.

People often say "she is under stress" or "the baby is running a temperature" when what is really meant is that the person has an excess of stress or of

body temperature. Stress, just as temperature is all-inclusive containing both positive and negative aspects of these concepts. We need to differentiate between the harmful variety of stress called distress and the pleasant form of stress called euphoria. During both the body undergoes virtually the same nonspecific responses to the various positive or negative stimuli acting upon it. The fact is, however, that euphoria causes much less damage than distress which graphically demonstrates that it is how one perceives the stress that determines whether one can successfully adopt to change.

Doctor Selye gives many "medical textbook" definitions, experiments, and examples of what constitutes stress but for the purpose at hand, I believe one of his best examples of distress is a list of self-observable signs and symptoms. They are as follows:

1. General irritability, hyperexcitation, or depression. This is usually associated with unusual aggressiveness or passive indolence, depending on one's disposition.

2. Pounding of the heart, an indication of high blood pressure.

3. Dryness of the mouth and throat.

4. Impulsive behavior, emotional instability.

5. An overpowering urge to cry or run and hide.

6. Inability to concentrate, flights of thought and general disorientation.

7. Feelings of unreality, weakness or dizziness.

8. Predilection to become fatigued and loss of the joy of living.

9. "Floating anxiety" or being afraid but uncertain of what we are afraid of.

10. Emotional tension and alertness, a feeling of being keyed up.

11. Trembling, nervous ticks.

12. Tendency to be easily startled by small sounds, etc.

13. High-pitched, nervous laughter.

14. Stuttering and other speech difficulties.

15. Teeth grinding.

16. Insomnia.

17. An increased tendency to move around without any reason; inability to physically relax.

18. Sweating.

19. Frequent need to urinate.

20. Diarrhea, indigestion, queasiness, possibly vomiting.

21. Migraine headaches.

22. Women with premenstrual tension or missed menstrual cycles.

23. Pains in the lower back or neck.

24. Loss of or excessive appetite.

25. Increased smoking.

26. Increased use of legally prescribed drugs.

27. Alcohol and drug addiction.

28. Nightmares.

29. Neurotic behavior.

30. Psychosis.

31. Accident proneness (pg. 174,75,76 & 177).

Any of the previous responses can be the result of external or internal stressors which produce the stress responsible for these responses.

Selye offers some very simple but sound guidelines guaranteed to reduce excess strain in people. The premise of his advice sounds very much like what one would expect to hear from the late Doctor Albert Adler, a remarkable psychatrist who believed that if we could but love our neighbor as ourselves many neurosis would disappear. Dr. Selye advises we should:

1. Find our own natural stress level. Since all of us to some degree are influenced by hereditary predispositions and the expectations of society, we need to use self-analysis to determine what we really want. Too many people suffer all of their lives because they are too conservative to risk a change and break with traditions.

2. The most effective way to give vent to our pent-up energy and to create enjoyable, beautiful, useful things is to be free with our goodwill, respect, support and love of our neighbors.

3. We should try to earn our neighbors love. Earning love, unlike love on command is compatible with man's natural structure and is based on altruestic egoism. Man is a social being and should avoid remaining alone in the mist of the overcrowed society by which we are surrounded.

As we will see in the following pages, different authors use a slightly different manner to discuss stress but in the end there is virtually no disagreement about what stress is and what its end result can be

Stress is defined by Stoff and Pellegrino as "Physiologically, stress is the state produced within an organism in response to a demand made upon it that requires some readjustment or adaptation. Since circumstances and the environment are always changing, we are always under some stress. From a clinical perspective, stress may be defined as the internal state that results when the capacity to adapt to what is has been exceeded" (pg. 82).

How any person reacts to stress is subjective since we all perceive life and its pressures individually. The construction of our nervous system allows for two possible responses to stress. The less common of the two is when a person responds to a threat by passively withdrawing. An extreme example would be someone who was totally catatonic. Less dramatic would be a response whereby fear produced inibition and a decrease of all physiologic functions, loss of muscle tone, mental lassitude, and eventually depression. In this response it is not necessary to tap the body's biochemical storehouse.

The more common reaction to stress is that of

stimulation which is called the fight response. "The body activates all of its biochemical arsenal and prepares to either stand and fight or flee" (Stoff & Pellegrino, pg 84). It is adaptive to mobilize all of the body's systems and resources periodically but if sustained for a long period of time, overload, and burnout occurs.

Accoring to Stoff and Pellegrino there are four main stress responses.

1. "We surender to the flow of circumstances (life) fatalistically.
2. We ignore life as we pass through it, until an accident mades us conscious of our circumstances.
3. We attempt to resist, which often wastes energy and fuels stress.
4. We use our circumstances to help us achieve our goals" (pg. 84).

With regard to stress, the book Chronic Fatigue Syndrome quotes from Science News "Tending to a relative with Alzheimer's disease is not just psychologically stressful - over the long run, say researchers at Ohio State University College of Medicine in Columbus, it can undermine the caregiver's immune responses. Janice K. Kiecolt-Glaser and her colleques compared 11 men and 23 women caring for family members with Alzheimer's disease with controls matched for age, sex and education. Subjects caring for an Alzheimer

victim reported more distress and poorer mental health than individuals with no such responsibilities. Care-givers also had indications of poor immune function: lower percentages of T-lymphocytes then controls, as well as a lower ratio of antibody-stimulating cells to antibody-surpressing cells" (Stoff & Pellegrino, pg. 80).

When a psychosocial stressor presents itself, we first must recognize the event and perceive it as a challenge. We then have to evaluate its relevance to ourselves and the degree to which it poses a threat to our physical or psychological well-being. If we ignore a stimulus, or view it as unimportant, than it won't trigger a stress response. Finally, we have to evaluate our available coping resources and decide how well they can meet the challenge. "We are all born with a genetic inheritance that links our body's ability to adapt" (Oliver & Bock, pg. 182). One might think of this amount of adaptation as a bank deposit which can be drawn on but not overdrawn. We have the ability to choose how much and when to make a withdrawal but we cannot make deposits. The size of some people's initial deposit may be a great deal larger than others according to their inheritance. While we can't add to the balance we can reduce our automatic responses to psychosocial stressors (Oliver & Bock, 1987).

According to Goliszek, "In psychology, the external force is a stressor and the strain it produces is referred to as stress" Goliszek, pg. 16). Exactly the same definition as initiated by Selye. In order to understand the concepts of stress management better, we need to recognize the three elements involved in stress. Goliszed breaks them down as

1. " The stressor, which is the event or situation that puts us on alert and gets us ready to respond.
2. Stress, which is a condition or state of imbalance between the stressful situation and our ability or capacity to cope with that situation.
3. Stress reactions, which are the physical and emotional responses resulting from exposure to stressful situations" (pg. 16).

The unifying concept of stress is that no matter what the source of the stress is, the results are always the same. It occurs regardless of the factors producing it. Although we all respond to stress events in exactly the same way, the degree to which we respond and the extent to which we are affected depend on the intensity and duration. Also, because we all perceive stressful events differently, what might be upsetting to one person may be of no consequence to another person.

Stress response can become a habit. A habit becomes stronger over time and responds whenever a certain mental cue is given. For example: Joan's husband John is suffering from Alzheimer's disease. He has reached the stage of wandering at night and forgetting how to get back into bed. The more sleep Joan loses, the quicker her stress reaction is to be activated. Soon she begins to anticipate the stress of bedtime and before long becomes anxious as soon as it begins to get dark outside. A chronic stress response is the end result of a conditioning process out of control and like any bad habit it needs to be controlled through changes in our attitudes, behavior pattern, and lifestyles (Goliszke, 1987).

Zarit and Orr agree with the Science News that there are few other problems which place so much stress on the family members involved as the stress which caregivers of Alzheimer's patients face daily. They routinely report stress-related symptoms, such as anxiety, depression, or feelings of fatigue. They are often angry or resentful, feel guilty about not doing enough, even those who spend 24 hours a day with the patient. The stresses they experience have many sources. Often they must assume tasks which the patient can no longer do such as dressing, bathing, and feeding themselves. They much watch the patient very closely to prevent elopement, fire from stove burners being

turned on and used improperly, small floods from faucets being turned on and left on,and the patient's own specific behavioral disturbances. They must forget what it means to sleep all night or have friends in to dinner or many of the other little things we all take for granted. While it is not enough that they give up all of their time due to increasing demands, they may be criticized by relatives who do not offer to assist and cannot know what it means to devote every hour of each day to a person who may not even recognize them (Zarit & Orr, 1985).

Karen Reever discusses coping and stress relative to Alzheimer's patients and their caregivers. She says:

> "Coping is not merely one skill but a process with historical components, outside influences, and feedback that modifies the coping process. The process begins with the existence of a stressful situation. For our purposes, Alzheimer's disease is the stressor. The sources of stress for a caregiver extend beyond the Alzheimer's victim, however, and can encompass other aspects of family life such as retirement, declining health, strains in family relationships, and cultural expectations of caregiving.
>
> Everyone has a range of personal and social resources for coping with stress. Personal

resources include income, education, health, and psychological characteristics such as a sense of mastery and high self-esteem. Social resources consist of formal services and informal support from family and friends.

To the outsider, it is often surprising to find one family reporting no strain despite the constant restlessness and verbal abuse by their relative with Alzheimer's disease, while another family feels unbearably pressured by their relative's forgetting a name or misplacing a pair of glasses. The family's perception of stress is a composite of not only the severity of the disease but also the family's ability to tolerate unusual behavior, its perception of its resources, and its confidence in its ability to mobilize those resources.

Once the stressful situation is defined, coping strategies are put into action. Although one cannot change the presence or course of Alzheimer's disease, a specific stressful situation can be changed or avoided. For example, a catastrophic reaction induced by frustration in buttoning a shirt can be avoided by switching to pullover shirts. Controlling the meaning one gives a stressful situation can be highly adaptive, as in the case where a wife

recognizes that her husband's hullucinations are not a result of craziness but due to the physical brain changes of Alzheimer's disease. For those problems that cannot be avoided, one can learn to manage the inevitable stress. Re-structuring the family to better meet the challenge of caregiving is a relatively sophisti-cated coping strategy.

By monitoring coping strategies, caregivers may decide to expand their resources, alter their perception of stress, or employ another coping strategy. The outcome is a dynamic level of adaption that aims to reduce stress" Reever, pgs. 23, 24).

Support Groups

There are a number of different ways of structur-ing support groups. They can be open or closed, which means they may or may not accept new members. They can vary in size and composition. Spouses and children of patients can meet separately or together in groups such as Al-Anon and Alateen. If the illness is such that the patient can attend, all three may meet together. It this proves unworkable, a third option is to have the family meet alone and include the patient at the end. The format may be structured or unstructured and can even in-clude a speaker occassionaly.

The way a group is structured will have implication for group interaction. Closed groups will develop more cohesion but there is likely to be attrition over time and eventually the group may become too small to be helpful. Open groups are faced with the problem of integrating new persons into a group where members have already established relationships with each other. It is easy in that situation for the new members to feel isolated or rejected and for the other participants to get impatient as the new member raises issues they had previously resolved. Groups which integrate children and spouses will face more problems developing cohesion, and there may even be conflict between generations on some issues. A structured format can provide a lot of information, but participants may not feel free to bring up personal matters. A completely unstructered group may run along erratically without allowing members to resolve important issues. A comfortable setting for the group meeting, serving refreshments, and other efforts to make meetings pleasant help to build group cohesion (Zarit et et., 1985).

One of the most important factors in the success of a support group is cohesion, Yalom (1975) defines cohesion as the degree to which members are attracted to and have a sense of having something

in common with others in the group. He believes that the development of this sense of cohesion develops from positive interactions and from identifying with others who have similar problems. It can be promoted by the leader through the development of positive group norms (Zarit et el., 1985).

The stress-management approach takes on new dimensions in groups, due to the curative properties described by Yalom (1975). Group members are often the best source of information on how to find good, low-cost in-home help or a doctor who can provide special attention to dementia patients and their caregiver, if that is the need. Alternatives for dealing with problem behavior can best come from a caregiver based on personal experience. People are more apt to try something new if the method is suggested by another caregiver who has been there rather than a counselor (Zarit et el., 1985).

Caregivers in a group get a sense of helping and being helped by each other. This support is central to the success of the group. Not only do group members problem solve but they serve an important role in validating each other's experiences. Taking care of dementia patients can be isolating and caregivers often feel they are experiencing it alone. Group members value each others support because they all have gone through similar circumstances and the

thought that others have felt the same way helps (Zarit et el., 1985).

Joseph Zinker who is the author of Creative Process In Gestalt Therapy, describes his idea of what a group is in chapter seven, "Groups as Creative Communities." He says "At its best, a group is not only a small, cohesive community in which people feel received, accepted, and confronted, but it is also a place and an atmosphere where people can become creative together. An ideal group is a place for testing one's growth boundaries, a community which members can develop at the highest levels of human potential (pg. 156).

A group cannot be accounted for simply by adding together the individuals in it. Every group is a unique system, with its own special character and its own sense of power: A conglomeration of energies exuded by individual members and interrelated in a systematic pattern. It is a whole, an entity, A Gestalt whose nature is greater than the sum of its parts" (pg. 156).

In Breaking The Stress Habit, Andrew Goliszek advises "Mutual help groups can aid us in finding the hope and personal support we need because they offer us the most important outlet for recovery - the understanding and help of others who've gone through similar experiences" (pg. 124).

Karen Reever who is program coordinator for both the Aid to Caregivers of the Mentally Impaired Aged project and the Family Respite Care Program at the Philadelphia Geriatric Center, and formerly was president and co-founder of the Alzheimer's Disease and Related Disorders Association of Los Angeles writes about support groups in the Pride Institute Journal. She says "The chronic nature of Alzheimer's disease lends itself to an intervention that emphasizes coping and support for the caregiver rather than rehabilitation and cure of the patient. A support group needs minimal professional involvement, making it an efficient way to use limited social service resources. Reciprocal helping in a support group gives isolated, overburdened caregivers a brief respite and an opportunity to socialize that they may otherwise not allow themselves" (Reever, pg. 23).

The 1930s appears to have been a time when the roots of many self-help groups, most still in existence today, began to take hold. Three of these which most people would be familiar with are Alcoholics Anonymous, Recovery, Inc., and the United Cerebral Palsy Foundation. Gartner lists 130 names and addresses of the over half million different self-help groups he states are functioning today. Gartner also gives excellent examples of why self-help groups or supports groups are so valuable. They are much more economical than professional and

institutional approaches; they are appropriate for a wide range of constituencies such as women, youth, the aged, and the physically handicapped; self-help activities have been useful in caring for chronic illness such as arthritis or cancer, etc.; and they increase feelings of personal power. Gartner lists six features which he believes are critical to self-help groups and distinguishes them from organizations such as unions, cartels, corporation boards, and service organizations. They are:

"1. Self-help groups always involve face-to-face interactions.

2. The origin of self-help groups is usually spontaneous.

3. Personal participation is an extremely important ingredient, as bureaucratization is the enemy of the self-help organization.

4. The members agree on and engage in some actions.

5. Typically the groups start from a condition of powerlessness.

6. The groups fill needs for a reference group, a point of connection and identification with others, a base for activity, and a source of ego reinforcement" (Gartner & Riessman, pg.7).

Self-help/support groups have developed largely because of the unwillingness or inability of professional organizations to deal with the average persons problems

and because of organizations overly intellectualized orientation, excessive credentialism, and limited reach in regard to various populations. The self-help orientation is much more activistic, consumer centered, informal, open, and inexpensive as opposed to the traditional professional models. The self-help approach stresses the aprofessional dimension, the concrete, the subjective, the experiential, and the intuitive. These statements do not reject the value of professional orientation, both are needed to fulfill the needs for a better human services practice (Gartner & Riessman, 1979).

Rational Emotive Therapy

Rational Emotive Therapy or RET as it is usually called, is an idea as old as ancient Greece. Both Epictetus and Marcus Aurelius expressed views in harmony with the modern practice of their concepts as established by Albert Ellis. Epictetus was quoted as saying "Men are disturbed not by things, but by the view that they take of them" (Gilliand et al., pg. 192). A quote which could just as easily have been attributed to Ellis or Albert Adler.

A brief overview of RET would describe it as a comprehensive approach to treatment and education that employs on theoretical grounds cognitive, emotive, and behavioral approaches. It advocates a humanistic, educative model of treatment, as opposed to a medical model and "consists of a theory of personality, a system

of philosophy, and a technique of psychological treatment" (Gilliland et al., pg. 192).

One of the most valuable contributions RET has provided is that it has emphasized, as well as clarified, the relationship between human thinking and emotion. It is obvious that an effective way to change one's emotions is by changing the content of one's thinking. Another contribution is its emphasis on the fact that it is not past events or traumas themselves that create human disturbances but one's interpretation of them. One aspect of RET which opens the practice up to the public is the fact that RET does not insist that a counselor be "the keeper of secret knowlege." It advocates that people can learn and change through a variety of means, including impersonal methods such as tape recordings, films, and lectures.

RET has several shortcomings according to some proponents of other psychological schools of thought. One would be its de-emphasis of the therapists relationship. Ellis claims that therapeutic change may occur even when the client actively dislikes the counselor. However, clients must stay in therapy long enough to understand the principles of RET and to begin to incorporate these principles into their lives. If a client feels misunderstood or not valuable it is possible that they may terminate counseling prematurely.

Another area of contention is the fact that RET proponents believe it is desirable to confront clients immediately regarding their irrational thinking and to make interpretations in the initial sessions in spite of a client's defensiveness. However, timing in terms of when a client is ready to listen is important and pounding away to make a point to a person with their defenses up will not be effective. Once a client feels a trusting relationship has been established they will be more inclined to listen to what the counselor has to say (Gilliland et al., 1984).

Some therapies such as Gestalt believe that in some cases it is more effective to let someone completely experience an emotion rather than trying to block the expression of it. They believe that sometimes more energy is expended simply by letting oneself fully experience and work through rather than against the feeling (Gilliland et al., 1984).

Another limitation which probably applies to all therapies is that RET is most effective with intelligent highly motivated, verbal clients who have good contact with reality.

Finally the RET therapist has a large degree of power because of the directive nature of the therapy and psychological harm is more possible in RET than with a less directive client centered approach (Gilliland et al., 1984).

When using RET to cope with the stress of being a caregiver for an Alzheimer's patient its use allows caregivers to identify and change their dysfunctional emotional responses without spending an inordinate amount of time and money in therapy. Its use helps them to learn to live with the reality of Alzheimer's disease and accept the fact that the person with a brain disorder is not capable of controlling their responses nor their emotions. Neither are they capable of conforming to socially acceptable norms. Their bizarre behavior is not volitional; the person is a prisoner in their own brain (Oliver & Bock, 1987).

RET points out that unacceptable behavior is the trigger or stimulus which effects the caregiver's emotions. This behavior cannot be controlled. However, by exercising choice concerning your beliefs about what is happening, you determine your emotional response. If one expects a demented person to act in a demented manner and they do, then the expectation is fulfilled. Once they are able to do this, they won't be taken by surprise and are less likely to feel anger. Reminding ourself to be realistic in our expectations will help us to accept those behaviors which upset us (Oliver & Bock, 1987).

It is inappropriate to view a demented adult as if they were a spoiled child. They may respond stubbornly as a way of saying "I'm not a child, don't treat

me like one, you can't make me do what I don't want to ." At this time, you can let yourself become furious, or not. It is more adaptive to accept the refusal and tell yourself the person is acting dementedly, not childishly or stubbornly. This is the only way they know how to act and I won't become angry but I can be annoyed. If you separate the annoying act, your response to it and the person who committed it, you will find the behavior easier to tolerate and generate less anger toward the person (Oliver & Bock, 1987).

While it is human to get angry, it is unproductive to stay angry. We exhaust ourselves and alienate others. Since anger is often generated by our insistance that the world meet our expectations, once again, it comes back to unrealistic expectations (Oliver & Bock, 1987).

RET asks caregivers to look at the situation of embarrassment and shame much as Al-Anon does. When the affected person placed you in an embarrassing situation one must ask themselves the question: Am I responsible for the person's behavior? No; Can the person control their behavior: No; Can I control the person's behavior: No; Is the person ashamed of their behavior? No. By being embarrassed you have taken on the obligation of being ashamed of behavior for which you are not responsible, that you cannot control, that

the person who committed the offensive act cannot control and for which they are not ashamed. The caregiver must stop thinking in terms of "should nots" since these are absolute demands which cause a person to upset themselves. It is best to say to oneself, "I wish he wouldn't do that" instead of saying "he embarrassed me." In reality, he didn't embarrass the caregiver, the caregiver was embarrassed by what they said to themselves about the incident. By stating a wish to themselves or a preference, they may feel annoyed or displeased but not shamed (Oliver & Bock, 1987).

Self-pity can also be alleviated through the use of RET principles. Feeling sorry for yourself at times is to be expected, however, staying sorry for yourself is debilitating and not in anyone's best interest. "Poor me" thinking says "I can't stand it any more" when in fact you are standing it every day. You can't change the situation but you can change the way you feel about it. By saying "I can't stand it" you feel miserable and coping becomes more difficult. If you change the phrase to "I don't like it but I can stand it" you ease the emotional burden and stop feeling sorry for yourself. You are then free to look for ways to make the situation more tolerable. Self-pity induces anger and frustration. Disappointment because you didn't get what you had hoped out of life

is a more adaptive response than anger or frustration because it doesn't lead to loss of motivation or self-defeating behavior. RET holds the belief that words not only express our thoughts and mirror our beliefs, they also shape and alter them. We can change beliefs and attitudes by changing the words we use. Since emotions come from our beliefs, we can change our feelings this way. If something becomes "hard" instead of "impossible," it then becomes achievable. The terms we use to describe a situation or how we feel need to be flexible in shades of grey instead of inflexible in back or white, otherwise we paint ourself into a corner with words (Oliver & Beck, 1987).

Guilt is an emotion caregivers must deal with daily as the disease progresses. Under stress it is natural to lash out at the Alzheimer's patient when they have gotten up for the fourth time that night or taken off all of their clothes and hid them for the third time that day or any of the other irrational acts which have become a daily occurrence. The guilt comes from thinking "I should have said this" or "I should not have done that." When we think we "should have" it becomes an absolute and doesn't provide for any exceptions and offers no allowances for human limitations. Far better to think I "could have" which allows for the possibility of finding

a better way; or maybe not, but it is a conditional statement, not an absolute. This allows for mistakes without an accompaniment of guilt feelings. Once a caregiver accepts the fact that they do not have control over the patient's behavior nor, at times, their own because they are only human and therefore infallible, inappropriate responses to inappropriate behavior will cease (Oliver & Bock, 1987).

When caregivers confuse perfection, selflessness and nobility with a decent standard of behavior, guilt becomes a punishment for not acting perfectly. A decent standard of living involves caring, sharing, and giving; it does not mean having the caregiver stretch themselves to the breaking point in total self-sacrifice. Everyone has limits and we must all decide for ourself what these limits are. If it means going away for a week-end once a month or going out to dinner and a movie once a week, it needs to be done without residual guilt. As soon as caregivers are able to turn "should haves" into "could haves," such as "I could have stayed home last week-end, but I chose not to," they will be able to make guilt-free decisions in the future (Oliver & Bock, 1987).

Being the caregiver to a person with Alzheimer's creates a great deal of anxiety. This is understandable: However, it can be controlled. There is a

big difference between dwelling on anticipated problems and being prepared for eventualities which may happen. If a person completely avoids thinking about something unpleasant, they tend to overestimate the threat. This increases the sense of vulnerability which triggers anxiety. The result is usually more frequent and more intense anxiety, more things perceived as threatening, more avoidance, and a constricted life (Oliver & Bock, 1987).

It is appropriate to be concerned; recognizing and accepting that unpleasant and possibly dangerous events may occur is adaptive. It causes you to make contingency plans to minimize the likelihood of such events or allows you to be prepared to deal with them should they occur. For example, in the case of a wife who is the caregiver and whose husband occasionally becomes uncontrollable, it would be practical for her to know the number of her local police station. Also, it would be well to have already obtained a sedative from the family physician in advance for her husband. By acknowledging the possibility of unpleasant things happening and providing options in case they do, the caregiver no longer has to spend time anticipating them and raising her level of anxiety (Oliver & Bock, 1987).

Depression is a response that all caregivers probably face at one time or another. Some are able

to adapt to a realistic sadness while others fall into a chronic depression. Sadness is a component of depression but sadness alone doesn't become the overwhelming, predominant mood and it doesn't exclude other emotions. Depression does. Feeling sad does not interfere with the ability to make rational choices and decisions, depression does. Depression becomes a pervasive all-or-nothing state of mind. It doesn't just happen due to a bad set of circumstances. It happens as the result of a persons view of themselves, the world around them and their ability to cope. It is an emotional overresponse to what is perceived as a crushing blow. Since the evaluation of a situation is within a person, not in the event itself, it is within a person,s power to change it (Oliver & Bock, 1987).

Stress is an end-result caregivers are apt to have to deal with. It may seem strange to them that while they lose their appetite, develop high-blood pressure, and catch every bug going around, their affected spouse remains in good health physically. Stress, however, is just the wear and tear on a caregiver's body caused by the challenges of living with an Alzheimer's patient which that patient does not experience. To reduce stress RET provides a fourfold process involved in realistic acceptance of life as a caregiver.

They are:

1. Acceptance of the fact that you can change how you feel.

2. Acceptance of the disease process and its downhill course over an indeterminate period of time.

3. Acceptance of the patient and their full humanity.

4. Acceptance of the effect your loved one's illness is having on your life (Oliver & Bock, 1987).

RET is called cognitive restructuring which means that by examining your evaluation of what is happening, and changing it to a more reasonable and realistic evaluation, emotions become less extreme and therefore more adaptable. Without the additional weight of stress, anger, anxiety, guilt or depression, the caregiver has more time and energy to develop flexible coping skills which will allow for improved care for the Alzheimer's patient and a better more healthful life for them.

Chapter 2

Theoretical Orientation

I believe a vast majority of people would agree with Webster's general defination of mental stress as being "a mentally or emotionally disruptive or disquieting influence." A simple to the point statement. However, having agreed on this premise, there is a vast range of individual perceptions regarding what is stressful and what is not. In the event an agreement could be reached by a group of people, regarding stressors, the degree of stress produced by these stressors would, no doubt, run from scarcely noticeable to extremely disturbing. In my opinion, this discrepancy in how stress is perceived is due to the fact that people's reaction to stress is much like their reaction to pain, subjective. The subject of stress is discussed in a different chapter from the viewpoint of several people prominent in the field of stress research. Each chooses to approach the subject in a slightly different context but for the most part, all are in agreement as to how stress occurs if not how to measure it.

Since the focus of this thesis is not so much on what stress is clinically, but to what degree can a person's perceptions of their stress level be reduced through group support, I have also referred to quotes from various experts in the field of support group therapy. All of the authors were chosen randomly in

order to escape bias, and yet all are in agreement; group therapy or support groups in general are beneficial in the reduction of stress in individuals, some more than others. What we must keep in mind, however, is that in this case we are interested in the opinion of the real experts involved; those people experiencing stressful situations who have been interviewed regarding their own perception of their personal distress level. In the end, for them, their reality is their perception of just how they feel, not how they should be expected to feel.

It is my contention that given a chance to participate, most people will perceive a reduction of stress and a lifting of their spirits when actively participating in a support group. Being able to share a burden usually appears to make it more endurable. For some of the people involved, their support group may be the only place they have where they can share their unique problems with like-minded individuals.

My expectation is that the survey I will be conducting will bear out my hypothesis that support groups reduce the stress experienced by caregivers of Alzheimer's patients. While one might expect both men and women to benefit equally from attending support group meetings, I believe that the survey will find men receiving less emotional release from the meetings than women. Also, the expectation is that the survey will find men to have

reduced their emotional stress more than women when placing their spouses in a nursing home.

Another factor which might be expected to occur if the survey is to correlate with available literature, is that most of the caregivers will have experienced a decline in health after they have provided two or three years of caregiving to an Alzheimer's patient.

In Stressful Life Events Dohrenwend offers several hypothesis about the life-stress process. The one which most closely parallels the coping process of caregivers for an Alzheimer's patient indicates that stressful life events, moderated by preexisting personal dispositions and social conditions that make the individual vulnerable to the impact of life events, cause adverse health changes. This speculation can best be proved or disproved in a small way by the participants of the survey portion of this thesis (Dohrenwend & Dohrendwend, 1981).

Chapter 3

Research Methodology

Babbie stated that "The utility of a social theory or social correlation is enhanced by its generalizability. The larger the scope of phenomena it explains, the more useful it is" (pg29). This author agrees that a wide scope of subjects should be polled in order to collect an overall view. This was the reason for including all support group participants who wished to be interviewed in the research rather than those of a certain sex, age range, etc.

The interview schedule used for this project refers to the word caregiver several times. For clarification, caregiver in the context of this thesis and the survey, refers to that person who either provides care for the Alzheimer's patient in their home or who supplies the major source of economic and/or social support to the institutionalized patient.

The sampling of the population utilized for this study were caregivers of varing ages, the majority who were between 60 and 80 years old, with the oldest being 83 and the youngest 49. There were husbands, wives and children of Alzheimer's patients, however, a preponderance of wives attended the support group meetings during the times I met with the groups and therefore, as you will see, wives comprise the majority of the caregivers interviewed.

The St. Louis Alzheimer's Association allowed me to attend area support group meetings with the permission of the group's coordinator and that of the members. This survey covers North, West, and South County, the mid-town area and St. Charles County. The caregivers in these groups seemed pleased to cooperate with the survey and were most generous with their time in an effort to provide information which might be of assistance to other caregivers with less experience and understanding.

In conducting this survey, all primary care members of each group were used with the exception of two members who declined to participate. It was felt that the best way to get a representative sample of area caregivers was to interview each member rather than an arbitrary number of people from a particular type, i.e., husbands, wives, or children. This method provided a general range of response which is indicative of the area population.

As the hypothesis of this thesis is relative to the stress experienced by caregivers, the survey questions are geared toward this end. It allows the caregiver to choose a range of zero to one hundred to indicate their stress level or lack of one on subjects such as degree of financial stress, depression due to stress and health related stress. It also provides

information regarding the caregiver's relationship, age, and sex. Some questions may appear to be out of step with the nature of the survey such as "what country was the caregiver born in ?" This question was asked in order to address the speculation that people born in Europe may not be as easily stressed as native born Americans due to the Europeans's previous lifestyle. Another question which might provide cause for wonder is "what is the sex of the caregiver?" This was included in order to assess the theory that it is easier and/or more likely for a female to provide care than a male.

In order to ascertain each interview placed the same emphasis on all questions and answers, the survey was conducted in total by this author. The reason I chose to use a questionnaire, administered by myself rather than a mail survey, is three-fold. First the completion rate is substantially higher than a mail questionnaire, secondly it provides a guard against confusing questions and thirdly it is possible to observe the respondents general reactions to questions which might be considered too personal as stated and, therefore, rephrase them (Babbie, 1973).

Both the subject and the interviewer used an interview schedule in order to be sure the questions were understood completely. At the outset of the project

it was decided that a tape recorder would be used, however, after the completion of the second interview, it became apparent that this would be unnecessary as the stories were sufficiently interesting and dissimilar as to be retained without a playback.

All survey instruments have certain positive features and certain liabilities. In the case of this particular survey, I believe that on the positive side it allowed for questions to be clarified and answers to be expanded upon which would not have been possible had other survey techniques been used. Another positive aspect is the fact that all respondents were questioned by the same person which provided consistent coverage of all respondents. However, a liability which could occur is that the same person could have a built in bias which was not evident but which could color the answers. It is also possible that the responses to one interviewer might be different than those to another which might also elicit different information on the interview schedule. All things considered, however, this author believes the most effective way to conduct any survey is through personal interaction between the surveyor and the respondent regardless of how these respondents are chosen to be interviewed.

QUESTIONNAIRE

1. What is your relationship to the Alzheimer's patient?
2. What is the sex of the caregiver?
3. What is the age of the caregiver?
4. What country was the caregiver born in?
5. Do you provide care for this person in your home?
6. If so, do you have outside help to assist?
7. If you provide home care, what do you anticipate will be the deciding factor which will necessitate placement?
8. If you do not provide home care, did you for a period of time and if so, how long?
9. If institutionalization was necessary, what was the deciding factor?
10. How long has it been since the initial diagnosis of Alzheimer's Disease?
11. When did you first become aware of Alzheimer support groups?
12. How long was it between diagnosis and your first visit to a support group meeting?
13. When did you attend your first support group meeting?
14. What were you hoping to find in a support group?
15. What problems did you bring to the group regarding your role as a caregiver or significant other?
16. Did you receive assistance with any of these problems?
17. If so, what and how?
18. Do you feel the assistance you have received from the support group could have been found through another source?
19. If, so what prevented you from using this source?
20. Do you intend to continue participation with your support group?

21. Do any other family members or significant others of the Alzheimer's patient attend a support group?

22. Do you have a confidant to share your day to day ups and downs with? If so who?

23. Are you and other family members in agreement regarding the care and treatment of the Alzheimer's patient?

24. Is there one person who generally makes the decisions regarding the day to day and overall care of the patient and if so, are you satisfied with this arrangement?

25. If the decision maker is you, how do you feel about this; if it is someone other than yourself, how do you feel about this arrangement?

26. On the stress scales below rate where you believe you fall between a 0 indicating no stress to a 100 indicating maximum stress as you perceive it.

a. Level of depression before diagnosis of Alzheimer's.

0 100

b. Level of depression after diagnosis of Alzheimer's.

0 100

c. Perception of overall health before diagnosis of Alzheimer's.

0 100

d. Perception of overall health after diagnosis of Alzheimer's.

0 100

e. Amount of perceived financial stress before diagnosis of Alzheimer's.

0 100

Chapter IV

Research Results and Conclusions

The conclusions reached after interviewing thirty members of various St. Louis area support groups were not quite what I had anticipated. I had expected to find more people in immediate financial need due to the nature of the disease, however, only one wife struck me as really having to struggle. She was trying to keep her lifestyle intact as best she could until the Homestead Act came into effect in October. She did this by working at a job which paid just enough extra to maintain her and her husband plus hire a sitter for him five days a week. She was left to cope the rest of the time by herself except the night she attended her support group meeting. This is not to say that finances were of no concern to the rest of the participants, however, they all appeared to be managing fairly well at the time I spoke with them.

Only two people were financed completely by Medicaid, one by VA and several who received assistance from the Alzheimer's Association for Day Care expenses. The rest of the caregivers managed on savings, pensions, and Social Security.

The breakdown of care and caregivers was much as expeced due to the nature of American society and the ratio of male to female longevity. Of the group of thirty respondents, 57.9% were wives, 15.8% were husbands and 26.3% were daughters caring for their mothers. There

were no sons who were primary caregivers, however two were in attendance at meetings with their mothers who were caring for their fathers. Of these wives 57.1% care for their husbands in their home, 33.3% of the husbands care for their wives at home, and 66.7% of the daughters care for their mother at home. Day care plays a large part in the lives of 33% of these caregivers. Several of the caregivers expressed the opinion that if it were not for day care to give them some respite they would be unable to maintain their loved one at home. There was very little sharing of responsibilities among families either due to lack of desire or more often due to the fact that there were no other family members locally to share the burden of caring for the Alzheimer's patient.

As information indicated most (96.7) of the respondents intend to continue participation in their Alzheimer's support group. Only 3.3% were unsure of future attendance. I found that 6.7% intend to continue their participation with their group in order to provide new members the benefit of their experience.

When inquiring of the caregivers the reason for attending their first support group meeting the answers were fairly uniform. 83.5% of the caregivers came to learn more about the disease of Alzheimer's and how other people cope with it. 9% came specifically to have

someone to talk with about their problems who empathize with them, and 7.7% of the caregivers came to learn how to cope with the stress created by lack of sleep due to the wanderings of the Alzheimer's patient a night. Several of the caregivers continue to work days while spending their nights putting their spouses back to bed over and over night after night.

As the main theme of this thesis is stress, following on the next two pages is a breakdown of each of the individual stress ratings as perceived by the participating caregivers regarding their personal experience with stress related depression, health issues, financial situations and stress relief provided by their support group.

Question 26a asks the caregiver to rate their level of depression before the patient was diagnosed with Alzheimer's disease. All stress levels range from a low of 0 to a high of 100%. The individual percentages for 26a are:

0% 0% 0% 0% 20% 0% 0% 15% 0% 0%

0% 0% 25% 0% 30% 0% 0% 5% 5% 0%

0% 0% 20% 0% 15% 0% 0% 5% 10% 15%

Question 26b asks the caregiver to rate their level of depression after the patient was diagnosed with Alzheimer's disease. The individual percentages for 26b are:

10% 60% 65% 50% 0% 30% 50% 25% 60% 50%

60% 70% 25% 0% 40% 50% 0% 30% 10% 30%

35% 25% 5% 75% 25% 49% 0% 55% 30% 25%

Question 26c asks the caregiver to rate their perception of their overall health before the patient was diagnosed with Alzheimer's disease. The individual percentages for 26c are:

0% 15% 25% 0% 0% 0% 0% 50% 0% 15%

0% 15% 10% 0% 25% 0% 0% 10% 5% 0%

0% 0% 50% 0% 0% 45% 15% 0% 25% 0%

Question 26d asks the caregiver to rate their perception of their overall health after the patient was diagnosed

with Alzheimer's disease. The individual percentages for 26d are:

0%	40%	50%	50%	0%	0%	0%	50%	30%	25%
30%	35%	10%	0%	25%	50%	0%	30%	5%	0%
0%	50%	0%	0%	60%	25%	0%	50%	35%	0%

Question 26e asks the caregiver to rate their perceived financial stress before the patient was diagnosed with Alzheimer's disease. The individual percentages for 26e are:

0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	15%
0%	0%	0%	0%	10%	0%	0%	5%	5%	0%	0%
0%	10%	0%	15%	0%	0%	0%	0%	0%	0%	10%

Question 26f asks the caregiver to rate their perceived financial stress after the patient was diagnosed with Alzheimer's disease. The individual percentages for 26f are:

0%	0%	10%	50%	0%	0%	55%	75%	30%	20%
0%	95%	0%	0%	50%	25%	0%	15%	30%	0%
40%	30%	0%	60%	15%	30%	0%	45%	25%	35%

Question 28 asks the caregiver if they feel being a member of a support group has decreased their overall stress level and if so, how much. The individual percentages for 28 are:

30%	45%	50%	10%	30%	25%	50%	80%	60%	50%
70%	95%	15%	75%	50%	50%	20%	59%	50%	10%
30%	50%	45%	20%	95%	50%	75%	20%	55%	40%

In conclusion, it would appear that the survey results were quite varied on most of the perceived stress evaluations. The question eliciting the most uniform results was in regard to the caregiver's level of depression prior to the patient's diagnosis of Alzheimer's Disease. Those people who did not answer zero on the survey indicated the depression prior to the diagnosis was due to the uncertainty of what caused the behavior in the loved one. After diagnosis one wife stated that she was relieved to at least know there was a reason for the bizarre behavior her husband was exhibiting. Also, it would appear the vast majority of the support group participants experienced a high level of stress reduction from the group meetings according to the survey questionnaire.

It is my conclusion from the results of the survey instrument and my conversations with the various group members that Alzheimer's support groups are a valuable tool available to caregivers in need of major support or simply empathic conversation.

Chapter V

Summary and Recommendations

The result of my research into the lives of Alzheimer's patients and their caregivers has only served to reinforce my position that this disease is one of the most devastating illnesses affecting families today. There are few diseases of such magnitude which continue to so baffle medical science 83 years after identification.

Ten years ago the average person had never heard of Alzheimer's. Several of the respondents whose family members had been diagnosis eight to ten years ago stated that the only information available to them at the time was the book "The 36-Hour Day." Support groups were just beginning and people had no idea where to turn for help. Now that the disease has become well publicized by the media; public figures such as Rita Hayworth and Norman Rockwell have been identified as having died as a result of it; the public stigma has almost been erased in most people's minds. Families no longer feel the need to hide a diagnosis of Alzheimer's in the family in the same manner people used to hide insanity, alcoholism, illegitimate children, all of which were considered a disgrace.

The more information which becomes available about the symptoms and progression of this disease, the better the patient can be cared for either at home or in a nursing facility. One example of forward thinking is

open wards with a circular walkway and a locked door which allows institutionalized patients the freedom of movement they require without fear of injury or elopement. This is a giant step forward from the days when all Alzheimer's patients were overmedicated and/or physically restrained in a chair to maintain peace in their environment.

It would seem that a disease which affects so many lives each year would be a priority with government researchers and pharmaceutical firms. Loss in revenue to the government and profits for the successful pharmaceutical firm should be strong enough incentive for them to devote as much manpower and money as it takes to find a cause and effect a cure for this 100% fatal disease. I know of only very few diseases that one can say positively "the patient will die as a result of this disease" and certainly none that claims as many victims every year.

It is my hope that family members will realize the enormous good which may some day result in their participation with their local brain bank and while it will not reduce the suffering they have endured, it will enhance the lives of many other family members and victims of this catastrophic condition.

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