A psychosocial study of the effects of Alzheimer's disease

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A PSYCHOSOCIAL STUDY
OF THE EFFECTS OF ALZHEIMER'S DISEASE

A Thesis
Presented to
the Faculty of the School of Social Work
San Jose State University

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
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May, 1985
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This thesis is dedicated to the memory of my father, Louis Haskel, whose kindness, wisdom and values, will always be remembered, and to my grandmother, Fannie Haskel, whose suffering during the last ten years of her life, inspired its writing.

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Chapter 1

INTRODUCTION

Purpose of the Study

The objective of this study is to examine the psycho-social impact of Alzheimer’s Disease. Psychosocial impact refers to the psychological and social factors which affect caregivers and family members of the Alzheimer’s patient. This will be accomplished by focusing on how families and individuals cope, when a family member is suffering from this disease. The purpose of this study is to identify how the needs of caregivers and family members are being met and how Alzheimer’s Disease affects them both emotionally and socially.

A secondary objective of this study is to present alternative methods of intervention to those which currently exist and to promote education and awareness to professionals, service providers, and the general public so that they can better combine their resources to provide more effective intervention.

The intent of this study is to help fill this informational void, and perhaps encourage others to begin studying the effects of Alzheimer’s Disease from the standpoint of the caregiver and the family.
Significance of the Study

Alzheimer's Disease not only takes the life of the patient, but it is also a major social problem which cannot be ignored. As the elderly population increases in the United States, so will the number of Alzheimer's patients. This will put an increased demand and strain on existing support services. Therefore, there exists today an increasing need for research into the psychosocial aspects of this disease.

This study is significant because there is a need to identify and document the psychological and social stressors which impact on caregivers and families of Alzheimer's patients, so that appropriate efforts can be made to deal with them. This can be accomplished through greater utilization and networking of existing services and exploration of new areas of intervention. Areas of intervention need to be explored in an effort to develop adequate and appropriate services to Alzheimer's patients and their families.

Class and financial status are important factors in obtaining an early and correct diagnosis of this disease. Status also effects the ability of individuals to cope with the many complexities of Alzheimer's Disease, both physical and psychological. Certainly, this is an area that deserves more attention and investigation. Of particular interest are the effects of family support systems that exist, or do not exist, among the different classes and how these systems
contribute to the management and progression of Alzheimer's Disease. Environmental influences should also be studied and taken into account, in connection with the prevalence of this disease among the different classes. This too may be a clue to its etiology. It is evident, however, that adequate social research into these aspects of this disease are lacking.

Perhaps the greatest significance of this study is the fact that most studies in the past have focused on medical research of the disease and the physical deterioration of the patient. Therefore, there is little information available today on how this disease affects caregivers and families.

**Background of the Problem and Problem Statement**

Alzheimer's Disease is a progressive deterioration of the brain. It was first identified by Dr. Alois Alzheimer, a German Neurologist and Psychiatrist, in 1907. Dr. Alzheimer's discovery of neurofibrillary tangles separated Alzheimer's Disease from the other forms of dementias. His discovery opened the door to the diagnosis and study of the disease.¹

Alzheimer's Disease is responsible for the intellectual impairment of 500,000 to 1.5 million American adults and that it can strike its patients in old age, middle age and sometimes in early adulthood. It is, however, pre-

dominantly a disease that takes the life of its patient in old age. The youngest patient is reported to have been 27 years old. It is estimated that up to 10% of all people over the age of 65 and one out of five people over the age of 85 are afflicted with this disease.  

According to a recent Congressional Report, this disease costs the nation an estimated $20 billion in nursing home and other medical costs each year.  

"50% to 60% of the 1.3 million people in nursing homes constitute Alzheimer's patients, accounting for more than half of the $25 to $26 billion spent on such care." These dollar costs do not come anywhere close to the costs related to human suffering and anguish that is experienced by the patient and their loved ones. This is a slow insidious disease that frequently takes years to progress. Along with this progression comes the loss of productivity and a deep sense of helplessness and despair to all concerned.

The first signs of Alzheimer's Disease begin with simple forgetfulness. Initially, forgetfulness may be overlooked or put off as being a temporary problem. Many times it is thought to be quite amusing. In the past, forgetfulness was thought to be a natural process of old

2Ibid.
4Ibid.
age. In Alzheimer’s Disease, however, this forgetfulness becomes more pronounced and affects all areas of functioning and cannot be easily overlooked. For the patient, it becomes a serious problem even in its beginning stage, due to intense feelings of embarrassment and fear. As the disease runs its course, the patient finds it increasingly difficult to put thoughts into words. In an effort to minimize its effects, he or she becomes quite proficient at covering it up. This further complicates the disease by preventing early diagnosis and causes the patient to experience various degrees of depression, feelings of confusion, lack of understanding and increased difficulty in coping. For the majority of patients, the disease continues to develop into its more progressive stages of deterioration before the individual is diagnosed as suffering from Alzheimer’s Disease.

"The symptoms include gradual, progressive declines in memory, learning, attention, and judgment; disorientation in time and space; difficulties in word finding and communication; and personality changes. Alzheimer’s patients undergo a gradual general debilitation, become unable to care for themselves, and eventually die."\(^5\)

Late diagnosis of the Alzheimer’s patient prevents researchers from following the disease from its early stages of onset. This inhibits them from carefully monitoring the progression of the disease and gaining much needed information

as to its etiology and its eventual cure. Unfortunately, it is quite difficult to make an early diagnosis of Alzheimer's Disease because there are so many factors involved.

The only way to make a definitive diagnosis of this disease is through an autopsy of the brain after death. In addition, there are over 50 conditions that can cause symptoms that mimic Alzheimer's Disease and the other types of dementia. About 20% of individuals diagnosed as having some form of dementia can be reversed once the cause is identified.\(^4\) Alzheimer's Disease, on the other hand, is irreversible and will ultimately lead to the death of its patient.\(^7\)

As the disease progresses from simple forgetfulness to a profound loss of function, the Alzheimer's patient looses most vital bodily and mental abilities— all the human functions that are necessary to sustain normal mental and physical health. In the late stages of the disease, the brain atrophies. The individual is unable to communicate with people in their environment, cannot recognize close family friends, is not aware of their surroundings, and has no concept of what is happening to him or her. The patient is left only with intense confusion and eventually ends up in a total state of helplessness which requires constant custodial care. Not all patients progress to the end stages of this  

\(^4\)Steinke, M.D., Gary W., Overview of Common Geriatric Problems, p. 6, unpublished paper.  
\(^7\)Aronson, op, cit., p. 6.
disease at the same rate nor do they all die at the same stage. The disease may run its course over a period of many years, moving slowly from stage to stage. During this time, the patient usually experiences a great deal of depression which further complicates its insidious effects. Depending on which part of the brain is affected by the disease, some patients die earlier. Death may be the result of heart failure, stroke, kidney failure, infection, or other medical problems — all brought on by inadequate brain function and its affect on bodily functions. Others linger to the very end with no awareness of what is happening to them — suffering from a total loss of cognitive functioning. The following list identifies the various stages of Alzheimer's Disease. It is important to note, however, that not every patient experiences each of these stages. They vary according to the individual patient. Progression may be similar, but does not necessarily follow the same course as indicated below. The following list covers many of the stages and complications which can occur.

"Early Stage of Dementia"

1. Difficulty in focusing attention to important events.
2. Declining interest in the environment and present affairs.
3. Indifference to ceremonies and courtesies of social life.
4. Forgetting to use nouns in speech (may not be able to recall).
5. Vague, uncertain, and hesitant in initiating action.

Advanced Stage of Dementia
1. Shows obvious defects in memory, retention and recall.
2. Hesitates in response to questions.
3. Displays disorientation as to time; confuses night and day.
5. Resents interference of younger people.
6. Loses important papers; loses way home in familiar community; forgets to pay bills; lets housekeeping chores slip and newspapers pile up; does not dispose of garbage.
7. Does not take medications.
8. Forgets appointments, usual organizational meetings, dates, holidays, and birthdays.
9. Loses possessions and claims that they have been stolen; may name person who took them.
10. Unable to retain simple directions.
11. Neglects use of health and hygiene measures.

The Later Stage of Dementia

1. Disorientation as to place; wanders aimlessly, gets lost, and loses way to bathroom.
2. Loses possessions.
3. Disorientation as to person; forgets personnel, misidentifies personnel as familiar person, may not recognize familiar person, develops illusions.
4. Deterioration in motor ability; writing deteriorates to illegible scribble; problems in dressing, eating, and getting to the toilet.
5. Sexual exposure; immodesty.
6. No time sense; cannot recall meals or earlier events in the day.
7. Communication difficulties; incoherent, forgets words; nonverbal language principal means of communication.

Final or Terminal Stage

1. Incontinence of feces and urine.
2. Severe motor control impairments, with loss of ability to walk or make purposeful acts.
4. Somnolence.
5. Inability to communicate.
6. Little or no response to stimuli.
7. Susceptibility to infections and injury.
8. Inability to recognize family.
9. Marked loss in weight unrelated to caloric
intake.
10. Little or no human characteristics."

The preceding list is important because it clearly identifies the many aspects of this devastating disease and its terrible consequences. The anguish of the patients and the pain and helplessness of their loved ones, who must share this experience with them, can be easily understood.

Alzheimer's Disease shows no prevalence among any cultural or ethnic group and has not been shown to be more common among any of the classes of our population. It strikes the rich, middle class and the poor, all of whom must deal with its devastation. The strain on the family, both emotionally and financially, is profound. Emotionally, the family must deal with the death of a loved one far in advance of its actual occurrence. For them, the patient dies twice - first in the deterioration of mental and bodily functions and then again in actual death. Along with this comes feelings of helplessness, guilt, depression, and anger. Financially, the costs are staggering - doctor bills, hospital bills, nursing care, medications, home health care, and for many the horrendous costs of convalescent home care.

Social class and financial status affect the management and progression of the disease. The wealthy have no problem with medical costs, obtaining information, and obtaining and

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utilizing outside resources needed in the management of Alzheimer's Disease. Depending on individual motivation, access can be gained to current interventions and even to the newest experimental procedures. The wealthy can also afford to pay for counseling to take care of their own psychological needs during this period of great stress. The middle class suffers a great deal because the costs can wipe them out financially - their income making them ineligible for public assistance until they have depleted all of their resources. This does not allow them the flexibility to obtain and utilize necessary services and interventions.

In California, the poor are covered for some medical costs, and have access to medical care services which are covered by Medi'Cal and Medicare. Some of the support systems which are needed when faced with a catastrophic disease (e.g., home health care, convalescent home care, and non-profit or public mental health facilities), are also available. Recent cuts, however, in health care benefits and social services to the poor, and those elderly who rely on Social Security, do not provide for adequate long term care and intervention. It is also interesting to note that just because services are available to the poor and the elderly, does not mean that they are able to or do take advantage of them. This is often due to the many physical and cultural barriers that exist between these individuals and the institutions that are set up to meet their needs.
The problem with the poor is compounded because of low levels of education. People frequently do not understand what is available to them with respect to existing services, and they may not know how to take advantage of these services.

Minority groups, guided by the norms of their own culture, will often themselves, care for family members who become "senile." It is a part of their culture to care for the elderly, and they often work around what is perceived as senility or the normal effects of old age. The result of this is that these elderly do not get diagnosed, because the family often feels that there is no reason to take the person to the doctor. These elderly, when they are diagnosed, are often diagnosed as an aside. The family, for example, may bring them to a doctor because of a pain that they are complaining of, and the doctor finds signs of Alzheimer's Disease during the examination. Other cultural differences lead to the treatment of family members in the home, with various "herbal secrets" passed down from previous generations. Home treatments and other remedies prevent diagnosis, and the use of existing support services.

Ethnicity also has an effect on aging. It has been shown that the Chicano, for instance, has a shorter life span then the Anglo.

*Dr. Ismael Dieppa Dean, School of Social Work, San Jose State University, San Jose, California.*
"Minority Persons have a much shorter life expectancy than Anglos. The average for all minorities is less than 60, whereas for Anglos, it is over 70."¹⁰ This is due to the fact that they suffer from more diseases, experience the devastation of poverty and because they have a long tedious work life in occupations that take a great toll on them, both physically and emotionally. Most work is done in the fields doing seasonal farm work, in the factories doing boring tedious work, or in other menial, low paid jobs that provide little opportunity for the "good life" that the middle and upper classes in our society enjoy. Because of the harsh circumstances of their lives, Chicanos age earlier than Anglos, and along with this they do not have adequate health care. In addition to this, present programs, such as Medicare and Medicaid are, inadequate and do not meet the needs of this population. Many, who would otherwise utilize these services, are not entitled to them because of a sporadic work history and long periods of unemployment making them ineligible for Medicare benefits. Others, who may be living in poverty, fall through the "cracks" because their income is not low enough to allow them to collect Medicaid benefits. Along with this, the cost of medications are prohibitive and many of those who can qualify for medical care are unable to treat their illnesses because

they are not covered for many medications and cannot afford to pay for them. Cultural differences and language barriers also prevent Spanish speaking and other monolingual ethnic minority elderly from obtaining services.

"Monolingualness prevents older minority individuals from obtaining the benefits and services for which they are eligible. Cultural differences impede participation in mainstream services because the "cues" are not the same; the minority elderly cannot relate to the manner in which Anglo society delivers services."11

Most elderly Chicanos have a great fear and mistrust of doctors and hospitals. This often prevents them from seeking medical care early in an illness. Much of this distrust exists because of the lack of bilingual/bicultural health care personnel in the clinics.

"Differences of language and culture prevents older minority individuals from obtaining the benefits and services for which they are eligible. Cultural differences impede participation in mainstream services because the "cues" are not the same; the minority elderly cannot relate to the manner in which Anglo society delivers services."12

By the time they do go for help, an illness might be quite far advanced making it more difficult to recover quickly and fully. They also find it very difficult to get medical care because they lack transportation to medical clinics. This is especially true in the rural areas. The elderly in this population also lack adequate nutrition which frequently contributes to their health problems.

11Ibid.
12Ibid.
"The morbidity patterns of elderly Chicanos reflect their histories: middle and upper class are afflicted with heart disease and cancers much as are their Anglo peers; former agricultural laborers suffer from chronic diseases, years of poor diet and the absence of health care reminiscent of those borne by Philippino farm laborers. Overall, Chicano elderly are thought to under-utilize services, choosing to ignore conditions until they become incapacitating."\textsuperscript{13}

Cultural beliefs as to the causes of illness also stand in the way of prompt medical attention. Home remedies and reliance on the cures offered by the "curanderos" often take precedence over seeking prompt medical attention.

"Within the Raza/Latino subcultural groups, diseases are attributed to various factors: (1) spiritual or supernatural punishments; (2) the hot and cold imbalance in the human body; (3) magical origin, such as witchcraft (4) the dislocation of internal organs (5) natural disease; and (6) emotional and mental origin (Clark, 1970, p. 164; Brownlee, 1976; p. 181; Dorsey & Jackson, 1976, p. 43; Baca, 1978, pp. 67-71; Spector, 1979, pp. 251-254)."\textsuperscript{14}

Thus, as a result of a lifetime of poverty, discrimination, hard work, inadequate nutrition, cultural beliefs, lack of obtaining adequate medical care, housing, and educational opportunities, the health needs of the minority elderly, particularly the Chicano elderly, are not being met. All of these factors are tied into the low economic status and discrimination that exists for the Chicano and other minority elderly in our society today.

When a family is faced with the care of an elderly

\textsuperscript{13}Ibid.

member who is suffering from dementia, the strain on them both emotionally and financially is profound. This is especially true for Chicano and other minority families who must deal with the problems that face their elderly without the financial resources and support systems which may exist outside of the family.

Dementia takes its toll on the elderly due to various forms of disease which effect the once healthy brain. Contrary to popular belief, which has persisted for many years, dementia is not the normal result of aging. The normal result of aging is a healthy, functioning brain, and not pronounced memory loss and inability to function.

The concept of senility among Anglos and Chicanos is very similar. Both groups look upon senility or dementia as being the natural result of old age. In speaking to both of these populations, this researcher found that those who were more informed are beginning to become aware of the fact that senility can be caused by diseases that effect the brain. Most people, however, stil believe that it is the natural result of old age and that nothing can be done about it. Others believe that dementia is caused by hardening of the arteries.

According to Dr. Steinke, a leading gerontologist in San Jose, arteriosclerosis is only one cause of dementia along with what he estimates to be about 50 other causes. Of those dementias that are reversible, Dr. Steinke states that
the most important one is what he calls the "pseudo dementia of depression." According to Dr. Steinke, this type of depression is very common and can be too easily overlooked and treated as an organic disease when in fact it is not. In giving an overview of the history of dementia, Dr. Steinke stated that:

"In 1900 4% of the population in the United States was over the age of 65. In 1980 the percent of elderly had grown to 11%. While 5% of Americans more than 65 years of age are afflicted by dementia to the extent that they are unable to care for themselves, another 10% suffer from a mild degree of this disorder. Without effective treatment or prevention, the prevalence of dementia may triple in the lifetime of our grandchild-ren." 15

Thus, it can be seen that dementia is a major social problem which effects all the members of our society. Symptoms of dementia, whether reversible or not, can leave the individual in a physical state that drastically alters their intellectual functioning. Patients loose their ability to remember past and present events in their lives and experience various degrees of personality change. Most often, they are not able to care for themselves or provide for their own needs.

Dr. Steinke states that dementia:

"...is a broad term used to describe a condition wherein an individual exhibits specific disabilities of problem solving, memory, orientation, appropriateness of behavior in relationship to the environment. Other characteristics of dementia are amnesia, decreased ability to learn, altered attention span, lack of spontaneity, paucity of ideas, apraxia, changes in consciousness,

15Steinke, Dr. Gary W., Overview of Common Geriatric Problems, Valley Medical Center, San Jose, CA, unpublished paper, p. 6.
disorientation, effective disturbances, paranoia and
ingnosis. "

It is easy to see how these kinds of deteriorations can
lead to dependency and the need for constant custodial care.

Research Questions

The main focus of this study is to assess the ability of
caregivers and family members to cope with the psychosocial
impacts of Alzheimer's Disease.

The following psychological factors will be examined in
this study:

1. Stress. Are there increased levels of stress due to
the progression of Alzheimer's Disease and the inability
to change its course? Is stress also experienced due to
an inability to cope with the daily care and needs of the
patient?

2. Depression. Do caregivers and other close family
members experience depression? Do they find themselves
unable to concentrate and do they experience a marked reduction in social and work related activities? Do caregivers
experience other signs of depression such as frequent crying spells, sleep disturbances, loss of appetite, fatigue or
substance abuse?

3. Helplessness. Do caregivers experience feelings of
helplessness due to their inability to cope with the progress-

14Ibid.
ion of Alzheimer’s Disease? Does the deterioration of the patient, and not knowing what to expect intensify feelings of helplessness?

4. Guilt. Are there marked feelings of guilt on the part of the caregiver, and other family members because they cannot do more for the patient? Are feelings of guilt the result of negative feelings towards the patient? Does guilt result from having to institutionalize the patient when they can no longer be cared for at home?

5. Denial. Are caregivers and close family members unable to accept the prognosis and progression of Alzheimer’s Disease? Is denial used as a defense mechanism to protect caregivers and family members from facing the reality of what is happening?

6. Frustration. Do caregivers experience frustration because they cannot cope with the many demands they are faced with? Is frustration experienced when they cannot find a doctor with a cure? Do families shop around for doctors and resort to unorthodox medical practices. As medical costs deplete their finances, are they further frustrated due to inadequate financial assistance for the family? Do they experience frustration when they find they have no time for themselves, and little or no time away from the burden of caring for the patient?

7. Role Reversals. Are caregivers experiencing role reversals which may take place when a daughter becomes the
caregiver for a parent? This can also happen when a husband becomes the caregiver for a wife and must take over all the duties she previously had. The reverse can also be true. A wife can become the caregiver of her husband who she had totally relied on during their years of marriage. All will be faced with new roles which may be difficult for them to adjust to.

8. Fear. Is there fear of the future, for the patient, for themselves, and how they will manage with and without the patient? Is there fear of losing all that they have worked for, loss of control, and of being alone? Is there any fear that the disease may be inherited?

9. Anger. Is there anger because there is no cure? Does anger result from an inability to communicate with the patient? Does anger develop due to feelings of being abandoned by the patient? Is it caused by the unavailability of support services and financial aid? Is anger increased when there is no relief from caregiving, and due to lack of understanding and apathy on the part of others and the social system?

10. Suicidal Ideation. Do caregivers or close family members have thoughts of suicide or any suicidal ideation?

The following social factors will be examined in this study:

1. Disruption of family functioning. How are family
relationships being affected due to Alzheimer's Disease. Is the family the main system of support or are they torn apart because they cannot cope with the affect of Alzheimer's Disease?

2. Withdrawal from social activities. What impact does caring for an Alzheimer's patient have on the caregiver and close family members? Are they able to live their lives as they have in the past or do they become socially withdrawn and isolated due to lack of time, energy and money? Is there loss of freedom and mobility? Have they lost the freedom to come and go as they please?

3. Impact in the work place. Do families who care for an Alzheimer's patient find themselves unable to continue to work or are they severely limited in their ability to function at work. Does this lead to a loss of productivity and an inability to provide and maintain an adequate family income.

4. Financial hardships. How is the family affected by the financial burdens of this disease? Are families able to afford the care that the patient requires? If not, where do they get help? Must the caregiver rely on public assistance and, if so, is this assistance adequate to meet their needs?

5. Impact of institutions on the family. How do institutions such as nursing homes, board and care homes, impact on family functioning? Are families knowledgeable
about these institutions and the services which they offer or do they just take what they can get? Do these institutions give patients adequate care and attention and are they supportive to the family?

A major question to be answered by this study is: Are families and patients receiving appropriate services and interventions needed in the management of Alzheimer’s Disease, or are they only receiving limited, fragmented services?

All of these questions, as well as the objectives of this study, will be addressed by means of three individual family case studies. The findings of these case studies will be related to a larger population by the use of a self-administered questionnaire given to 29 individuals who are involved with caregiving to Alzheimer’s patients.
**Explanation of Variables**

**Major Variables and Their Operational Definitions**

**Age:** Age of patient.

**Sex:** Is the patient male or female.

**Marital Status:** Is the patient single, married, divorced, or widowed. If they were married, how long were they married, how many marriages did they have. Did they have a happy or unhappy marriage. Were there any unusual stresses in the marriage such as alcoholism, drug addiction, serious illness of marriage partner.

**Place of Birth:** Where the patient was born. Do they have U.S. citizenship.

**Ethnic Group:** What ethnic group does the patient identify with. White, Black, Mexican American/Chicano, Latin American, Other Spanish, Chinese, Japanese, Filipino, Vietnamese, Laotian, Cambodian, Native American, and Other.

**Educational Level:** How much education has the individual had. Elementary 0-4, Elementary 5-8, High School 1-3, High School Graduate, College 1-3, College Graduate, Advanced degree/course work.

**Occupation and Employment History:** What type of work has the individual done and what was their occupation at the time of the diagnosis of this disease. Was the individual employed at their level of training and capability, employed below level of training and capability, unemployed and seeking
work, unemployed and not seeking work, student, homemaker, retired, disabled for reasons other than Alzheimer's Disease.

**Occupational Hazards:** Did the individual work under any unusual occupational hazards such as danger from chemical or radiation exposure, serious environmental pollution, excessive exposure to extreme weather conditions, or unusual job stress.

**Alzheimer's Patient:** Any individual who has been medically diagnosed as having Alzheimer's Disease by a qualified physician.

**Psychosocial Impact:** Psychosocial impact refers to the psychological and social effects of Alzheimer's Disease on caregivers and close family members. Proxy variables will be used to measure psychological and social impact on individuals. These proxy variables will include:

a. **Stress** - increased levels of stress manifested by emotional, physical and social dysfunctioning.

b. **Depression** - inability to concentrate, tearfulness, sleep disturbances, loss of appetite, fatigue, and substance abuse.

c. **Helplessness** - loss of a sense of control over one's life. Inability to make decisions.

d. **Guilt** - pronounced feelings of guilt manifested by concerns of not being able to do more for the patient. Feeling responsible for or adding to the patient's problems, both physically and emotionally. Pronounced feelings of guilt
due to institutionalization of the patient. Guilt focused around decision making.

e. Denial - the inability to realistically accept what is happening in their lives.

f. Frustration - Frustration due to the inability to cope. Feelings manifested by a sense of not being able to accomplish what needs to be done. Inability to meet emotional and social needs which lead to feelings of frustration.

g. Role Reversals - Reversal of previously held roles in the family. Taking on the responsibilities of the patient and taking on the role of caregiver to an individual who was once self-sufficient.

h. Anxiety - feelings of fatigue and how often are they experienced and for how long. Inability to concentrate - the individual has difficulty paying attention to tasks. How often this occurs and does this affect the individual's work performance and how long this has lasted. Insomnia - is the individual unable to sleep at night and how often does this happen and how long has it lasted. Sweating and heart palpitations - does the individual experience these and how often and how long has it lasted.

i. Fear - Manifested by realistic and unrealistic fears about future events. Concerns about inability to cope, fear of abandonment, fear of being left alone. Hypochondriical concerns. Fear of heredity.

j. Anger - Manifested by feelings of rage towards others
and towards the patient.

k. Suicidal Ideation – Manifested by thoughts of suicide or suicidal attempts. Feeling that there is nothing to live for.

l. Disruption of Family Functioning – Manifested by a marked alteration in previous family functioning and relationships.

m. Withdrawal from Social Activities – Manifested by a marked alteration social activities.

n. Impact in the Work Place – Ability to function at work, productivity and inability to continue working due to caregiving responsibilities.

o. Financial Hardship – Amount of financial stress experienced by the family due to the care of the Alzheimer’s patient.

p. Impact of Institutions on the Family – Ability to utilize existing institutions. Ability of institutions to meet the needs of the patient and the family. These institutions would include skilled nursing home facilities, board and care homes and hospitals.

Caregiver: Any individual or group of individuals who are responsible for the care of the Alzheimer patient. This will include both family and non-family members.

Family Medical History: Incidence of Alzheimer’s disease in family. Incidence of other types of dementia in family. Incidence of other chronic or serious disease in family.
there any history of Down’s Syndrome or chronic mental illness.

**Medical History:** Individual medical history to identify any chronic or serious disease which the patient has had in the past. Any history of alcoholism or drug abuse. Any disabilities such as blindness or serious visual impairment, deafness of serious hearing impairment, speech impairment.

**Socio-economic Status:** Level of income, do they belong in the classification of lower, middle, or upper class according to national standards of income. This would be measured on a nominal scale according to national figures.

**Health Insurance Coverage:** Type of coverage, extent of benefits for catastrophic disease coverage, coverage for medications, and long term care both at home and in an institution.

**Family Support Networks:** Number of members in the immediate and extended family. How many family members help with the care of the Alzheimer’s patient. Are there other family members who are available to take over for the caregiver so that the caregiver can have some time off. Do family members provide verbal and financial support to the caregiver. These proxy variables can be scored on a yes/no basis and shown on a graph to illustrate the degree of availability of family support networks.

**Community Support Networks:** Are there any community agencies that are able to provide direct support to the patient and to
the caregiver in the management and maintenance of this disease. Do these agencies charge for their services and if they do, are their fees affordable and reasonable. Are the services provided sufficient to meet the needs of the patient and family. Do any self-help groups exist in the community. Does the family feel that this type of group is useful to them. These proxy variables can be scored on a yes/no basis and shown on a graph to illustrate the degree of availability of community support networks.
Research Methodology

This study consists of two parts. The first part involves the use of three case studies of individuals who are caregivers to an Alzheimer’s patient. Part two involves the use of self-administered questionnaires given to twenty nine respondents, who were caregivers and family members. This research involves the use of three case studies of individuals who are caregivers to an Alzheimer’s patient. The subjects for these three case studies are all members of a local self-help group. During a monthly meeting this researcher presented the proposed study to them, and they volunteered to be participants.

The questions raised in this research project can only be answered through the individual experiences of those who have personally suffered from its effects. Each case involves a family of a different ethnic background and economic status. The study focuses on how each family copes with this disease. An open ended type of interview took place, in which the researcher attempted to adhere to asking the same questions to each of the three cases, inasmuch as was humanly possible. The three case studies attempt to identify how well their needs are being met, and how this disease affects their psychological and social functioning. Both commonalties and differences will be identified through the use of the three case study interviews.

In an effort to relate the case studies and their
findings to a larger population, a questionnaire was developed and self-administered by a group of people that are similarly involved with caregiving to Alzheimer patients. This structured questionnaire was distributed to individual family members who were attending a self-help group meeting. Members were asked to complete the questionnaire on a voluntary basis. These respondents were asked not to put their names on the questionnaire, to assure anonymity. Of the thirty three questionnaires distributed to the group, twenty nine were completed and returned. In addition to offering people real anonymity, the questionnaire provides more quantitative data for statistical analysis.

This data will be analyzed by comparing the three case studies with the twenty nine questionnaires. The purpose of this will be to identify common areas of psychosocial difficulties in the management of Alzheimer's Disease. Statistical data will be used to quantify the information gathered from the questionnaires and these findings will be compared with those of the three case studies.

**Limitations of the Study**

This study has the following limitations:

1. The study focused on a small group of participants who were from the same geographical area and were members of the same self-help group.

2. The data could not be generalized to a larger population because the study was limited to a relatively small sample.
3. The subjects for this study were not randomly selected, resulting in an inability to generalize the data to the population at large of individuals and families experiencing the effects of Alzheimer's Disease.
A review of the literature indicated that limited data is available on the psychosocial impact of Alzheimer's Disease. This limited data highlights the importance of this study and the need for more research in this area. The literature contained many articles on the medical aspects of Alzheimer's Disease, and related research studies. The medical data indicated the need for continued research and the need for additional funding.

A United States Senate Committee report (May, 1983) states that "little is known about the causes of Alzheimer's disease although a number of drugs are being tested which may result in improving the cognitive functioning of Alzheimer's patients." One thing is known for sure at this time, the disease is irreversible. At the present time, there is no cure and no way of slowing down its progress. In recent years, there has been renewed interest in Alzheimer's Disease because of its increase in occurrence. As a result, there is a great deal of effort being made today to find its cause and its cure. More demands for research funding and new education efforts are stimulating public awareness. Contrary to common belief, research has shown that this is clearly a neurological

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disease and not a natural process of aging.

"The cause is unknown as yet, but investigators are studying the possible role of such causes as: viral, genetic, immunologic and environmental/toxic factors which may be involved singly or in combination. Investigators are also studying the epidemiology of the disease as well as its natural history. Cure is currently not available.-"  

At the present time there is no one theory that answers the many questions as to the cause and the cure to this disease. The current research is fragmented, hypothetical and is still in its early stages of development. Funding is inadequate and there is a great deal of work to be done. One major theory as to the etiology of Alzheimer’s Disease is the Cholinergic Hypothesis. It has been found that patients with Alzheimer’s Disease have decreased activity of an enzyme in the brain called choline acetyltransferase or CAT. This enzyme is responsible for the production of neurotransmitter acetylcholine (Davies and Maloney, 1976). It has been determined that the cholinergic system is involved in the areas of learning and memory.

"The most exciting findings in Alzheimer’s patients show a correlation between this change in neurochemical activity and changes in both cognition and brain pathology, particularly the number of characteristic plaques seen at autopsy."\(^{1\circ}\)

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\(^{1\circ}\)Aronson, Op. Cit., p. 6-7.

\(^{1\circ}\)Butler, Robert N., SDAT Research: Current Trends, Generations, Western Gerontological Society, Vol. VII. no. 1, p. 15.
These findings have generated much hypothesis as to their relationship to the causes and/or affects of this disease. Thus, researchers are most interested in trying to find out why this system is malfunctioning. This has led scientists to the discovery that in Alzheimer's there is:

"a profound loss - as much as 80% of neurons in the nucleus basalis, a region at the base of the brain (Whitehouse et al, 1982). This loss of nerve cells can be directly correlated to the reduction in cholinergic activity in the Alzheimer brain. On the basis of this research, the nucleus basalis is considered to be a major outside source of cholinergic input to the cortex (Johnston et al, 1979)."\textsuperscript{20}

The author goes on to say that this is the first time a group of nerve cells has been identified in the development of Alzheimer's Disease. It is, therefore, felt that much has been gained in this area of research which will ultimately lead to treatment of the disease. Attempts have been made to treat Alzheimer's victims with various drugs and dietary supplements. These attempts, however, have not been successful; although, in some cases there has been a small amount of improvement for a short period of time. This has been done through the use of ingestion of the drugs choline chloride and Lecithin. There has been no improvements seen, however, in the more advanced cases of Alzheimer's. Other drugs have been experimented with which have had the affect of inhibiting the rapid degradation of acetylcholine in the brain. One such drug in this group, physostigmine, was found to have a

\textsuperscript{20}Ibid.
positive effect on memory. Researchers feel that this is only the first step in developing "more effective drugs or drug combinations for the treatment of Alzheimer's Disease."

Other drugs such as oxotremarine, have been found to stimulate brain activity but as yet there is no drug known that will prevent or stop the progression of this disease.\(^{21}\)

Another area of research study which is being developed is in genetic studies. There has been a great deal of investigation into genetic factors and their relationship to an individual's propensity to develop this disease. In a study of patients in a Swedish mental hospital it was noted that "the risk of the condition among relatives was 4.3 times as great as in the general population (Larsson et al, 1963)."\(^{22}\) It has also been found that "there is a greater incidence in Down's Syndrome, as well as a number of hematological malignancies and myeloproliferative disorders among siblings and parents of Alzheimer's victims (Heston and Mastri, 1977)."\(^{23}\) In this same study, which took place in 1977 and consisted of 30 patients who had Alzheimer's Disease, it was found that:

"there is clearly a risk of developing the disease if a parent or sibling was affected at an early age. On the other hand having a sibling who developed Alzheimer's dementia after age 70 did not increase risk. Also, excess incidence of Down's syndrome seemed to be limited

\(^{21}\)Ibid., p. 16.

\(^{22}\)Ibid.

\(^{23}\)Ibid.
to the relatives of younger Alzheimer victims in the study. The earlier the onset of dementia, the more severe the course of the disease; the more severe the disease, the greater the frequency in family members (Heston et al, 1981)."^{24}

It is now thought that pathologic changes in Down’s patients and the symptoms of Alzheimer’s are similar because all Down’s patients who survive to the age of 30 or 40 experience the same degeneration as Alzheimer’s patients.

All of these findings and further research into the possible genetic links to this disease will bring researchers the vital knowledge that is needed to find its cause and cure. This certainly is an important area of study and requires continued emphasis.

Another area of speculation in research has revolved around the possibility that a slow virus is the cause of the disease. Unfortunately, researchers have not been able to isolate any such virus and this is only speculation at this time. Efforts are still being made, however, to find and isolate such a virus. A great deal of research along this line is now being done at the University of California at San Francisco, where some new discoveries have been made.

Another important area of research involves trace metal studies and is probably the only area that has aroused a great deal of public interest because of the high incidence of these trace metals in our environment. Of particular concern is the finding of increased amounts of aluminium in the brains of

^{24}Ibid.
Alzheimer's victims. It is presently thought, however, that this is the result of a deteriorating system rather than the ingestion or absorption of aluminium. "This thinking is consistent with the recent findings of a general increase in brain concentrations of aluminium with age (Markesbery et al, 1980)."

"Researchers have found that 90% of the brain's nerve cells with neurofibrillary tangles had aluminium in the nuclear region of the cells. Adjacent, nontangled nerve cells were virtually free of detectable amounts of the metal (Perl and Brody, 1980)."

Canadian researchers have experimented with a drug that removes aluminum deposits from the brain. The results of this have been quite promising but the drug has serious side effects. It is also important to note that these researchers have concluded that cooking in aluminum pots does not lead to increased amounts of aluminum in the brain. The use of aluminum cooking pots has been a concern for many people.

Nancy L. Mace, and Peter V. Rabins, M. D., wrote the book, "The 36 Hour Day - A Family Guide to Caring for Persons with Alzheimer’s Disease, Relating Dementing Illness and Memory Loss in Later Life." The book gives caregivers tips and various solutions to the daily task of caring for the Alzheimer patient and the various problems which come up as

23Ibid., p. 17.
26Ibid.
27Ibid.
the disease continues to progress.  

Newsweek Magazine featured "The Agony of Alzheimer's Disease" in their December 3, 1984 issue. This article provided the readers with an overview of the medical problem of Alzheimer's Disease and also included the stories of three families, and how the disease impacted on their lives.

Lenore S. Powell, Ed.D., and Katie Courtice's book, "Alzheimer's Disease - A Guide for Families," addresses the needs of the patient and the caregiver. This book provides a great deal of useful material which is relevant to the needs of this population group.

"Precipice - Learning to Live with Alzheimer's Disease," is a personal account of the wife of an Alzheimer patient. This book provides insights that are helpful to the individual caregiver.

Two issues of "Generations," which is the quarterly journal of the Western Gerontological Society, were solely devoted to the impact of Alzheimer's Disease and the effect it

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31Seymour, Claire, Precipice - Learning to Live with Alzheimer's Disease, Vantage Press, New York, NY.
has on the caregivers, and the family. There was also a great deal of information provided as to the medical research and its relevant findings. Areas of social policy and various interventions and support services, were also presented.32

The review of the literature indicates the continued confusion and lack of knowledge as to the etiology and cure for Alzheimer's Disease. It is apparent that research is rapidly increasing in these areas but, as of yet, no definitive conclusions have been reached. Hopefully, as these research efforts continue and increased funding is made available for this purpose, a cause and a cure will be found. As of now, there is only speculation which leaves little hope to those afflicted with Alzheimer's Disease and their families.

Case Study I - Rebecca and Samuel

Rebecca and Samuel met while they were inmates of a concentration camp, in the early 1940’s. When the allies liberated the camp, they gained their freedom. They married a few years later and immigrated to the United States, settling on the East Coast. They have two children. Rebecca is 57 years old and Samuel is 64.

Today, Samuel lives in a locked board and care facility. He suffers from Alzheimer’s Disease and Parkinson’s Disease. The following is a transcript of an interview with Rebecca who also suffers, as she watches Samuel’s continuous deterioration into a world she can no longer share.

Interviewer: What did your husband do for a living when he came to this country?
Rebecca: He worked as a mechanic for 25 years.

Interviewer: And what did you do?
Rebecca: I worked in a coffee company. They used to make all kinds of coffee and those kind of things. I worked in the sample room for 20 years. We both worked very hard after we came to this country. With two small children. Life wasn’t that easy but its better then what I have now.

In 1970, Samuel began to get sick. In 1978, I took him to the Medical Clinic for verification, to see if it’s right that he had Parkinson’s or it’s the nerves or whatever
it is. They said, it's Parkinson's Disease and plus he had a deterioration of the brain. They called it, at the time, "premature aging" because he wasn't even 50 years old. He's only 62 now. They said, he might get better or he might stay on the same level.

Interviewer: At that point did you look around for other opinions, or did you go by what they said?

Rebecca: No. The Medical Clinic in Boston, that was it. I mean you cannot go higher then that. I wasn't satisfied with the doctors in Boston, because they were treating him for nerves. He had checked into a psychiatric ward on his own will, because he couldn't sleep at night, and he had fears. Fears took him over. But after a while, a couple of weeks, he went back to work. He had two shock treatments in that hospital, and my opinion is since he had the shock treatments his condition went down - his memory. That did him in. That's my opinion.

Interviewer: Shock treatments do cause memory loss.

Rebecca: Yeah, but then it's supposed to come back. But he never got better after that. I think he never got better, and that did it. And that did it. Maybe it would happen anyway with his Parkinson's, because Parkinson's does take a toll of your movement and everything else. He went back to work after the shock treatments. He was able to perform, but not that well. His hands weren't coordinated anymore, and if the boss said something or watched him, he became very tense.
He had crying spells, and they called me one day and told me that I should do something about him. Get him to the doctor or do something. That was before I took him to the Medical Clinic in Boston; to the doctors. (Voice rises) It took them a long time - a neighbor of mine told me, "Rebecca, Samuel looks like he has Parkinson's Disease," because he was shuffling, and his hands were like he had a stroke or something. When I went to the doctor, I said "What's the matter with him, something's wrong with him, does he have Parkinson's?" He checked him over and he said, "Yes he does." So, I had to tell the doctor that he has Parkinson's, and then I took him to the Medical Clinic. He'd also been to a neurologist because he had headaches. I took him to a neurologist right away. I went away on vacation with Samuel and she said to me, "Oh it's nothing serious. On his brain he has like little specks." I said, "What means little specks?" She said, "Oh like a little dust, you know, on the brain - spots." So that's the explanation I got, and I didn't really understand the meaning of it. And when I went to the Medical Clinic and they gave him a workup, with everything, the doctor called me in and showed me the scan on his head. He showed me the spots, and said, "That's the deterioration of the brain and the cells, they are dying and won't refurbish themselves anymore."

Interviewer: They were able to pick that up on a scan?
Rebecca: Yeah! But see - she (the neurologist) did it
too! But the explanation was not in my language!

Interviewer: No. That's a funny way to describe it - dust.

Rebecca: Little specks. Like little dust. Specks of dust.

So there it was - but still, he went to work. I took him to Israel, too. To a psychiatrist. I don't know what he did that time. I think he diagnosed him, and he told me afterwards that "He'll never get better." That was in 1970. That, "He'll never get better. He might stay the same or get worse," and they told me years ago. And then, when we came back and he went to work, and he worked, I thought, "Ah, a lot that he knows, the doctor."

Interviewer: So you didn't believe the doctor in 1970?

Rebecca: No. Not when he went to work. But then after the shock treatments - he still went to work after the shock treatments. But it didn't last for too long. He always dreamed about retiring when he was going to be 55, and enjoying life, but it backfired. He did go out in 55 on disability, but we still could go. It wasn't that bad. But then, he began falling a lot, and little by little I did for him, almost everything. Help him wash, help him shave, help him dress, to make it faster, and that was a mistake. You've gotta push them as long as you can, they should do for themselves. People would tell me, "You are doing too much for him." But when I started to stop, it
was already too late. My advice would be to people, "As long as he can function, if it takes longer or whatever it is, let him do it - everything he can, it's wonderful!"

Interviewer: It's hard to let somebody do something for themselves when you see them struggling.

Rebecca: (Big sigh). That was me, but not right.

Interviewer: It's a very human response to help somebody who is struggling or can't do it.

Rebecca: Yeah, or make it faster. I could make it faster shaving him. So I took it over, little by little, until he didn't have anything, and I did it to him. He tried to, but I'm sure it was the brain damage.

Interviewer: How many years passed from the time you started helping him until he couldn't do things for himself?

Rebecca: Oh, I would say maybe 6 years, or so, that I helped him. I always helped him. Always helped him.

Back East he used to go out for a walk a lot and fall. He broke his arm. He fell down twice on the steps in the house. Once, I thought he killed himself when he fell and opened up the back of his head.

Interviewer: You mentioned that you took him to a psychiatrist in the early stages of the disease. Did you and your husband feel that this was a psychological problem?

Rebecca: Yeah, nerves, stress.

Interviewer: You didn’t feel that this was due to a disease?

Rebecca: No. He was treated almost two years for this by
the psychiatrist. Maybe more then two years. Once, I had
one psychiatrist and then they changed it to another one.
Interviewer: Did they put him on any medication?
Rebecca: Yes. The first psychiatrist. You name it, he
had all kinds of medications. He was like a walking zombie.
He had thorazine, mellerile, you name it. The whole shaboy-
gan, the tranquilizers. When they changed him to the other
psychiatrist, he treated him differently. A little bit
different. Like he had fears for a knife or something, so he
made him face things. He told me, "Go out and get a rubber
knife and give it to him to face head on." I thought, "My
goodness, he (the psychiatrist) must be crazy!"
Interviewer: Did that help him?
Rebecca: Maybe it did.
Interviewer: Did he lose the fear of knives?
Rebecca: Yeah. I remember that I had a beautiful kitchen
knife and I had to dispose of it in his presence, because
he was scared of it. He was always scared that he was
going to do something to me.
Interviewer: Do you relate this back to his experience in
the concentration camp?
Rebecca: I don't know. Well, that didn't help, because
he went through a lot. He went through very much.
Interviewer: It could be that the psychiatrist kept that
in mind. He may have felt that, because Samuel was in a
concentration camp he was suffering from a mental problem
rather than a physical problem.

Rebecca: Yes. Yes, at the time yes, because he was well, sometimes shaking a little bit. He doesn't have the tremor like some other Parkinson's patients have. I had all these experiences with psychiatrists, with neurologists and his private doctor. He wanted to be helped so much when he checked into the psychiatric ward, on his own. I think I coped with all of that. I did everything. Then, my daughter moved out here five years ago. She says, "Mom, what are you going to do there? Why don't you come, it will be easier for dad, it's warmer here?" I did come out here. We still could go places, even though it was hard because dad had to go to the bathroom, or do something. It was always things. He kept going out for a walk, and wouldn't know how to get back home because all the houses looked alike. We used to live right by the expressway. After a while I used to tell him, "just go back and forth on the street, don't go around the block." He used to get lost, and nobody knew him. Once he walked into a neighbor's house. We looked for two hours down there, and I didn't know where he was. A lady walked into her house and saw him sitting on her couch. All the apartments were the same. She called the police and he didn't want to move. He said, It's my house." Well, finally they found out who he was and they brought him home. So, I had to keep a close eye on him. But, even so, that was all right with me. The reason why he is now in a nursing home is, since I moved
here, things didn’t go so well for me. First, I fell and injured my right hand. So that wasn’t bad enough. Then I got sick. My gynecologist found out I had cancer. I had an operation, it’s over two years now. Samuel was still home with me, while I recuperated from the operation. I had chemotherapy for ten months, and I was fine. I was cured, sort of. Two and a half years later, it came back. At the same time, I got involved in buying a new house. I guess after all the anxiety and everything else, I couldn’t function anymore. I tried to keep him and do the things for him, sometimes very exhausting, but you forget these things. But I got so bad that my nerves were really giving out on me. So we had to make the decision to put him in a nursing home (voice cracking). He’s been there since 1984. It’s very hard. I keep on going, but I don’t know, it breaks my heart. I go see him every day. He wants to go out. I haven’t had him home in a long time.

Interviewer: Does he know who you are?
Rebecca: He knows - he knows the kids (crying). When I go there, he knows who I am. It’s a familiar face. Sometimes, even when he used to be home, and I used to be sick he’d say, “Where’s my wife?”

Interviewer: What about the care that he’s getting at the home. How do you feel about that?
Rebecca: Well, he lost a lot of weight now, in the new home. He looks good, but I wish I could have him home.
He gets better care at home then in any home.  
Interviewer: You don't feel that you would be able to care for him?  
Rebecca: 24 hours. If I wouldn't have my problem. I go every four or five weeks to the hospital for treatment. Any home is not good. The first time, they said they were going to put him in a home, I said, "I would rather go to a funeral."  
Interviewer: I'm getting the impression that it was not your decision to put him in a home.  
Rebecca: Well, I went along with them.  
Interviewer: You felt that what they were suggesting, was the best thing for you and for your husband.  
Rebecca: Yes. Because he felt my agitation too, because they are very sensitive.  
Interviewer: How did he react to being put in a nursing home?  
Rebecca: I told him that I cannot take care of him, so he goes in there for awhile, and then I'll take him home. And that was my impression too, that it was only for awhile. But as they say, "the doors are wide to get in, they get narrow to get out." Now, I can't bend that well, and I cannot take care of him the way I used to take care of him. Maybe it's a crutch, but if I would be well, if I would not have that problem....  
Interviewer: You think you could do it?
Rebecca: I could do it, and then maybe have help in the house, because you are a shut-in. You can’t schlep (drag) him along in the store and tie him up like a little baby with a leash.

Interviewer: Do you think that he functions better in the home, or did he function better when he was here?

Rebecca: In a way, he functioned better when he was here. You’d sit him down, and he was sleeping. But I’d try to wake him. I used to try to shake him out of it. Up there, they don’t shake out. This one sleeps and that one sleeps.

There’s nothing going on there. So, when you are in Rome, you do just like the Roman’s do. I wonder sometimes, if his mind’s clear, if he thinks or he doesn’t. Before it was hard. When he was in the first home, I used to take him home a lot. But then, to bring him back, it was terrible because he didn’t want to go there. He’d run after me when I left.

Interviewer: He knew what was happening to him?

Rebecca: He said, "I don’t belong here, with other old people." Now I don’t take him out that much. People would tell me, "Take him out, but don’t take him home because it’s too hard to take him back." It’s difficult. It’s confusing for him and it’s hard for me. Then there’s another lady who has her husband at the same home and yesterday when I was there she took her husband home for a couple of hours, and then she brings him back. He chatters a lot. He talks a lot. He doesn’t make any sense, but he talks a lot. But
Samuel, when he says something, it's very hard to understand him. He speaks a lot of Yiddish and you gotta tell him, "Speak English because nobody understands you."

Interviewer: How does that affect him in the home? I would think that there are not too many people there that speak Yiddish.
Rebecca: No. But there's one woman that speaks only German.

Interviewer: What about the people who are caring for him in the home? Does anybody there understand what he says?
Rebecca: No. No

Interviewer: That's a problem. There's a language barrier.
Rebecca: Oh yeah.

Interviewer: You had him in another home before this. What kind of place was that?
Rebecca: I gather the people were very nice to him. It's a bigger place. And we had a very nice relationship with the owners. Even now, I call them up and see how things are going. But the trouble was, the reason why we took him out is because he used to wander away.

Interviewer: He used to run away?
Rebecca: Not run away, go out for a walk. It was open and every couple of weeks we'd have to go look for him. He went away once and he wandered into the local hospital.

Rebecca: He sat there, for hours before they started working on him. He didn't have any identification, and they called
the police. Somehow they found a record of him. I don’t know how it happened, and they transferred him to another hospital. While he was in that hospital, his doctor was on duty and saw him. And that’s why they happened to find him.

Interviewer: Did you have to take him out of that home because they couldn’t watch him closely enough?

Rebecca: No. They would still keep him there, but I couldn’t take the anxiety about him walking away.

Interviewer: They couldn’t protect him and prevent him from walking away?

Rebecca: No. This home has 21 patients and the other one had about 40, and they had more open space. This one is sort of like a locked facility. If the front door opens, a buzzer goes off. They know if somebody is going out. In the back, they can go out and walk, and they cannot get out of there.

So it’s good one thing, and others its not. The grounds were nicer at the other place. As far as care goes, he gets better care where he is now. Maybe a little bit cleaner, then he was there. He’s in diapers now, which he was not before. That’s another expense on my part. It’s about $90 a month. The expense is crushing.

Interviewer: How do you handle that? Do you have insurance to help you pay for this?

Rebecca: He’s getting Social Security. He gets $1,000 and that takes care of his expense. Thank God, we are
still covered with Blue Cross through his company. Otherwise, with my sickness, I couldn’t exist. If something happens to him, then I’m only covered for two years.

Interviewer: What about Medicare?

Rebecca: Well I’m not of age, I don’t get nothing.

Interviewer: And disability?

Rebecca: I don’t get a cent. I only get $50 a month from my company because I’m 55. So I’m not here, I’m not there, I’m nothing.

Interviewer: So you have a lot of insecurity in that area.

Rebecca: Yep.

Interviewer: Besides the illness being a terrible tragedy, not being able to feel secure about finances.... Rebecca: (interrupts) How long I have left to live, I don’t know. Like the doctor said to me. I went for my check up because I have pains, and he said that tumor is there and its not spreading, its confined. But he said, "You have to go on with your treatment, because without it you wouldn’t be here." So I still keep on going. I don’t know.

Interviewer: Are you concerned about something happening to you and Samuel being the one that’s left?

Rebecca: Well, the kids will take care of him, just like I take care of him. Maybe they’re not going to see him that often, but....

Interviewer: You have very good children.

Rebecca: My daughter is. She has a burden to carry - she
is carrying - but I think I was a good mother too. I still try to help her out, when I can.

Interviewer: If you could come up with a living situation or some way to make this more comfortable for you, more acceptable to you on a day to day basis, what would it be?

Rebecca: Well, if I had the choice and I had the means, I would have 24 hours, somebody in the house for him.

Interviewer: Do you feel, that of all the alternatives that are available now, to people in your situation....

Rebecca: (interrupts) What alternatives are available in my situation? (laughs as, if this is a joke)

Interviewer: Not much. So, the best thing would be to have someone in the house, 24 hours a day.

Rebecca: And then, people say that's not so good too because you wind up doing the work. See, I got used to the thing already. Now if he coughs, if he has a headache, or he has a pain, you know about it in the house when you are there. Up there, if he has a pain or he has a headache, nobody gives a hoot because he won't say, he wouldn't do nothing, so he'll just take it for what it is.

Interviewer: The ideal situation would be for the two of you to be together. Some place, where you could have a lot of help caring for him. How have you dealt with Samuel's sickness throughout the years?

Rebecca: I handle it, I think, pretty well. Pretty well. Sometimes when you get mad and say, well I wish the end would
come, forgive me God, because I can’t go on.... Sickness is a problem and that’s it.

Interviewer: Do you feel that the stress that you’ve experienced from Samuel’s illness has caused you to become ill too?

Rebecca: It didn’t help. It didn’t help. It didn’t help. It still doesn’t help. It’s such an effort for me to go down there. I’m there almost every day. And if I skip, he doesn’t know the difference. I’m the one that’s hurting, he’s not hurting. Maybe, once in awhile, he knows a little bit more then other days. It’s then that I say, "What is he doing there?" But sometimes I think, wouldn’t it be wonderful that one day he’ll get up and say "what is up, what I’m doing here’, and just take the bus or find information and come home. (Crying) That’s my dream. I’m sure he’s not dreaming that.

Interviewer: It’s your pain.

Rebecca: (In a whisper) It’s my pain. My pain. And a big pain. Without that they say okay, you have cancer but you are doing better then some other people. You look good, you tend to things but they don’t realize that I have a double burden to carry, and I cannot forget him. You try to push it away maybe, but not forget, you can’t forget. Sometimes I wish I would forget and say, "oh it doesn’t exist". If I would be a different person, you know, just go see him and stay a little while and ah goodbye, get away. Love him and leave him. But when I see the other
girl takes her husband out and she takes him so often, home for a ride and this and that. I cannot do it because I’m scared he’s gonna fall or have a heart attack, getting him out of the car or whatever it is, and I can’t handle it. It hurts.

Interviewer: What about when your daughter is there. Are you able to take him out?

Rebecca: Well, I very seldom go with her together.

Interviewer: You usually go alone?

Rebecca: Yeah. This week we ran down together for a couple of minutes, but we didn’t take him out. She used to take him home for a couple of hours. But then, one time, she had an episode. She had him for supper. He didn’t want to get out of the house. And it was very - I wasn’t there - but he was agitated, he wouldn’t move and they couldn’t get him out. I guess since then she’s not taking him out with her. So what do you do in a case like that, you just suffer. Sometimes, I wish I go to bed and I don’t get up anymore.

Interviewer: Your doctors have told you that you’re doing very well. They feel that you can recover.

Rebecca: Not recover.

Interviewer: What have they told you?

Rebecca: They just - under control. It’s the best, but I gotta keep on with the chemotherapy. For how long - I got already eight treatments.

Interviewer: How many more treatments?
Rebecca: Who knows?

Interviewer: That must make you feel very ill, too.

Rebecca: I go in the hospital. I'm supposed to stay in the hospital over night, but I get so sick that I stay two nights instead of one.

Interviewer: You impress me as being a very strong person.

Rebecca: Yeah. Everybody tells me.

Interviewer: You've certainly been through a lot in your life. You've been able to survive so much.

Rebecca: So much. (long pause) I don't know. I'll go see him today. I gotta pick up the children from school.

Interviewer: How do you manage picking up the children from school? It must be pretty hard for you. Is it hard for you to drive?

Rebecca: No. I think that keeps me going.

Interviewer: It's good for you to have something to do.

Rebecca: (Tone of voice brightens) You always have something. I've got so much work to do in the house. I gotta clean my house, you see my table is all dusty. And yet, I don't know - till I get to it. I have a lot of friends.

Interviewer: You have friends that live close by?

Rebecca: I have one that lives here.

Interviewer: So you have somebody you can talk to.

Rebecca: Yeah, I always have somebody to talk to. I can be with my family when I want to. They are very good to me. My daughter says to me, "you gotta go for exercise,
you gotta do this and this." I ain't got no need for it. I go, but I have to push myself whatever I go. My heart is not in it. And why, why is not my heart in it? Maybe, if I would be a woman that did things before, like going out with other men, or do that or do this, maybe it would be much easier. But only having one man all my life. If I would have a different life, maybe it would be easier. So I gotta live with it for how long, I don't know how long. I know depression is not good for me, but I have it, and I am depressed.

Interviewer: You feel depressed.

Rebecca: Oh yes. I'm very, very depressed right now. Even talking about it.

Interviewer: Is there anything that you have done to try to get out of your depression?

Rebecca: I'm dealing with it the best that I can. I can't afford to go to a psychiatrist, a psychiatrist can do nothing for me. Something you have to do yourself. But as I said before, it would be much easier if I had to deal with just with myself.

Interviewer: Right. You have double pain. Being depressed in the situation you're in is - anybody would be depressed.

Rebecca: They tell me I shouldn't be depressed (getting angry).

Interviewer: Well you've got good reason to be depressed.

Rebecca: I should go out. "If you go out shopping, you
should have your heart in the shopping. Be happy with the things you do." I can't - my daughter force me - not force me, she wants me to go out with her, because I gain weight, I should get something. She was very happy about it, I wanted to go with her, but deep in myself I was tired and I said, "Nothing doing".

Interviewer: Part of your depression has to do with your illness and not feeling well. A lot of people get depressed just because they are very ill. Like you said, you have double trouble. So your depression is quite understandable. It sounds to me like you are doing the best you can with it.

Rebecca: Looking at me, people think I got no trouble whatever.

Interviewer: People can't possibly know. How long were you in the concentration camp?

Rebecca: I got in there when I was 13. I got in there in 1941. And I got out in 1945.

Interviewer: Can you relate that experience to this experience in any way?

Rebecca: No. Because I was young at the time. Very young, I didn't think that much. I didn't have any youth. So, when I got liberated, I got married and had a family right away and that was my life.

Interviewer: You can't relate your struggle to survive in the concentration camp....

Rebecca: Well, there was struggle things that ah....
Interviewer: You were young, and you were healthy.
Rebecca: Well, if I wouldn't be healthy I wouldn't have survived. Definitely not. Because I am the only survivor of my family. Six children.
Interviewer: You are a survivor.
Rebecca: Yeah (laughs) for what? Survive for having a life like now - sickness.
Interviewer: In between the time you got married and the time there was sickness, you worked hard, but life was good.
Rebecca: Maybe it wasn't that good, I worked very hard, but I'll go back to it.
Interviewer: You'll take it.
Rebecca: I'll take it. Without a complaint.
Interviewer: You certainly have a lovely daughter. I'm really impressed with Ann, she is really nice.
Rebecca: She is. I give her help if she needs it. What they are going through with me. I get very upset if something has to be fixed, or something has to be done. My refrigerator went on the blink, so I had somebody and it cost me $125. So that's my life story. What a life. I'm like a worm. Chop off the head, and it keeps on wiggling. That's me. (long pause)
Interviewer: Do your children help you financially?
Rebecca: No. Right now I don't need their help. My son needs help, he needs financial help.
Interviewer: How old is your son?
Rebecca: 35.

Interviewer: Is he married?
Rebecca: Yes.

Interviewer: So you have that worry too. You worry about your son’s finances too.
Rebecca: Well, I cannot help nobody.

Interviewer: It sounds to me like you have a lot of pressure on you from all over. From your husband’s illness, your illness, your son’s finances. You’re worried about all the aggravation you’re giving to your daughter. You have a lot bombarding you at one time. And you’re depressed. It’s understandable why you are depressed. Is there anything that relieves your depression?
Rebecca: (Laughs) Only when I sleep. Not too much though. I don’t get out of bed, but I’m up early.

Interviewer: But you are able to sleep at night?
Rebecca: I take a pill. I went to bed last night it was after 12 o’clock. I spoke with a friend of mine, then I went to bed. I took some aspirins. I didn’t take my tranquilizer. You know, a sleeping pill, just to calm me down.

Interviewer: Have you spoken to the doctor about your depression?
Rebecca: They know.

Interviewer: Does he give you anything?
Rebecca: (interrupting) No! He gave me some pills, but I
hate to take something when I drive. I don't like to be drowsy. And yet depression pills are not going to help you. They might help you a little bit, but you got to work on it yourself. Make the day count. Make it count. If not, you gotta lay down and die.

Interviewer: It sounds to me like a lot of people still need you. And they need you to make the day count.

Rebecca: Oh yeah.

Interviewer: Your husband, your daughter.

Rebecca: My husband - I don't know if my husband needs me.

Interviewer: He knows who you are when you come there.

Rebecca: Yeah, yeah.

Interviewer: So in that respect, he needs you.

Rebecca: But, you know, I'll say like yesterday. I always bring him something, but I didn't spend too much time with him because I had to go pick up the children. And today's gonna be the same thing, because tomorrow I'm going away for two days. So I won't see him. And I hope I'll be okay to go.

Interviewer: Where are you going?

Rebecca: I'm going to Hearst Castle.

Interviewer: Oh how nice. Have you been there before?

Rebecca: No. If I had been I wouldn't have gone.

(the conversation continued about which tour was the best to take. Rebecca appeared to be looking forward to her two days away).
Interviewer: Are you connected in any way to the Jewish Community Center?
Rebecca: Yeah. I'm a member.
Interviewer: Do you participate?
Rebecca: No.
Interviewer: Have you ever considered using Counseling Services.
Rebecca: I did already. I went a few sessions there with a girl.
Interviewer: Did you feel that was helpful to you?
Rebecca: Shrugged.
Interviewer: It doesn't take away the reality of what's happening to you.
Rebecca: I guess nothing - when you talk you talk. When you go out its the same things. I went to the counselor once and she said to me "when you walk out of here, go down to the Park. Take a walk by the little stream there, and just take a deep breath and watch the trees." I said, "Okay, I'll do it." I went down there, and I felt worse then before.
Interviewer: Because you were alone?
Rebecca: Because, when my husband got sick I used to take him out for a drive, and go down to the lake and sit there in the evening, and watch the water there. It's so nice and peaceful. But I got depressed, I'm going alone there. I told her "forget it"! I felt worse then when I started. So...
Interviewer: You know, I think it’s really important to know that it’s okay to be depressed. Depression comes for a reason, and you have a reason to be depressed.

Rebecca: Oh yeah!

Interviewer: And everybody’s telling you not to be depressed.

Rebecca: I’m not doing it from something that I have fun. It’s something that hurts, it’s a hurt, and I wish I could forget the hurt and that’s that. But it’s going to be always that way.

Sometimes my husband knows that I’m sick. But when he was home and I was sick he’d say, "You’re not sick." He knew that he was sick, but not me.

Interviewer: So, here you are in a time of your life where you’re very ill. You need someone to be caring for you in your illness. You could use a husband who is available to you, to take care of you.

Rebecca: Take care of me. Yes! I mean to be somebody, you know, that’s breathing, and this I never had. I try not to dwell on my sickness. But when I get a little pain – I went yesterday to the doctor. I thought he’s really going to lay it on me because I felt so crummy. And he said, "No, things didn’t change". The tumor is there, and he talks openly about it. It’s one thing, I never learned how to relax. Like lay in bed around until 10:00 o’clock. Put on a robe and lounge around the house and you know just.... I can’t.
Interviewer: You must have had a lot of energy all your life. Somebody who was always doing something.
Rebecca: That’s my daughter, my daughter.
Interviewer: Yes. I can see that she has a lot of energy.
Rebecca: I know that she has the energy.
Interviewer: And you were the same way?
Rebecca: Yeah, I was. Working, keeping a house and bringing up a family. And after that he was helping out and (big sigh) and now I don’t have somebody who, as you said, to take care of me, and relax. Some people get involved in the soaps and watch and relax. I cannot do it. I got out of bed today, it was 8:30. My God, I didn’t sleep till 6:00 o’clock. So I listen to the news. I don’t have the paper, I cancel off my paper. I get all the news from the radio or go to my daughter, I look over the paper. And to get out back and get ambitious and start cleaning - I mean you cannot clean every day the house. I don’t have that cooking and things I used to. And I don’t have my husband. I have to get out. I tend my business, what I have to do. Get out of the house. So I go to my husband. Till I get done with him. I go after lunch to see him.
Interviewer: What do you do with him while you are there?
Rebecca: Just go out with him for a walk. Try to play cards with him, but he cannot concentrate.
Interviewer: Does he get frustrated playing cards?
Rebecca: No. Just drops them.
Interviewer: How many hours a day do you spend there?
Rebecca: Right now I don’t spend — yesterday maybe I spend an hour there. But usually, sometimes, I’ll spend two hours. And that’s getting tiresome for me.
Interviewer: It’s hard for you.
Rebecca: I walk with him, and walk back and forth, and try to make conversation. And what hurts me most is that I don’t take him out. Like today is a beautiful day. What’s wrong; taking him out for a ride?
Interviewer: Can you ride with him in the car?
Rebecca: Oh, it takes some time until he gets in the car, and who knows it might be frustrating for him to get out. He might not want to get out or whatever. He’s very wobbly.
Interviewer: Does the home he’s at have any transportation for their residents?
Rebecca: No. They don’t have any entertainment, they don’t have nothing.
Interviewer: Is it a private home?
Rebecca: It’s a private care facility.
Interviewer: Do they have licensed nurses?
Rebecca: They have no nurses on duty there.
Interviewer: Do you find that you get more upset after you go to the home to visit? Do you feel worse after you see him?
Rebecca: No. It does not. No.
Interviewer: Not seeing him is the worst for you.
Rebecca: Not seeing him is the worst. Then when I get in there's always something. Something to do with him, to brush his teeth. Lately, I didn't shave him. They do the shaving. But sometimes I give him a haircut.

Interviewer: You're quite a woman. I'm really impressed with you.

Rebecca: Oh the things that I did with him. And I still do those things.

Interviewer: And how much do they charge.

Rebecca: I pay $900. But it's $1,000. What happened is the other place I paid $800. But they raised me the price. After he was there two weeks, they told me that he was more then they bargained for. So they wanted $1,000. I said, "I cannot pay it," with my illness and things like that. She said, "maybe you should go into a nursing home". I said, "Let's split the $200." So I paid another $100. She said, "It's not fair to the other ones." Well they give me for $900. And now this month, I'm going to get a bill for the diapers. Now he's in diapers, too. I'll tell you one thing. God should have mercy on me if I have to go in a place - any place. It's hard on the family. Because the majority that are there don't know no one. There are a couple of them there whose minds are okay. Maybe two people that - maybe three people, had their minds perfect. What do you do with those people, their minds perfect? They read. And they sit all day long. Watch television, sitting in their bedroom. So
that's terrible.

Interviewer: You have enough income to support yourself to live here?

Rebecca: Right now. I don't know for how long.

Interviewer: Do you think that there's ever a chance that things might get better?

Rebecca: (laughs) How?

Interviewer: Well, that you might stabilize and that he might stabilize.

Rebecca: Well, I am stabilized. For how long who knows.

Interviewer: You could be around for a long time you know.

Rebecca: Yeah. That's what the doctor says.

Rebecca: Well, I got to be around till next August. That I know.

Interviewer: What's happening in August?

Rebecca: My oldest grandson's Bar Mitzvah.

Interviewer: You must get a lot of pleasure from your grandchildren?

Rebecca: I do. The two of them that are here, I do.

Interviewer: They need you around. Right?

Rebecca: Like my little one, he's eight years old. And what did he say yesterday to me.... he said, he knows I'm sick. He gives a big sigh, because I have a little pain.

Interviewer: He's very sensitive to the fact that you are in pain.

Rebecca: Very, yes. So he says, "Grandma, do you think I
would cry." I said, "Why would you cry." He said, "I guess if you wouldn't be here; if you would die I would cry." He said to me, "Grandma I love you, I'll never forget you even when you die, I won't forget you." The little one is very sensitive.

Interviewer: He loves you.

Rebecca: "I love you grandma." Both of them. I took care of them for a week. And every night I tuck them into bed. "I love you grandma, I love you." "I love you too." So he would miss me, if I would die.

Interviewer: He would. So besides your children, and your husband, your grandchildren need you. There are people in this world that need you. It's important to them that you live.

Rebecca: Yeah. I took him yesterday to Cub Scouts and then I picked him up from Cub Scouts.

Interviewer: Not many children, today, have the privilege and opportunity to have a grandparent around to care for them like that. It's important.

Rebecca: They are lucky. They have both grandparents. But see, I was always closer. The big one, I practically brought up. The little one not that much. And they know me because I was with them. It's regretful that their grandpa cannot - he enjoys them when he sees them. He knows.

Interviewer: They come to visit him?
Rebecca: Yes.

Interviewer: He gets a lot of joy out of that.

Rebecca: Yes. He kisses them and always talks about them. They know he’s sick. And the big one always says, "Grandma, when you gonna take him home?" When I first put him in the nursing home. "When you gonna take poppa back home. I don’t want him to be there. Why don’t you bring him home for awhile." That’s what he says to me.

Interviewer: How did you answer him when he said that?

Rebecca: Well he knows that he’s sick. I said, "You know honey I cannot take care of him." He said, "But you can take him out for a while." He didn’t know that I’m scared to take him out. Before I was never scared, but now I am scared.

Interviewer: It sounds like you’re using very good judgment. If you take him out something could happen that you might loose control over.

Rebecca: It happened to me a couple of month’s ago. I got out of the hospital, and two weeks later I went to see him. I took him out in the back yard for a walk. And all of a sudden, I could feel that he’s sliding down. I was trying to hold him back because he wasn’t against the wall. If he would be against the wall, I would have just let him slide down. I was holding on to him with all my might and he was holding on to me, and I was yelling for help. They were cleaning the rug, so they couldn’t hear me. Finally the owner...
heard me, and he came out and took hold of him, and he wouldn’t let go of me. So finally, they sat me down because I was in worse shape then him.

Interviewer: When something happens it can have a worse effect on you then it can on him. That’s a problem.
Rebecca: And I don’t have the strength to lift him, to hold him.

Interviewer: You’ve been through a lot of physical problems, which you still have. It would be very difficult for you to keep him at home. You’d be putting yourself at risk, and him.
Rebecca: Risk to him, because some people are very sensitive and they sense your attitude. Oh yeah, if my attitude would change, if I would get annoyed or something, he’d sense that, and he would let me know about it. It’s much easier now. Now I tell him if I go in there, I say, I gotta go now or I tell him a white lie like: I have to go see the doctor or something, and I’ll see you. He says, "Are you coming back, I want you back later. I want you coming back." And sometimes he’ll say to me, "I want to go home and stay over night." I used to take him home to stay over two nights and then I would take him back. But then he wasn’t that much incontinent. I had to put a diaper on him and make the bed so my mattress wouldn’t get soaking wet. He used to get up at night and try to go to the bathroom and get off the diaper. So it’s - I don’t have to go through that 24 hours.

Interviewer: This is really the best way to handle it.
Rebecca: It's the best way to handle it. This way is the best. And then I was thinking, oh a couple of months ago, to try to get somebody in the house. That wouldn't cost me any less than the home. I talked to one, and they would come in from 7 to 7 and that would cost $800 a month, and where's the food?

Interviewer: You have to feed them. That's right. And you're still not getting 24 hour care.

Rebecca: No. Everybody is against it because he'll call for me. I had help for four months. She didn't have a home to live in; so I told her I'll pay her $50 a week to help me in the house and help me with my husband. But my husband used to get up a few times a night, call for me, and she didn't budge. So most of the time I was going in to his room and checking him out. And she made me so nervous. I think she caused a lot of my anxiety that time, too. Finally, she told me that "You are my worst enemy." I said, "If I am your worst enemy, then we cannot be together under one roof and you have to go."

Interviewer: That's another big problem.

Rebecca: But then she told me, but in this she case was right. She said, "He needs just a person to be with him alone. And for this I charge $900 a month." And help all the time - help him dress, help him wash. He needed help all the time because he was going down. I couldn't see it that much, I guess. But I had to let her go. We parted.
I had to handle it.

Interviewer: That's the trouble. You get people into your home and you have to deal with their personalities and their ...

Rebecca: She told me she didn't do a lot of things. She did clean the house once a week.

Interviewer: That's not a big help.

Rebecca: No, it's not. I'm not used to having domestic help in the house. I always did it myself. So I have tried that kind of help. When I had my operation, my daughter came over. She was four weeks with me. My husband stayed here with us. But there were always problems with him. You know, you forget those things. And I say, "Damn it, why can't I just make peace for myself. It has to be like this? The heck with everything else, it's you that counts."

Rebecca: Sometimes I try logic. When I know I gotta go down to him and I go. It's such an effort, it's such an effort. Once I get down there, things don't change. He's the same. If I don't see him for a couple of days, like I was in the hospital and I didn't see him for four days. It didn't really make any difference.

Interviewer: So you have to take care of yourself.

Rebecca: Yes I do. And I'm trying.

Interviewer: You are, you really are. I know, I know the pain that you're feeling. You're doing the very best that you can in a very difficult situation. And you are important,
Rebecca: As long I don't have pain, can do so many things, and I can take care of myself. Nobody waits on me, nobody takes care of me. The only time was with my daughter. I got so bad, and she didn't realize what was happening to me. I used to call my son in Boston and just cry on the telephone. She realized that something was terribly wrong with me. She took me to her house for a whole week and took care of me. I was in a daze - sitting and staring and clasping my hands. I was going mishuga (crazy), but I knew what I was doing. And that's when the decision came about that, we gotta save the one that's drowning. The one that drowns we can do nothing for him. They're drowned. Can do nothing for him. So, can you imagine the poor kids; it was a couple of weeks of sleepless and helpless days of crying and everything else. She went and she looked for homes and got information. I couldn't look. Even when we transferred him from this home to the other home, I wasn't here, she did it.

Interviewer: She's younger and stronger.

Rebecca: Yeah. (Goes on to talk about her operation and how her cancer came back and her need for surgery).

Interviewer: It's incredible.

Rebecca: That I still go on?

Interviewer: That you're able to do everything that you're doing. That you're able to be there for your husband, that you're able to be there for your daughter, for you grand-
children.
Rebecca: But maybe that's what keeps me going.
Interviewer: Maybe. That very well may be. It's good for you. Do you find it helpful to talk to other people who have members of their family with Alzheimer's Disease, or does it make you feel worse?
Rebecca: It doesn't make me feel worse, because we are going through the same thing.
Interviewer: So it helps.
Rebecca: It doesn't help much, not that much because you know you are in the same boat and that's it. You compare notes sometimes.
Interviewer: Do you get ideas from them about things you can do?
Rebecca: No. I think when you're at home you look more for ideas, when the person is home. But once they're not in the house, you hope for a miracle.
Interviewer: That's probably the biggest thing, that you keep hoping for a miracle. Do you feel that you have to be the strong one in the family?
Rebecca: Who else? With the children I don't have to be strong, I just can't kvetch (complain). You always have to put on a face, smiling face. You know my grandchildren - I used to laugh a lot, and my grandchildren used to tell me, "Grandma you're always laughing, you're always laughing," but grandma is not laughing anymore.
Interviewer: That's another burden making other people think that you're doing okay.

Rebecca: Yeah. They look at me and they think nothing's wrong with my life - nothing's wrong with me. Well that's okay too.

Interviewer: You're comfortable with that.

Rebecca: It's better then people should have pity on me.

Interviewer: That would be worse?

Rebecca: Yeah. If people know me, they know I'm sick. Nobody can help me. I help myself.

Interviewer: You're right. You do have to help yourself.

Rebecca: But, you need people, too.

Interviewer: Yes. You need people, too. I'm really impressed with you. I think you're making the best of a very, difficult situation. You're doing a darn good job of it. And a lot of people love you and need you. I hope this interview wasn't too difficult for you.

Rebecca: No. In a way it is. It's depressing, but I pick up my pieces - like a puzzle, put it back together and go on.
Case Study II — Tony and Maria

Tony and Maria have lived in the same home for the past 35 years. Tony is 75 and Maria is 77 years old. They have been married for 46 years. They have three children and live together, with their dog, in the middle of an urban neighborhood that surrounds their small farm — one of the few remaining in their neighborhood. Their home is simple and comfortable and has great significance to them. They built it themselves, and this is where they raised their children. Two years ago, Maria began to show symptoms of forgetfulness and was diagnosed as having Alzheimer’s Disease.

Tony: For the last two years, we have been having difficulty with this forgetfulness. We went to The Medical Center and they said that there was nothing they could do about it. As long as she was 70 years old, it was mostly caused by old age. We had our grandkids over here — my son got a divorce and his wife ran away, and left two little kids in diapers. We had 'em here, and I raised the little kids, and got them out of diapers and had 'em for about a year and a half. She ran across Main Street with them kids. She had one in one hand, and the other in the other hand, and they jumped a curb and they pulled her down and she hit her head on the cement, and then she got worse. Her face was all black and blue.

About 5 years ago she had Cancer and a hysterectomy, and that saved her. These things cause you to run your resistance
down. Then 12 years ago I had a hip operation, and they left one leg shorter and that wore out. Last Christmas I had another operation. I have two hip joints one is a short one and one is a longer joint. When I went through that operation she failed us.

Interviewer: When you were away she got worse?
Tony: Yeah.

Interviewer: Was she here?
Tony: I was at the Veterans hospital for 15 days, and my daughter had to come and stay with her all the time. She ran away from my daughter and had to be brought home. We are just her and I now, nobody else. We do the cooking and the washing and anything that's required. My daughter comes over, and helps us clean this floor and make the bed every once in a while. She takes care of the daily bills, because we have other property, too. She helps us to take care of the other property. I have a son and he has property, too; him and I together.

Interviewer: How old is your son?
Tony: Well my daughter's 42 and she's the oldest so, he's about 40. We have three children. The other one is a son.

Interviewer: Where were you born.
Tony: I was born in Seattle, Washington. We came here to California in 1923. We have a big family.

Interviewer: Where was your wife born?
Tony: She was born in Sunnyvale. Her dad and my dad came
from the same town in Italy. They came here in the same boat and then they split up. (He goes on to tell where they settled and how they met).

Interviewer: How long have you been married?
Tony: We've been married 46 years. I was 25 and she was 27. A little bit late, but the depression kept us apart. I knew her when she was 15. We moved to Manteka and we pruned grapes and we picked peaches in the summer. And we done farm work. We had to be tough. We had to survive. (A siren starts to blast outside and Maria, who is also present during the interview says, "I hope the kids are in the right place." Tony tells her, "maybe somebody's having a baby, we don't know."

Interviewer: Does your union provide you any kind of benefits to help you?
Tony: I've got a pension.

Interviewer: Does it help you to care for your wife in any way?
Tony: Yeah, they're paying her the Medical Center bills and mine. It just started last year. My pension is $7,500 a year. That's over $100 a month and that's a lot of money. I'm a veteran of World War II. So I was covered by the Veterans. (Tony also tells me that he is not in pain from his hip operations. He stated that he is suffering from osteo-arthritis).

Interviewer: Is it difficult for you to get around with that?
Tony: It’s not difficult to do anything. Only just that we have to preserve what we got left. That’s all.

Interviewer: Did your wife ever work?

Tony: Yeah. She worked in the canneries for about ten years.

Maria: I cut apricots.

Tony: Yeah, she cut apricots. We picked prunes her and I together.

Maria: Picked prunes.

Tony: Farm people. Nothing here when we came. No industry.

Interviewer: When do you think that this disease started?

Tony: We knew it was coming, because about 5 years ago, she would come in at night and make a wrong turn. We knew that she had lost her night vision. She hasn’t driven a car for about two years now. That’s when it really started. Two years ago.

Interviewer: What did you notice when this really started?

Tony: Well, she’s been normal until about the last year or so. She’s been real well. Last year I had to take over the cooking and the....

Interviewer: What has changed in the last year? How has she changed?

Tony: Well, her duties have changed. I’m taking care of her duties. He cooking, her washing, her scrubbing and of course we’ve been together all the time anyway. We’ve never been separated. We were separated for 2 1/2 years during the war, World War II. Then, she got worse; when I had this hip
operation two years ago. Then she didn’t know where she was and my daughter had to be with her. They told us it’s Alz-
heimer’s. They said to come in every three months. There’s nothing they could do. It’s just like a talk show. They talk to her. They ask her who’s who and they weight her. She’s loosing weight. She eats steady, but she’s still loosing weight.
Maria: It tastes too good. (laughs)
Tony: Her rings just got to where they just fell off. You know, and the doctor said, "That’s okay, it’s not too bad".
Maria: You don’t have to have everything.
Tony: No. We just got rid of her rings. She lost them and put them away in her junk pile.
Interviewer: Is she on any medication?
Tony: They won’t give her anything. Just over the counter drugs. Take multiple vitamins and zinc. She hates pills.
Maria: As long as she feels all right, she can keep the pills. I mean they’re just....
Tony: The Veterans Administration has 1,500 people, and they got three kinds of drugs that they give them. One group they just give them sugar pill. And then they run a test on this section. We went to see them and they said, "We’ll put you in the control group." They sent us literature, too. But they want us to join the control group. So far, I’ve had to drag somebody else in beside me. My daughter and her sister is interested. Interviewer: Are you participating in this study
at the VA?

Tony: No. I don’t think so, because they have already determined that they have somebody else that is more suitable.

Interviewer: Have you gone to anybody else for a diagnosis?

Tony: We are just taking things as they are. We’re not going to spend no money at all.

Interviewer: The Medical Center told you, and that’s enough.

Tony: We’ve got money. We could spend ten or twenty thousand and we’d just making a bunch of crooks rich. The doctors, they have to make it in just a short time. They grab all of your wealth because they don’t care, because they’ve been through hell. I’ve watched the doctors. They have to get up in the middle of the night, all hours, operating for six hours. So that’s why they plunder your wealth. You have money they want it. To hell with ‘em.

Interviewer: So you’re comfortable with the way things are going right now?

Tony: Yeah. Yeah. And we’ll have to get somebody that can come either live here or just be in and out.

Interviewer: If things get worse.

Tony: Yeah. So we might make it for another year or three or four years. We don’t know.

Maria: We don’t know.

Tony: Just take it as it comes. My daughter has most of the papers from the hospital. We’re helping her, too; we’re giving her $100 a month for help and support, for the book
work. But she's lazy. She don't wanna go wash dishes. She's an office worker. They don't wanna hurt their finger nails or something. I don't know what the hell it is. (laughs) She gotta a boy 16, so she got enough work of her own to do.

Interviewer: Has this illness caused any problems in your family relationships?

Tony: No. We're all up in age. And we realize that we've lost so many people. We belong to the Veterans, too; and every month we run down there and bury somebody. We've lost a lot of our friends around here. We know, that as an age group, we're just about as stable as anybody.

Interviewer: There are no problems between you and your children?

Tony: No. I write the checks. (holding up his checkbook). If I'd give 'em a chance to write the checks, we'd be in hell. They're high on the hog. You know what I mean? So, if they need a couple of bucks, then I give it to them. We've got the wealth. I mean, we have it. We don't need no help from no charities and nobody. The only thing is that we're depression born, and we don't actually make our young kids happy. We went through hell, trying to get started; her and

Interviewer: Fifteen years in slavery almost, like the blacks shoveling coal out in Kentucky somewhere, or picking cotton for $1 a day.

Maria: We were doing that the other night with our....

Interviewer: What do you think is the cause of this disease.
Do you have any ideas about it?
Tony: I believe it's some kind of affliction that comes from like arthritis and crystallization of your sugars in your body. We're all blood and guts, or whatever it is. They've got fancy names for all these things, but when your time comes, you're senility doesn't go through any corrections. Your bladder might be the cause or your heart or your lungs or something that's defective you see. And this pulls on you. It's old age mostly.

Interviewer: So you think it's old age.
Tony: With her and I, it is. If she was 46 and got it, then I would think it's some other kind of.... Yeah. I think so.
Interviewer: You don't think this as a disease?
Tony: It isn't something that you would catch, out of the river or the mountains, or it just grows on you. I don't think so. There's no cure. I lived with animals. I lived with a horse doctor for ten years, and we take a different slant on life. Everything's got a replacement. You know, our replacement's here. It's a matter of time that we won't be here then, so that's all that it amounts to. A lot of people, they say that the finest water in the world is in Kentucky. And when they get into race horses, and they bring their race horses out here, they bring the water, and the hay. They don't change the feed. And what do we get through the local system? We get chlorination in the water and they got
all kinds of debris. And the guys fly over, and they spray the lake where you’re drinking from. So there are so many damn chemical mixes, that we don’t know it. They don’t tell you.

Interviewer: So you don’t know what you’re getting in your body that’s causing you...

Tony: No. You don’t know what you’re taking! Even if you buy a piece of meat, they color the meat with red dye and its got all these different preservatives. If you throw the meat down, the flies won’t even get on it. So how do we know what the hell we’re gettin. We got some oats. Them oats taste like iodine. Now they’ve sprayed them maybe in the mill - to kill the weevils in the mill. Then scrape it up and throw it in the bin. Nobody cares what you get to eat. I realize, as a farmer, we had to spray our crops. Some guys figure that a little is good, but ten times that much is maybe better. That’s the way farmers are. They waste chemicals and that’s what’s killing us I think.

Interviewer: So you think a lot of the chemicals that are on our foods and in our body could be causing things like Alzheimer’s Disease?

Tony: Yeah! Sure! I think that we’re being killed slowly with all this patented food that they got. They used to make them rolled oats and put them in 50 gallon barrels, and now, they put them in packages and the waxed paper and all the wrappings and everything is synthetic stuff. Even the clothes
you wear could be bad. These clothes are made of natural gas. They are no good because they won’t even hardly hold thread. We had a more hazardous life, too. We ate spaghetti all our life. Spaghetti and meatballs. Italian people, see. It’s possible that with the spaghetti starch we might of missed something important. A lot of people eat the red meat, and they eat the fruits. Everything for her and I came in season. When there’s peaches we got peaches. When there’s fish, we got fish or whatever it was. We got it off our own property.

Interviewer: You think your diet may have something to do with Alzheimer’s Disease?
Tony: It might have something to do with this.
(goes on to tell me how he didn’t get an education because there were no jobs)

Interviewer: You’ve had a hard life. Both of you have worked hard.
Tony: She used to walk eight miles a day twice a day to come and go.

Interviewer: Does she still get out to walk?
Tony: Well, we walk, but I don’t walk too much. It’s hard to walk. I ride a bike.

Interviewer: So it’s hard for you to get her out for a walk?
Tony: Yeah. It’s hard. I walk with a cane. But I have to watch her crossing the street.

Interviewer: What is biggest problem with relationship to
the Alzheimer’s Disease?
Tony: We’re pretty compatible. We’re about equal in fiber and in strength and brain power. And she fails me in the evenings, and I have to leave part of the lights on; and she’s doing fine. She eats good, and she can take care of her body functions.
Maria: Well, hurry up so I can get some cookies.
Tony: Where are they at? Where the cookies at?
Maria: (laughs) I’ll have to look.
Interviewer: So your biggest problem is at night? Does she sleep?
Tony: Yeah, we sleep. We listen to the talk shows. They’re educational, and it’s like having people; like having company.
Interviewer: Does she dress herself?
Tony: She dresses herself. But sometimes she puts two legs in one pants legs, and she tries to put her shirt where her pants are supposed to be. She goes to bed with her clothes on and gets up in the morning and she don’t have to dress.
Interviewer: In the beginning, when you first got this diagnosis, did she understand what was wrong with her? Was she told?
Tony: I don’t know. She says her head is going bad. That’s all she ever says.
Interviewer: Was there any depression?
Tony: She’s doing fine; she don’t have any.
Interviewer: Frustrated?
Tony: No, she don't have no tantrums or nothing. She thinks she's waiting for somebody, and she won't go with us. Up to, now she was even doing pretty good in the supermarket. I'm able to get her to go with the shopping cart, but sometimes she want's to get somebody else's shopping cart away from them. She don't realize which shopping cart is hers. But, we buy all the food. We get them rolls of paper. She likes them rolls of paper. She folds them up and uses a lot of paper. Interviewer: Has she ever wondered away from the house?
Tony: A couple of times. The cops brought her home at night about dark.
Interviewer: How did they know where to bring her?
Tony: We've had our name in the book for years. She told her name, and they looked it up.
Interviewer: Did you know she was missing?
Tony: No. I was working in the back of the house, and I was cleaning up. I thought she was in the house. This place was lit, up and here comes a cop up the driveway. I was putting the garbage cans out. So the police drove in and said I got your wife. So we're getting a band - they cost about $20. Interviewer: Have you spoken with other families who have members with Alzheimer's Disease?
Tony: Well, not too much. There's a boy next door who says his grandmother has it, and they brought her down from Davis to here; and she just went haywire because they took her out of her environment. So I'm not letting Maria get out of her
environment. Actually, if you’re going to hire someone it will cost over a $1,000 a month. We might as well have a thousand between her and I. Until we can’t do it, then I’m willing to pay two thousand for care.

Interviewer: You don’t see any problem in being able to afford that care?

Tony: No. We’re pretty well healed. I’ve got property all over the country. As long as we don’t have a disaster, like an atomic bomb. I’m a pretty good saver. It’s useless to use money for something you can’t buy. They could cut out things and replace it with metal like with me. She has Social Security about $350 a month, and my union is paying me $625 a month.

Interviewer: So, financially you don’t see anything as a problem. The problem is the illness, and how bad it can get.

Tony: That’s right.

Interviewer: Do you think this has happened very fast?

Tony: We noticed it in the last three years. It’s been slow.

Interviewer: How has it caused you to feel? Have you become depressed or discouraged?

Tony: We’re both Siciliano; and Siciliano, they don’t get no divorces, they don’t fight. We might be crazy a little bit, but we’re both of the same temperament, the same fire. We just stay in the family, and handle it. We’ve watched old people in our families. The old people used to have a farmhouse, and they just smoked, and just sat there until they
died. They couldn’t handle their water. This is a problem that’s coming up. You know, if we can’t handle our water. Then we have to have nurses or somebody. They have diapers and things. We’re still doing pretty good. We get up three or four times a night now. We turn the radio on. It shuts itself off every half hour; so if you want to hear it, you gotta turn it back on. Just go to sleep or rest. Actually old people don’t need more than about three or four hours of sleep a night. (Goes on to tell me how they have cared for their parents until they died). So we’ve had this – this sickness and disease.

Interviewer: You know what to expect. And you feel that you’re both strong enough to live through this and to handle it. It sounds to me like you have a very strong, loving relationship.

Tony: Yeah. We’ve got a lot. Kids and grandkids. So we have a lot to live for. (Spends some time showing me pictures of his family). We’ve traveled all over the country.

Interviewer: You feel that you’ve done all the things you’ve wanted to do?

Tony: Yeah. Just about.

Interviewer: Has anyone ever told you that she’s in a certain stage of the disease?

Tony: No. I don’t think so. I think it’s the beginning now. Maybe in six months she won’t recognize people. That’s what happens and pretty soon they quit. (Show’s me more pictures).
Interviewer: How do you spend your day?

Tony: We listen to the radio a lot, and I waste a couple of hours riding the bike, and at 10:00, I get some sandwiches and get something to eat, and then I usually do some yard work. Maria tries to do yard work, too. We mostly take care of our business. We've got rental property. (Starts talking about how they built up their property investments).

Interviewer: What do you see becoming a problem for you due to this disease?

Tony: The biggest problem is when we can't take care of our waste matter. Then I'll have to hire a trained nurse and somebody to come and clean the place or put her in a rest home. Or if she runs away, then I'll have trouble gettin her back. I'm worried about anybody demented running out on Main Street. You know, they'd get run over, because them guys are cuckoo.

Interviewer: How do you think you can prevent her from running away?

Tony: Just be with her all the time. My daughter wants me to put a chain link fence around this place, but it might hurt her mind more then anything, when she thinks she can't get out. I had her penned in here, and she pulled the latches off of the door and came out of the garage.

Interviewer: She gets pretty agitated when she can't get out.
Maria: I don't do it often anyway.
Tony: Yeah. So we've been together; and we go see her brother.
Her brother and his wife - she had a heart bypass. We see eye to eye with anybody in our age group.
Interviewer: So you have a lot of family and a lot of friends. Right now you don't feel that you're isolated and alone.
Tony: No pressure of any kind. Yeah. Yeah. You can tell by the pictures, we've had a pretty good life. Maybe I didn't look like a millionaire, but I didn't have to.
Interviewer: You're satisfied with your life.
Tony: Yeah.
Interviewer: If there was anything that you could say to a family who has a member of their family with Alzheimer's Disease, what would you tell them?
Tony: If they were religious people, I would tell them, God has taken this person away from you. That's a pacification, and that's the truth. Really young people don't get this. I've heard of people 46 getting it but.... We have to leave this earth because we weren't made to last forever, and that's what I'd tell 'em. I'd tell people, your time is about up now.
Interviewer: So you feel it's an act of God.
Tony: Yeah, it's an act of God. That's the most peaceful thing you can tell anybody.
Interviewer: Have you found religion to be a great help to you?
Tony: I never went for no religion because I never had no education.
Interviewer: Just your belief in God.
Tony: Yeah. Yeah. I believe that we had a good life, and that now we have kids to take our place; and there's no backing out. (Starts talking again about his travels through the United States).
Interviewer: You've been around and traveled and you really feel good about that. You've done all the things you've wanted to do.
Tony: Oh yeah!
Interviewer: How do your children react to the fact that their mother has this disease?
Maria: They know. They know.
Tony: We're protecting the younger kids. We don't want them over here to see what's going on.
Interviewer: Your grandchildren?
Tony: Yeah, our little grandkids. The older one is okay, but the younger one, she's 10 and the other girl is 5. We don't want them around.
Interviewer: You think it would be harmful for them to be around?
Tony: Kind of a stagnation, you know. If you had somebody bad in your family, you'd say maybe they're cracking up
because your people are insane or something. We can't handle
the kids anyway.

Interviewer: It would be too much for you.

Tony: Yeah.

Interviewer: How have your children reacted to this?

Tony: Our kids are very sensible and very agreeable.

Interviewer: How about your daughter?

Tony: She feels that it's okay; that there's no stigma.
As long as they don't call it insanity, it's all right. They
changed the name, you see.

Interviewer: You understand that this is not a mental
illness, it's a disease.

Tony: Yeah. It's a decapitating - something that's going
over your brain interfering with the circuitry.

Interviewer: Do you think your daughter gets depressed over
this. Do you think it bothers her in any way?

Tony: No. No. They're going to inherit a lot of money when
I die, and they can't blow it. They ain't going to get it
until they're quite old, I'm seeing to it. Unless I blow it
for her (Maria). But we're not gonna make any moves, unless
it's in our favor. Whatever that move will be.

Interviewer: You are prepared for whatever is going to happen
and you can handle it.

Tony: Yeah! Whatever comes! She jerks a little, once in
a while, now. And her hands, she drops stuff.

Maria: Well my hands - food still tastes the same.
Tony: I feel that these are electric shocks down from part of her mind. It could be to her joints but it’s nerves. (Begins to talk about his surgery and how he survived).

Interviewer: It sounds to me like you are making the very best of this situation. You certainly are a very strong person and you know what you want in life, and how to take care of everybody.

Tony: I’ve drug people through the depression, and I’ve been in swamps, I’ve been in floods, and I’ve been shot at. I was even shipwrecked at sea.

Interviewer: So, you’ve been through war and you’ve been through the depression.

Tony: And I risked my life as an ironworker.

Interviewer: You risked your life as an ironworker, and this is one more thing in life that you feel you can handle.

Tony: Oh yeah!

Interviewer: I think you can, too.

Tony: Oh yeah! I believe that some people fail and get sugar diabetes, and they have their legs cut off. We had a man here that first one leg, and then another, and then they die. I’d rather we’d have this then some other kind of disease for old age and whatever you want to call it. We’ve been with old people and we know you’re not going to make it, you know, it don’t hurt us that much.

Interviewer: You said that you’d rather have this illness in old age rather then other illness. What did you mean by
Tony: Well, when you have sugar diabetes, then they start hacking on you, and they cut your legs off, and you can't walk around any more. And if you had Cancer, then your taking radiation and burning the hair off your head and everything. If you had even a stroke, people can't throw their voice out anymore. They can't walk well, and they shuffle along. We belong to VFW and we've been burying people with a military burial, and they've been dying from every imaginable thing. Some of them even die from stress.

Interviewer: How do you see this disease as being different?

Tony: This is very pleasing compared to others.

Interviewer: In what way?

Tony: It's a lingering thing, and least we're getting this much out of each other.

Interviewer: You have more time.

Tony: Sure! I have time, and I ain't going nowhere. I'm about half way shot with these two bad hips. So I'm really happy that it's ending like this rather then sudden death by accident - gettin drunk and wrecking your car.

Interviewer: You feel that there are a lot worse ways to end your life?

Tony: Oh yeah, there sure is a lot worse ways! Well we feel that right now we're stable.

Interviewer: I think you are, too.

Tony: This is what keeps us going, this check book.
Interviewer: What do you think about nursing homes?
Tony: I don't think much of them. They give you a lot of cheap food and stuff that don't cost too much. They give you stuff that makes you weak. They weaken them down right away so they don't give them no trouble. You go in there and people are sitting and just staring. My mother was in a rest home, and she tried to kill herself. She fell over with the wheel chair. She was all black and blue. She was pretty tough, and she made it anyway. "When you get old, you wish that death would come," that's what she would say.

Case Study III - Carol and Jack
Carol and Jack have been married for 15 years. This was a second marriage for each of them. Carol has one child by her first marriage and Jack has two. Jack is now living in a board and care facility and Carol lives alone in their modest home.
Carol: This disease alters your whole life. You're not married, and your not single.
Interviewer: How long have you been married?
Carol: 15 years.
Interviewer: Is this your first marriage?
Carol: No. Second (begins to cry) His son gave me support for a while, but he's turned away from the family. His daughter, we don't even see her, we don't even know where she is.
Joe is 44 and Susan is 40. She was here for a while, and she used to come and see him once in a while, but not that often.
She couldn't get through to him, I guess. They used to play golf and then she said, "He's not coordinated enough to play golf." That's the time I was working, and all I wanted them to do was come over days, so I wouldn't have to have a full load of it. Well, I finally had to quit work.

Interviewer: You had to stop working.

Carol: Oh yeah! Because I couldn't leave him alone. I tried to take him to day care centers, and he wouldn't stay.

Interviewer: How did it start?

Carol: I don't know, he just was very confused, very different. It started about six or seven years ago.

Interviewer: At the time, were you aware that it was some kind of disease process?

Carol: No. I had no idea what it was. You just don't talk about these things. I always blamed it on me. I thought, gee, I'm doing something, I must be imagining that he's doing these things. And I thought, I'm not going to say anything, and then his daughter decided something is wrong and she said, "Dad's not getting his right vitamins."

Interviewer: What made her think that something was wrong?

Carol: Oh. He'd get in the car and he'd get out of the car and leave it running. He'd lose things. He'd accuse you of things you were doing, and you weren't doing it. Still right now, he hallucinates an awful lot, which is great, because he will always try to hand me something and I'll take it, and then he's happy. I have no idea in the world what it is.
Susan says, well maybe he needs vitamins, so I was giving him 20 vitamins a day. We'd have to go down to this doctor in Santa Cruz and pick up the vitamins and come back. It was quite expensive. I said okay, I'd try it, and we tried it for three months and there wasn't any improvement.

Interviewer: What kind of vitamins?

Carol: Oh, a lot of different natural vitamins which this doctor prescribed.

Interviewer: Did he charge you a lot of money for his services?

Carol: Oh yeah, he did. We were not covered for our medical visits to him because we belonged to the Medical Center, and he was not one of their doctors. To satisfy her, I'd do anything. Just to satisfy her. Well, then it got real scary because sometimes he wanted to drive. I'd do everything in the world to talk him out of driving. But he'd want to drive, and I just didn't trust him. I couldn't trust him. He might make the wrong turn or something and I'd say, "Jack it's the next turn". "I know where I'm going!" He would get very hostile. He's not that type of a man at all. I figured that he figured that something's going wrong and maybe he's like most men, they're too proud. They won't admit if they can't take care of themselves, and you. Lots of times he say, "Don't you think it's time that I drove," and I'd think, oh good Lord above, what do I do now? So I'd pull off onto a side road so he wouldn't have to drive in traffic. He'd cut
people off and keep switching lanes. It was just too scary to drive with him.

Interviewer: Did he understand that he was forgetting things at that time, or he just wouldn't talk about it?
Carol: Oh, no. He would never admit it.

Interviewer: This must have put a strain on your relationship.

Carol: Right! Definitely, and he kept losing things and kept saying that I was taking things from him. Like his keys. His money, his billfold. We went on a trip back East and it was the travelers checks. He couldn’t write. He couldn’t write his name. Every once in a while he’d sign something. I’d write his name and I said, "Now you follow this." He realized that he couldn’t sign it.

Interviewer: How did he react to that?
Carol: He realized it. But like the checks. It was traumatic for him to give me the checkbook, because he took care of everything.

Interviewer: His functions were being taken over. These important things that he did were being taken over.

Carol: Right, right. He’d ask me if I wrote a check or something. He was very pinch penny, so he’d ask me if I wrote a check. I’m glad now. It’s a good thing that he did save up like that. If he knew right now how much it’s costing him to live there, he’d flip!

Interviewer: You slowly had to take over all the household
duties, and all the chores. Was he working at the time he became ill?

Carol: I think maybe it started after he retired; when he was 63. He wanted to work part time after he retired because he had no hobbies. His hobby was watching television because he didn’t read. Every once in a while I could get him to play cards, but not too much. He wanted to play cards because I played cards, but he couldn’t coordinate. He slowed down, and he couldn’t think properly. He’d get discouraged, and we’d all get discouraged with him because he was so slow. It’s no fun playing with him when you have to keep on saying "Come on Jack, it’s your turn, come on Jack, come on, it’s your turn." He’d get frustrated, and then he’d get mad and then he’d get up and walk away. Then he’d come back again. Lots of times I would have company from back East, and he would sit in the other room watching television, and he wouldn’t even come in and join us. That wasn’t like him. He became very antisocial because he realized that he couldn’t keep up with the conversation and what was going on.

Interviewer: Did it take a long time for the disease to progress?

Carol: No. I don’t think it took a long time. One of the funny things that happened was, we had a four door car. When he finally gave up trying to drive, he’d get in the back seat of the car, and I’d be up in the front seat. At first, I used to say, "Come on up in the front seat." Then I decided not to
argue with him. He was perfectly content to sit in the back seat, and I'm up in the front seat driving. I'd go driving up the street, and I'd laugh, because it was funny. He didn't realize that he was sitting in the back seat. Even now I'll take him out once in a while, and he'll get into the back seat. I don't know what makes him do that. I was glad though, because I could lock the back doors and it was safer for him.

Interviewer: Did you go for other medical opinions when Jack was diagnosed as having Alzheimer's Disease?

Carol: No. The doctor at the Medical Clinic diagnosed him. He took me aside, and told me, "You know, your husband isn't going to get better, even with medication." We went to a psychiatrist after that because they said that I needed it, and he didn't. I was trying to point out to the doctors that he's the one that needs it, and I'm not imagining things. The doctor couldn't see all the things that I was going through. So you see, the doctors don't know. The psychiatrist was right though. He could foresee into the future that because of taking care of Jack, I needed relief from him. That Jack should be taken care of, or I would go crazy. This was about 6 years ago. I also had to pay for the psychiatrist because my medical insurance didn't cover it. It cost about $50 an hour. I only went twice, because I felt that I am the type of a person who is determined to handle this by myself. I just took what he said. He said that I was taking things too
seriously, and Jack wasn't so bad. Of course, this was before Alzheimer's Disease came out into the open. Even the doctor at the Medical Center didn't come right out and say that it was Alzheimer's. A friend of mine who is a nurse, got involved and told me about a local support group. She told me who to contact, and I went. That was the most wonderful thing. To think that other people had the same problems that I did, and I'm not the only one who's going crazy! I really thought there was something wrong with me. My friends could see it though. They would say, "How come you put up with him like that." I said, "Well, what am I going to do." I'd have to keep giving in to him. If he wanted something, I'd give in to him. If he wanted to go some place, I'd give in to him. Just to keep peace in the family, because I'm not a fighter I don't fight with him. I'd rather give in, and when I'd give in, he was fine. Even now at the home they say, "Jack is a great guy, as long as you do things his way." Of course, they know how to work around him. They can calm him down.

Interviewer: Before you found the support group, you felt that people just didn't understand what you were going through?

Carol: Yes! They didn't understand. You don't understand it unless you live with somebody for 24 hours a day. His son could see it, too. Even my son would say, "Hey, what's the matter with Jack today?" Jack would pick on my grandson, who is the sweetest thing, and he'd always pick on Dennis; and
Dennis was trying to be so nice to him and trying to understand him.

Interviewer: How did that affect Bobby?
Carol: Well, we’d just tell Bobby, Jack is sick so just try to put up with him, and he was okay about it.

Interviewer: Did the children stop coming over when these things started happening?
Carol: Yes. That’s right. The kids didn’t come over that much, because they didn’t know how to take Jack. He was kind of rough with them. For a while, I took him over there, and he’d just sit on the couch and go to sleep for the whole time. Then we’d wake him up and he’d get angry and say, "I’m not hungry!" He’d get very disturbed. We didn’t know if we should wake him up and bring him to the table or shouldn’t we.

Interviewer: Was hard to take him anywhere?
Carol: Yes. But he did like to dance, and we’d go out to dance. I don’t know if it’s the music or what. He was kinda disturbed when you talked to him – kinda mixed up – but he did like to get up and dance. He always loved to go – even when I bring him back here now and give him something to eat, he’d say, "Okay, now we gonna go?" He loves people around him.

Which is great.

Interviewer: Has his personality changed?
Carol: Well, he talks a lot now. He used to be so quiet. He was the type of person you couldn’t sit down and communicate with. I don’t know that much about his family, because he
wouldn’t communicate with me. He was very quiet. Now he doesn’t make any sense. He just talks. Like at the home, he’ll look out of the window and he’ll say, "Oh, there’s Carol’s car, the yellow one."

And I’ll be sitting right along side of him. I say, "Does Carl come to see you?" And he answers, "Not very often."

Interviewer: Do you think his children stopped coming around because they couldn’t handle what is happening to their father?

Carol: I don’t know about the youngest girl because she is a very funny person. Her dad spoiled her. She was his little doll, and she’s very smart. I think she just can’t take it. He’s not communicating with her. Everybody always felt that she was a doll, and they all put her up on a pedestal. And she is. But she is very, very self centered. She couldn’t get all that attention from Jack because he couldn’t keep up with her mentally anymore. He just wasn’t coherent. He couldn’t respond to her the way he used to. Interviewer: How did she react to this change in her dad?

Carol: Well, I don’t know. I know that there were some things that were happening, because she would come over to visit him when I was working. She’d stay here for maybe an hour, and she’d leave before I got home from work. By the time I got home from work, he was very disturbed and very upset. But he would never tell me what had happened. I found out more from his son. He told me that they were arguing, but
I don't know what it was all about.

Interviewer: His youngest daughter pretty much out of the picture. Does she have any idea how he's doing?

Carol: When he gets sick, or like last year, he had to go into the hospital, or when he changes homes, I always call her and leave a message on her answering machine and let her know.

Interviewer: It sounds like she is not dealing with what is happening to her dad because it's too painful for her.

Carol: That's right.

Interviewer: And what about his son.

Carol: He's okay, but it's hard on him. Even though last time he was there, Jack was in such a good mood. He visits occasionally. He's trying. I think that he is concerned about this disease being hereditary. It might be that it's just like cancer. If it's in your genes, you're going to get it. He'll ask me once in a while and say, "Have they found out anything or have they decided about it being hereditary?" I've told him that I want to have an autopsy done on his dad. He says, "I don't care. I don't want to know if it's hereditary." He doesn't want to know if he's going to get it. He tells me, "so don't spend the extra money".

Interviewer: He's really frightened.

Carol: Yes. He is.

Interviewer: But, you'd like to know.

Carol: Well, I'd like to know for research. Because, I
figure that it won’t help Jack, but it will help somebody else. I’d like to donate his organs, but they won’t take them. You can’t donate his eyes or anything because they don’t know. Well, that’s only right, because if somebody had Alzheimer’s I wouldn’t want part of their body.

Interviewer: Has his son ever made an attempt to go to a support group meeting to try to deal with his father’s illness?

Carol: No.

Interviewer: Has it affected his life in any way?

Carol: Oh, I don’t think so. He just got his master’s degree and he does a lot of studying. He just thinks that his dad wasn’t very smart. That’s the only thing he says to me, and that’s why he pushes himself in school all the time. He pushes himself a lot.

Interviewer: He feels that if he pushes himself, this won’t happen to him?

Carol: Yes, yes. He says that after he retires, he wants to have something to do. He doesn’t just want to sit home and do nothing like his father. I know that his father didn’t have any hobbies, and I really tried. I’ve got so many myself, I’m busy 24 hours a day if I want to be. I love to travel, and that’s what I thought what we were going to do when he retired. Jack didn’t travel. He never wanted to go alone; he wanted someone to go with him. He always thought that was great; that we would go traveling together.
Interviewer: Did you miss a lot of time from work when he was sick?

Carol: No. Because they were very good to me and my neighbors here were just great. It got so that I was only working four days a week. If there was a problem or something or he would get lost - even the mailman would send him back home again. He was okay then. Many times he would get lost and go in the wrong house. Many times he went into the house next door. He would lock himself out. Both of my neighbors had keys, so they'd let him back into the house. He was pretty good there for a while, except for getting lost. He'd be disturbed because I wasn't here, and he'd do so many things here that I couldn't trust him. I'd scoot home on my lunch hour to check on him.

Interviewer: You were really under a lot of stress worrying about what he would do while you were at work. Coming home for lunch didn't give you any time to relax.

Carol: No. I didn't have lunch, I just would come home to check on him. I'd also call him on the phone, which was fine. He could answer the telephone, he couldn't dial out, but then, he wouldn't put the phone back on the hook again. I'd have to call my neighbor and ask if he would please go next door and hang up my phone. Of course, it got to be a joke and they didn't mind. They were here all the time, and you can't have your neighbors babysitting for you all the time. Then I was afraid that he would burn the house here
because he just loved to work in the kitchen. He ruined the stove because he left something on it and it burned. He'd do a lot of goofy things. He burned up the knobs on the stove.

Interviewer: When these sort of things started happening, what did you do?

Carol: Quit work! I had to! Even now when he comes over, he'll grab the coffee pot and pour the coffee down through the top of the stove. It got so that I was afraid. I felt that it wasn't worth it. So then I quit and stayed home. I had anticipated quitting before, but I wanted to keep working to make more money so we could travel. But in the end, I was only working about three days a week. It wasn't fair to them because I was one of their oldest employees and I knew what needed to be done. Then one of the other girls was sick, and I had to take over her job. I felt a responsibility to be there. They were very good to me, and if I had to leave early to take him to the doctor or to the hospital, they understood. Interviewer: How did Jack occupy himself when he was at home?

Carol: Mostly, he just watched television and took a walk. I tried to tell him what to do. I'd say, "Why don't you dust the furniture for me before I get home?" And he'd say, "That's not my job." I wouldn't dare tell him what I wanted for dinner that night because he would start to cook it. He loved to cook and I didn't trust him. I gave him a sandwich
sometimes, because I couldn’t leave him anything that he had
to cook or warm up. He forgot how to work the microwave oven.
I was thankful that he did forget, because goodness, he could
have burned that thing up. It wasn’t really too long that he
was by himself, after he stopped working. At work they
couldn’t cope with him. When he would come home from work
he’d be real mad at the boss because he said the boss picked
on him all the time.
Interviewer: Was there a lot of conflict at work?
Carol: Yes. It was his fault. It wasn’t the bosses fault.
They tried to give him work to do, sorting different items,
and he couldn’t do it. He’d put everything in the wrong
place. They realized that he couldn’t do that, and they tried
to give him another job sorting the mail and he couldn’t do
that either. They told me that something was going on, and we
went down to their doctors. Their doctors are the ones that
really told me a lot. That doctor was very nice to me, and
said that he thought he had Alzheimer’s, and I should take him
to our family doctor. Then they put him on disability.
Interviewer: How did you feel when he said that to you?
Carol: I didn’t know how bad it was. I really didn’t. I
though well, what do you do; you just accept it. I’ll do
all I can to help him. It’s just like if someone says to
you, "You have cancer." Your first reaction is, "Well, I’ll
see what I can do about it." I can go to a medical doctor and
get pills, knowing that there isn’t too many pills you can
take for mental disorders.

Interviewer: Were you relieved?

Carol: No. Maybe in the back of my mind I had anticipated it, because somewhere I had read about it. I thought maybe he does have it, but hopefully he doesn’t. But after that, we went to the Medical Center and the doctor there confirmed it. You can’t definitely come out and say that is what he has. But you assume that it is. So you just go on, and put up with it. So they put him on disability and Jack keeps saying, "As soon as I get better I’ll go back, I’ll go back." I knew that he wouldn’t get better, but he though in the back of his mind that he would. Even when we put him in the home, he said he thinks that he’s going to get better so he can come back home again. That was about a year ago. His son told him, at that time that, "Dad you’re not doing very well now and Carol can’t cope with it, and as soon as you get better, you can come back."

Interviewer: Was it his son that suggested that he go into the home?

Carol: No. It was my sister. They live out of town. One weekend Jack and I took a trip up there, and when we came back I just couldn’t take it any longer. It was a disastrous weekend. I was coming along in the car, and I don’t know what he’s going to do next! He was sitting in the back of the car, and I just couldn’t control him. I thought, oh good Lord, if I can only get home. And finally, I did. My sister came down
and she said, "You can't take this any longer." She didn't know if Jack was going to hit me or not. He was really mad, and really hostile. She said, "No more of this." She said, "We're going to put him in a home." So we put him in a home.

Interviewer: You felt that he was going to hurt you.
Carol: Oh yes! He just grabbed me and shook me! He was really mad! It was a terrible decision to have to make.

Interviewer: How did Jack react to this?
Carol: Oh, terrible! They had to tie him down in a chair. I don't know if he realized what was happening. I think it was the way that they did it. If they would have treated him nice or something. But they were very stern and said, "Well, you sit down!" Well you don't do that to an Alzheimer's patient. They said, "now you're going to sit there". He didn't want to sit there, he wanted to come up and sit with me, and they wouldn't let him. I had to sign the papers and everything, so they wouldn't let him. What they should have done was say, "Okay, Jack, hi;" come and invite him in and make him feel welcome. Where he is now they just welcomed him in and said, "Hi, Jack, how are you doing today," and they welcomed him in.

Interviewer: They treated him like a person.
Carol: Yes. They let him do it of his own free will. They ask him where he wants to sit, and if he doesn't want to sit, they say okay then you can go ahead and walk, and they let him walk. He's perfectly content. He thinks he has his life in order.
Interviewer: It's important for him to continue to make decisions even though he's not aware of what's happening.

Carol: Right! Even the others that are there, that's what they do, and they get along great with them. Once in a while, they get one that kind of riles everyone up, and then they just get that one out of the room. They just know how to handle it. They know how to cope with it.

Interviewer: How did you find the first nursing home?

Carol: I had a list of nursing homes. But at that particular time he didn't really need a skilled nursing home, but I put him in there. It cost $1,800 a month, and I couldn't afford that.

Interviewer: Were you covered by any kind of insurance?

Carol: Nothing! Then, I finally took him out and put him in a place where they charged $750. The only thing was that he kept running away all the time, and the police would bring him back. One time he fell. His son and I went over there that night. He couldn't walk. He couldn't stand on his two feet. He was sitting on the floor, and he couldn't even use the bathroom. Then they said that they couldn't handle him anymore. The doctors put him in the hospital, and gave him every kind of X-Ray to find out why he couldn't walk. They took every test they possibly could at the Medical Center. You'd ask him if he fell and he'd say, "I don't know."

Interviewer: He had an accident and nobody knew if he was hurt.
Carol: That's right. That's right. He had some black and blue marks on him, but we don't know. I don't know until this day how he got back to that home. They wouldn't tell me, they say they don't know. I didn't like that.

Interviewer: You suspect that the home wasn't caring for him properly?

Carol: Yes. The home was not locked. In order to put him in a locked facility, you have to sign a lot of papers. So I thought I'd take a chance and maybe they would watch him enough and keep an eye on him. I knew that he wondered. He wondered all around here.

Interviewer: Were they aware that he wondered when you put him in there?

Carol: Yes. They said don't worry about it, we'll watch him, we'll watch. Well several times, I found out from the other patients there, the police brought him back. He was laying out on the lawn somewhere, and the police got him and brought him back. So then, they put him in the hospital and he was there for about five days. And the poor guy, when they put him in emergency, they kept asking him, "Where does it hurt, where does it hurt?" And he wasn't coherent enough to say where it hurt. We really never knew. Then they wouldn't take him back again at that home so that's when I put him in the home he is in now.

Interviewer: Were they legally responsible for what happened to him while he was in their care?
Carol: Probably not, because they told me that it was not a locked facility. In the present home, they have a sensor on the door. He was in a wheelchair, and they took him even though he was in a wheel chair. His feet were just terrible. His legs were all swollen. Because the doctors didn't know what happened to him, they didn't know what kind of medication to give him or what to do for him. I'm very glad that I got him in there. When I take him out now, he says, "I can't go now, I have to get permission." At least now, that's sticking in his mind. Yesterday when I was leaving I said, "Goodbye, I'll see you later." He started going out with me and I said, "No you didn't get permission." He said, "Oh yes, I did!" They caught on to it quickly, because they see anybody who tries to go out that door. They just brought him back in and they watched him. They said, "Come on Jack, you're not going out this time." And he goes right back with them. If he wasn't doing that, I'd be worried to death.

Interviewer: What do they do there? Do they have any activities?

Carol: Once in a while, one of the girls will go out and they will try to get a game going. But they're not coherent enough. They can't do much. He doesn't even sit down and watch T.V. Tony: Their mind isn't active enough. He knows when I come to see him, or he watches the other people. It's funny because there's this little Italian lady. She is just precious. All she talks is Italian, and she talks to him and
she pats him on the leg, and she talks to him in Italian, and he sits there listening to her. It’s cute to see them comfort each other. Some of them there are okay, and they watch television. Once in a while, he’ll sing. Like around Christmas time when they had the carols and the singers come in. He sits there and he sings. He may not say the right words, but he sings.

Interviewer: What is it costing you now?
Carol: $1,000 a month.

Interviewer: You’re still not covered for anything?
Carol: He’s still not covered for anything. If he gets sick, he’s covered by the Medical Center.

Interviewer: How long do you think you can keep this up?
Carol: He gets $270 from Social Security, and $842 from his pension so that covers it. I’m very lucky in that respect. The only thing is, it’s not for me to live.

Interviewer: What about you?
Carol: (crying) Well, I have to dig into my savings. I get a Social Security check, but it doesn’t go very far. He has an honorable discharge from the Navy, but I cannot get him into the Veteran’s hospital because he did not see active service. That’s one of the requirements of getting him in there, unless I know somebody; and I don’t know anybody. Politics, politics. I’ve tried so hard, and so long, that I’ve just given up.

Interviewer: If he was able to get in there it wouldn’t cost
you anything?
Carol: That's right! They get very good care there. If I can't get him in there, why can't they help me financially? But I don't know who else to go to. So many people are in the same boat that I am in. I just don't know how it works. I've made more copies of his honorable discharge and sent it to more people. It's not fair.
Interviewer: How old is he?
Carol: He's 64.
Interviewer: This really happened to him at the age of retirement.
Carol: Right! That's what's really rough. That's what gets to me. You work all your life. Many of our friends are going on trips.... (crying). I think they're learning; don't stay home and save it. Spend your kids inheritance. Take off and go.
Interviewer: Are you able to do things by yourself?
Carol: I go on these senior citizens bus trips, and I like that.
Interviewer: You're really living in a very ideal place. There are a lot of things to do here.
Carol: Yes. Oh, yes. There's cards and bingo. I also go to exercise classes. So, I try. It's better then staying home and worrying a lot. When I stay home and sit around and think
about it, then I get all uptight. So, I do try to keep going a little bit to get my mind off of it.

Interviewer: Do you visit him every day?
Carol: Almost, but I shouldn’t. Everybody tells me don’t go every day, go every other day, because it gets to me.

Interviewer: Do you feel worse when you don’t go or do you feel worse when you do go?
Carol: I feel worse when I don’t go. I feel guilty. Because my problem is I feel guilty that I’m not taking care of him at home. That’s my problem in a nutshell.

Interviewer: I think that everybody feels that way, guilty.
Carol: I do. In fact, at Christmas time I was going over to my son’s house I said, "I’m going to bring Jack home to stay." He had a fit! And they said, "Oh you’d be so tied down." Then I looked back in my notes about what I had to put up with before. I wrote down little notes each day about what he did. All the goofy things he used to do, and I said gee, I don’t know if I could handle it again. Even when he’s here. Like going to the bathroom. If he wanted to go to the bathroom in the toaster, he’d go. If he wanted to go in the living room, he’d go in the living room.

Interviewer: Was he incontinent, or he just didn’t know where he was?
Carol: Probably, he didn’t know where he was. Even now, when he’s here, he’ll say, "I have to go see a man," and he’ll go in the second bedroom. He’s got diapers on so that’s
great. I’m not really that worried, but it’s just the idea that he wants to do something and I think, oh my gosh, what am I going to do? The other time I had him in here, I got him to the bathroom and I took off part of his diaper and he’s wetting all down his pants. So the diapers are wet, the pants are wet and the floors all wet. He won’t sit. He still won’t sit. A lot of them have that same trait. They just won’t sit on the pot. 

Interviewer: Maybe that part of the brain that deals with those messages is not functioning.

Carol: Yes. Could be.

Interviewer: When you don’t go to visit him you feel guilty. What happens when you do go?

Carol: Well, if he’s in a good mood, fine. Then all the way home I say, why can’t I handle him, why don’t I go back and get him, why can’t I handle him?

Interviewer: The guilt is reinforced when you go and see him doing well.

Carol: Yes! Right!

Interviewer: And if he’s having a bad day?

Carol: Then I think no, I’m glad. I tried taking him to a day care center and he wouldn’t go. He’s very, very possessive. He’s like my little shadow. If I’m over there, he’s there, if I’m over here, he’s here. If I turn around he’s right there with me. I took him over to the day care center. I’d leave him. He didn’t want to stay and I’d say, "No I’m coming back in a little while, I have to go to the
store." So I'd leave him there. From the time I would go to the store and I'd get back home again, the lady would call me. "Carol you have to come get him, I can't handle him." Once she told me she had him locked outside because he was so disturbing to the rest of the people that she couldn't handle him. He gets very hostile.

Interviewer: Does he actually hit people?
Carol: I think he might. I don't know if he's really come out and done it. But that night that he was really shaking me - oh! But if he would, I think he'd go all the way.

Interviewer: Are your children supportive to you?
Carol: My son is. They don't go down to see Jack, because they have their three kids but once in a while I'll bring Jack to their house.

Interviewer: Who do you talk the most about this?
Carol: Usually, the people who are in the boat that I am. We can communicate because we're on the same road. One friend and I would take turns bringing our husbands down to the day care center.

Interviewer: Is he on any medication to control his temper?
Carol: Now he's on Haldol. But then if he gets too much of it he still gets mean. He's still hard to control. Where he is now they are able to manage his moods and they handle him very well. I really trust them. They take good care of him. There's people over there who are very coherent, and if they would do something to the other patients, I'm sure we
would hear about it. They would tell us if something is going on. And besides that, I drop in at different times and other people drop in at different times. They never know when we are going to come over there.

Interviewer: What has been the most help to you in dealing with Alzheimer’s Disease?

Carol: The support group. For me, to know that it isn’t me. I’ve learned how to cope with it. I meet other people who’s spouses have many of the same problems and behaviors. Doing the little goofy things that they do. Like when I give him a plate of ice cream with a spoon, and he’ll just take his other hand and eat his ice cream with it. Other people have the same things happen to them. Now if I told that to my friends they would think, oh it must be you, because they still don’t understand.

Interviewer: These are people who understand, and don’t make you feel guilty.

Carol: Yes. Yes. Even at the hospital where he is, you see all these people eating. Jack is about the sloppiest one there and he used to be so meticulous. He wouldn’t go out of the house without polishing his shoes. It seems like he has really reversed in his eating. I think that is the most support that you can get - to know that you’re not alone. (crying) Because I know at first, I thought nobody in the world has this problem. And they do. They have it worse. Sometimes the spouse of the Alzheimer patient is
sick. So I think that I’m lucky, because I have my health.

Interviewer: What has been the most difficult thing for you to adjust to?

Carol: Being alone.

Interviewer: It’s like a prolonged period of mourning isn’t it.

Carol: Yes. Yes. The lady next door was sick with cancer and died a few months later. Sometimes he cheers me up, but I think, here he is and he’s coping with it. He’s able to be happy. But he’s single. He can go and do what he wants. I can’t. Once I went up to the singles club up here. They have it once a month. The first and second time I was okay, and then the third time someone came up to me and said, "Oh Carol, how’s your husband." It made me feel very bad. I haven’t been back. I just wanted to do something. But I guess they feel that there’s a lot of people in the neighborhood that are single, and I have no right to be up there. So you have to.... well I just sat there.... I want to get out, I want to do something to relieve the loneliness. I don’t know, you just have to go along in life I guess.

Interviewer: It’s hard because the thing that you need most you can’t do because it reinforces your guilt. But yet, you need to be out with people and it makes you feel better.

Carol: Right! Right! Right!

Interviewer: What would be your advice to someone else who was going through this experience?
Carol: You just have to go along with it. Don’t fight them. If they want to do something, just go along and do it. It doesn’t do any good. And of course, they don’t know what they are doing. You just have to go along day by day.

**Summary and Evaluation of Case Studies**

All of these families are experiencing great suffering. Alzheimer’s Disease has taken over their lives. The lives of the caregivers, in each of these cases, have become focused on the Alzheimer patient and the daily progression of the disease. The symptoms of Alzheimer’s Disease are not only seen in each of these patients, but are also seen in the psycho-social functioning of the caregivers. All of the family members involved in this study expressed and exhibited varying degrees of helplessness, depression, guilt, denial, anger, and impaired social functioning. Social functioning becomes impaired because there is no choice. It appears to be a natural consequence of this disease. The caregiver is forced to confront the realities of the ongoing deterioration of the Alzheimer’s patient. Daily living becomes a nightmare and a chore - another day to get through watching a loved one move closer to death. Life becomes unpredictable and the family never knows from day to day what to expect. Periods of stabilization and the "good days" raise false hopes and are often followed by intense feelings of hopelessness as the reality of the deterioration is again confronted. The
disease continues to mercilessly debilitate the patient.

Rebecca and Carol have both struggled in vain to care for their husband's at home. Their stories express the impact of this disease on their lives and the emotional pain that they are experiencing. They have both been trying to cope with Alzheimer's Disease over an extended period of time and have been financially strained. Both of these women have been and continue to be devoted and loving in their care and concern for their spouses. Their efforts to ward off the inevitable deterioration of Alzheimer's Disease have been profound and unending. Their suffering cannot be relieved by kind words, or offers of help and support from family and friends. Only a miracle can take away their pain and bring back to them their significant other and stop the progression of this disease.

Rebecca is a Holocaust survivor - she has lived a life of hardship and emotional pain. The loss of Samuel and her inability to continue to care for him and share their life together are taking a great toll on her, both physically and emotionally. Each day is a struggle to survive as her own health deteriorates and she tries valiantly to attend to Samuel's needs. Her worries are compounded by concerns for the welfare of her children and the suffering that they are going through. A great deal of stress is being experienced by all the generations of this family, in their efforts to cope with and accept the nightmare of Samuel's daily existence.
The same struggle is seen in Carol and her fight to save Jack. She too struggles with the emotional turmoil of guilt, depression, helplessness and anger. Carol's physical health has not deteriorated. Her ability to continue work and support herself have been severely hampered. Their dreams of traveling and enjoying their retirement years have been shattered. Her family relationships have deteriorated. Carol has become isolated in her grief and her struggle to be supportive and loving to Jack. She needs the company of other people, yet she finds herself confronted with unbearable guilt when she participates in local community activities, which are sponsored by the single's club. Jack's children have been severely traumatized and cannot deal with their father's profound deterioration. They run from their father's disease and cope with it through denial. In Jim's case, he uses over-compensation and projection, in his frantic efforts to change the direction of his life. Fears of the disease being inherited cause Jim to blame his father's life style and lack of education for his present condition. The effects of Jim's behavior on his own family and his ability to function at work will not end with Jack's death. Jack's daughter, "the doll" also suffers in her frantic efforts to avoid her father. She cannot cope with his deterioration and eventual death. The backlash of her denial and abandonment of her father will undoubtedly haunt her in the years to come and has the potential of causing severe social and emotional impairment.
Tony's wife of 45 years is still in the early stages of Alzheimer's Disease, but her deterioration has been rapid. Throughout the interview, Tony rationalizes that all life must come to an end, and uses this defense mechanism to cope with the inevitable loss of his wife. Tony knows what faces him, but he denies his feelings of helplessness and emotional pain. In an effort to deal with his tragic loss, he continually looks back on their life together to remember the good times they have had and reexperience past struggles which have been overcome. He blames their diet and environment for Maria's disease. Maria and Tony have a symbiotic relationship, and he has a great deal of difficulty separating her symptoms from himself, and often speaks as if he is suffering from Alzheimer's Disease. Tony has not yet lost hope because he can still care for his wife at home, and can still relate to her. Tony's message is that he is strong and can take care of anything that comes up, because he is still self sufficient and can continue to support himself and his wife. He has not yet experienced any financial strain. This is most probably due to the short length of time Maria has had Alzheimer's Disease. Tony's expressions of fatalism help him work through this last stage of life, and his ability to face his wife's death and his own inevitable death. "There are others to take their place on this earth - we all have to die." Tony's health is good but he does have some physical problems himself that may, in time, limit him in his ability to care
for Maria. He too feels depressed, guilty, and helpless, but he buries his feelings. He continues to plow through life and gives the impression of being headstrong and tough. For the most part, Tony and Maria have become isolated from the supports they most need. They keep their grandchildren away in an effort to protect them. Most of their relatives and friends are too old and sickly to spend time with them. In an effort to cope, Tony puts a great deal of pressure on his children to step in and take over for him. When interviewed separately, his daughter expressed feelings of depression, helplessness, and guilt because she cannot do more for her mother. She is a single parent, and works to support herself and her daughter. She stated that she is thinking of quitting her job so that she can care for her mother. Tony is unable to deal with his daughter’s emotional pain, and instead says, she is lazy and has a lot of her own work to do. This, of course, only intensifies his daughter’s struggle to deal with her mother’s illness, her own needs and the needs of her child. Her social functioning is impaired, her ability to support herself is threatened, and her relationship with her own daughter is strained.

There are many variables of personality, living conditions, financial status and ethnicity which are impacting on all of these families. These variables can be carefully analyzed and certainly would attribute to each individuals ability to cope with the devastation of Alzheimer’s Disease.
All of these families have a great deal in common, however, in that no matter whatever their differences may be, they are all suffering from depression, guilt, helplessness, fear, anger and varying degrees of isolation. All of these families must deal with separation from their loved ones and they lack adequate, appropriate and affordable resources, and support systems to assist them with the care of the patient.

They are all involved in a struggle to survive, and hope for a cure. The quality of their lives and the lives of the Alzheimer patient’s is certainly not what it should be. So far, there have been no miracles for these families. They must continue to cope in the best way they can. What they are most lacking is support and services which can only come from coordinated federal, state and local governments in the form of funding and program planning and implementation.
Chapter 4

Self-Help Group

All of the families in this study are involved in the activities of the Alzheimer's Disease and Related Disorders Association (ADRDA), a self-help group for patients and families.

This self-help group was formed in response to the needs of patients with Alzheimer's Disease and the desperate plight of close family members. These people were experiencing a great deal of difficulty coping with the many physical, emotional, financial, and social problems which plagued them. Lack of information, education, and support services, added to the stress of the family caring for the Alzheimer patient. Of great concern was the problem of inadequate research into the causation, treatment, and cure of Alzheimer's Disease. In an effort to cope with the many problems they were experiencing, this self-help group formed to pool their resources and gain strength by sharing their common needs and goals. It was felt that there was power in numbers, and this would work to bring about needed changes.

The ADRDA is presently trying to get a national registry established for reporting deaths which are due to Alzheimer's Disease. Present statistics of the incidence of Alzheimer's Disease are not accurate because the disease can only be diagnosed on autopsy and is often not reported. Lack
of accurate data negates the tremendous need for funding, research and help for families.

The goals of the group are:

"-To support research into diagnoses, therapies, causes and cures for Alzheimer's Disease.
-To aid in organizing family support groups in their own localities so as to give assistance, encouragement and education to afflicted families.
-To sponsor educational forums and information for both lay and professional people regarding Alzheimer's Disease.
-To advise government agencies (federal and state) of the needs of afflicted families, as well as the requirement to promote national research on a deserving scale.
-Most importantly, to offer help in any measure, whatsoever, when needed by those afflicted and their loved ones."

They have, as a result, been instrumental in instituting changes in public policy, obtaining more funding for research, and advocating and fighting for the rights of patients and families.

GROUP QUESTIONNAIRE

A structured questionnaire (see Appendix A) was administered to a local ADRDA chapter to further obtain data on the psychosocial impact of Alzheimer's Disease. Whereas, the earlier three case studies provided flexibility in probing and exploring complex and sensitive subjects, this questionnaire was administered to obtain statistical data from a broad sample, include data from children as well as spousal caregivers, and provide real anonymity.

ADRDA Newsletter, Alzheimer's Disease and Related Disorders Association, Santa Clara County, November 1984.
Chapter 5

DATA ANALYSIS

Thirty four questionnaires were distributed. Twenty nine valid questionnaires were returned and analyzed. The following is an analysis of the data which was collected:

1. The ethnic identity of those sampled was:
   - 93.2% - White
   - 3.4% - Hispanic
   - 3.4% - Asian

2. Caregivers were overwhelmingly female:
   - 93% - female

3. The relationship of the caregiver to the patient was roughly evenly distributed:
   - 57% - children
   - 43% - spouses

4. The median age of the caregivers was:
   - 50.5 years - children caregivers
   - 68.8 years - spousal caregivers

5. Of those sampled:
   - 73% - were caring for the patient in the home

6. Caregivers stated that their health was:
   - 60% - good
   - 40% - fair

7. The children felt they were in better health:
   - 64.7% - good
compared to the spousal caregivers who answered:

53.8% - good

8. The children caregivers stated that they were:

employed and/or homemakers

9. The spousal caregivers stated that they were:

retired and/or homemakers.

10. The children’s median income was:

over $25,000

11. The median income of the spousal caregivers was:

under $12,500

12. Patients cared for by spouses had a median age 4 years younger than that of the children caregivers:

74.2 years - children

78.2 years - spouses

13. For every 2 male patients, there was found to be 3 female patients.

41.4% - male

58.6% - female

14. The median age of all patients was:

74 years

15. Nearly 3 times as many patients were being cared for at home as were institutionalized.

16. When the spouse was the caregiver more patients were kept at home than institutionalized:

27% more - kept at home with spousal caregivers

17. Patients that were institutionalized had been ill longer:

a mean of - 10.7 years of illness
than those currently being cared for at home: a mean of - 6 years of illness

18. Caregiving at home represented a large investment in time:
   a mean of - 19 hours per day for spousal caregivers
   a mean of - 9 hours per day for children caregivers

19. The caregivers overwhelmingly believed that insurance was inadequate:
   77.3%

20. The children caregivers felt this to be more so:
   81.8%
   than did the spousal caregivers:
   72.7%

21. They collectively felt that only prescription drugs were adequately covered:
   80.0%

22. Some caregivers felt that insurance for home health care was adequate:
    22.2% - children
    0% - spousal

23. Even fewer caregivers felt that insurance was adequate for long term convalescent care:
    16.7% - spousal caregivers
    0% - children caregivers

24. Who helps the caregiver? The most frequent answer was:
51.6% - family members

19.4% - friends

3.1% - visiting nurse

25. Three times as many spousal caregivers responded "no one" to the question on help compared to the children caregivers response:

15.4% - spousal caregivers responded no one

5.0% - children caregivers responded no one

26. Help is also being provided to the respondents by the ADRDA.

Both the children and spousal caregivers agreed that ADRDA education and information was the biggest help to them:

43.1%

followed by increasing their ability to cope:

32.8%

and closely followed by providing contacts for help:

24.1%

Other comments were written in, notably: sharing, working for something positive, and "legalizing" Alzheimer's disease.

In order to further assess the caregivers' feelings on certain subjects, a series of 20 statements were presented as part of the questionnaire. Respondents were asked to rate their answers under 4 categories: Strongly Agree (SA), Agree (A), Disagree (D), and Strongly Disagree (SD). Those who did not respond to the question are coded as having no opinion (NA). The following are the questions which were asked and the data collected:
A. I feel guilty because I cannot do more for the patient.


B. Families with Cancer patients suffer more than we do.


C. Patients should be told their illness is terminal.


D. I often feel alone.


E. Doctors are patient and understanding.


F. I feel the patient manipulates me.


G. I have little time for myself.


H. Alzheimer's Disease is hereditary.


I. I often feel depressed.
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<td>J. I often take something to calm my nerves.</td>
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<td>K. I get frustrated trying to communicate with the patient.</td>
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<td>L. Nursing homes provide good care and services.</td>
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<td>M. I feel that my family avoids me.</td>
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<td>N. I can afford all necessary patient care and services.</td>
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<td>O. The costs for care have depleted my financial resources.</td>
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<td>P. The costs for care will deplete my financial resources.</td>
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<td>Q. It is easy to lose your temper with the patient.</td>
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R. This illness puts a severe strain on family relationships.

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S. I feel that my friends avoid me.

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T. People think I exaggerate about the patient’s condition.

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**DATA INTERPRETATION**

The majority of the sampled caregivers agreed with the following statements:

1. I often feel alone.

2. Doctors are patient and understanding.

3. I have little time for myself.

4. I get frustrated trying to communicate with the patient.

5. This illness puts a severe strain on family relationships.

6. People think I exaggerate about the patient’s condition.

The children caregivers strongly agreed, while the spousal caregivers only agreed with the following statements:
1. I feel guilty because I cannot do more for the patient.

2. The costs for care will deplete my financial resources.

The children caregivers felt the patient was manipulative while the spousal caregivers neither agreed or disagreed. On the other hand, the spousal caregivers often felt depressed while the children caregivers gave a mixed response. The spousal caregivers indicated that they do not often take something to calm their nerves while the children caregivers’ response was mixed.

The majority were in disagreement over the following statements:

1. Families with cancer patients suffer more than we do.

2. Alzheimer’s Disease is hereditary.

3. The costs for care have depleted my financial resources.

The spousal caregivers strongly disagreed while the children caregivers and only disagreed with the following statements:

1. I feel that my family avoids me.

2. I can afford all necessary patient care & services.

The children caregivers disagreed that their friends avoided them while the spousal caregivers neither agreed or disagreed.
On the subject of nursing homes providing good care & services:

children caregivers - disagreed
spousal caregivers - no opinion

Finally, on the subject of whether patients should be told their illness is terminal:

children caregivers - disagreed
spousal caregivers - agreed

The results of the questionnaire correlate well with what was discovered in the three case studies. The feeling of loneliness, frustration in communicating with the patient, little time for oneself, the strain on family relationships, and lack of understanding from others, was clearly identified in all these case studies. In two of the three studies, depletion of financial resources were a strong concern. This was also identified in the questionnaire as being a strong concern.

In the 2 case studies where the patients were institutionalized, the patients had been ill for:

10 to 12 years

The questionnaire indicated years of illness mean of:

10.7 years

The ages of the spousal caregivers, however, were below the questionnaire's mean age of:

68.8 years

The questionnaire indicated most patients were:
female and at home

The three case studies depicted:

two male patients in institutions
one female patient at home

The comparison of the three case studies to the 29 sampled by the questionnaire clearly demonstrates the importance of administering either a much larger number of case studies or augment the case studies with a suitable questionnaire sampling. The latter was chosen for this research.
Chapter 6

CONCLUSIONS AND RECOMMENDATIONS

Conclusions

The purpose of this study is to identify how families cope with Alzheimer's Disease. An attempt is being made to identify how well their needs are being met, and how this disease affects them psychologically and socially.

It appears from the results of this study that the family is the primary caregiver. Most often this care falls on the shoulders of one member of the family; usually a female. This was brought out in the three case studies and supported by the questionnaires. All three patients were being cared for by the family and this care was the main responsibility of the spouse in each of these families. Patients are only institutionalized as a last resort, when the caregiver can no longer cope with their daily care. In the case of the caregivers, Rebecca and Carol, their role could no longer be maintained due to the progression of the disease. Only as a last resort, they were forced to make the painful decision to place the patient in an institution. Both women experienced a great deal of guilt because they could no longer care for the patient. Guilt was also expressed in their occasional feelings of ambivalence towards the patient and the feeling that they, themselves, could not go on with their lives. It was
clearly shown in the three case studies that institutionalization is not what is desired by the caregiver or the family. This was also apparent in the questionnaires which indicated that the majority of the patients were being cared for at home and institutionalization was only sought as a last resort and when the disease reached the advanced stages. The financial burden was also identified as a deterrent to this form of care. When this decision is made, it causes a great deal of guilt and ambivalence on the part of the caregiver and close family members. The significant amount of uncertainty as to the quality of institutional care identified by the questionnaire, can be a contributing factor to this ambivalence.

At the present time, most families have a great deal of difficulty coping with the many complexities and conflicting needs which arise from this disease. Alzheimer's Disease is not usually a short term illness. It can take many years to progress, and during those years, the patient suffers from progressive mental and physical dysfunctioning. The questionnaire indicated a mean period of illness of 10.7 years for those patients institutionalized. This puts tremendous demands on the caregivers and close family members, causing them varying degrees of emotional and physical problems. This too was brought out in the case studies and in the questionnaire. Both Rebecca and Carol exhibited increased levels of stress due to the progression
of the disease. Rebecca stated that she often needed a sleeping pill at night. Only 24.1% of respondents to the questionnaire said they "often take something to calm my nerves." She voiced great concern about the progression of the disease and the difficulty she was having coping with Samuel.

Carol also expressed similar concerns and felt that her life was at a standstill. The questionnaire indicated that caregivers and families were experiencing stress, too. A large percentage of families (72.4%) stated that they often lost their temper with the patient which would also indicate increased levels of stress. Further stress and frustration was indicated in the questionnaire. A large number of respondents (75.9%) stated that they often get frustrated trying to communicate with the patient.

Another added stress factor which was brought out in the questionnaire and in the interviews with both caregivers, Carol and Tony, was the feeling that others do not understand the extent of the patient’s condition. A large number of responses in the questionnaire (72.4%) stated that "people think I exaggerate about the patient’s condition." This would certainly lead to a lack of the support and understanding which would help alleviate the pressure caregivers and families experience.

Another stress factor is the difficulty many caregivers expressed with respect to their family relationships. Carol
and Tony have both become relatively isolated from their families. The questionnaires indicated that a large percentage of respondents (82.8%) felt that "this illness puts a severe strain on family relationships."

The greatest tragedy of Alzheimer’s Disease, besides the eventual death of the patient, is the lack of adequate support networks, services, and interventions. Individuals and families may find themselves unable to care for their loved ones without experiencing an enormous amount of frustration, guilt, and despair.

Frustration was exhibited in the case studies with Rebecca and Carol who both had a great deal of difficulty getting a medical diagnosis and went from doctor to doctor. Carol found herself resorting to vitamin therapy which cost her a great deal of money and was of no use. Rebecca related her long search for an answer to Samuel’s problems and his psychiatric hospitalization and treatment which only made his condition worse when he was given shock treatments.

Many of the families (82.8%) who responded to the questionnaire stated that they have little time for themselves which would also indicated that they are experiencing the frustration of having to constantly focus their lives on the patient.

Depression was especially evident in the cases of Rebecca and Carol. Both women found themselves unable to concentrate and were experiencing a marked reduction in
social and work related activities. Rebecca and Carol cried often during the interviews and reported that they were experiencing sleep disturbances and fatigue. Strong evidence of depression was also found in the questionnaire. This was brought out by significant number of respondents who stated that they often felt depressed (69.0%). This can become especially pronounced during the last stages of the disease, when the family may not be physically able to care for the patient.

Denial was particularly evident in the case of Tony who expressed a great deal of ambivalence towards his wife’s condition. Tony appeared to be unable to totally accept the reality of his wife’s prognosis. This defense mechanism is used by Tony to avoid the reality of what the future holds for him.

Role reversals were clearly evident both in the case studies and in the questionnaire. Daughters become caregivers for their parent, wives become caregivers for their husbands, husbands become caregivers for their wives. All take over the responsibilities of the other and find themselves in reversed roles. They find themselves faced with new demands which are difficult to adjust to.

Fear of the future, for the patient, for themselves and how they will manage with and without the patient are evident in the case studies of Rebecca and Carol. They worry about being left alone and how they will manage
financially. Tony is also afraid but he covers up his fear with rationalizations and denial.

The questionnaire indicated some concern about Alzheimer's Disease being hereditary (27.6%). Carol's step-son is overly concerned about the disease being hereditary and overcompensates by putting all of his energy into his work and his quest for higher education. This is his way of coping with his fear. Carol's step-daughter is also fearful and avoids her father in an effort to deny the reality of his deterioration and eventual death.

Anger is expressed in all of the case studies. This anger is projected onto various professionals, doctors, psychiatrists, other family members and the patient. Anger is also expressed in the questionnaire by respondents who felt that they often feel alone (79.3%), that their friends avoid them (37.9%), that doctors are not patient and understanding (34.5%), that the patient manipulates them (37.9%), and that they cannot afford all necessary patient care and services (72.4%).

Carol expressed a great deal of this anger and frustration in her interview. She was particularly angered by her inability to obtain long term care from the Veteran's Administration because her husband did not see active duty. She tried to obtain services from them and was terribly frustrated by her inability to do so. Now only the anger and disappointment is left. The questionnaire similarly
identified concerns for affording necessary patient care and that the costs would eventually deplete their financial resources (27.6%).

Some suicidal thoughts were expressed by Rebecca who stated that she often feels that there is no use in going on. Her devotion to her family, to Samuel, and her innate need to survive, keep her going and prevent her from actually taking her life.

Disruption of family functioning was clearly shown in the case studies. Both Carol and Tony feel isolated from their families. As stated earlier, the questionnaire results also expressed concerns in this area of family relationships. The family appears to be the main system of support but many relationships are strained because they cannot cope with the reality of Alzheimer's Disease. The feeling that their family avoids them (24.1%) was seen in the questionnaire results.

Withdrawal from social activities is indicated both in the case studies and in the questionnaire. Caregivers are not able to live their lives as they had in the past due to lack of time, energy and money. Most caregivers suffer from a loss of freedom and mobility and find themselves tied to the care of the patient. They can no longer come and go as they please.

Due to the demanding and long hours of care, caregivers are often unable to continue working. This leads to a loss
of productivity and inability to provide and maintain adequate family income. This was certainly the case with Carol who found it increasingly difficult to maintain her job and finally had to stop working to properly care for her husband. This is also evident in the questionnaire in that a majority of the caregivers (75.9%) do not work and also have a limited income (under $12,500).

Financial hardships also result from the high costs of continued care both at home and in institutions. The source of income was not apparent in the questionnaire but many of the caregivers were retired and are probably receiving Medicare and retirement benefits from pensions. This was the case for Tony and Carol. Rebecca, on the other hand was too young to receive Medicare and was living on limited income from her and Samuel’s pensions. Their levels of income were not adequate to meet their needs and great concern was expressed about being able to manage financially in the future.

The impact of institutions were both negative and positive in the case of Rebecca and Carol. Initially they were not knowledgeable about the resources that were available to them with respect to institutions. It took them a long time to locate an appropriate placement for their spouses. Carol feels that her husband is now receiving excellent care. Rebecca feels that Samuel is getting better care but she still expresses concerns. Tony, on the other
hand, strongly resists any thoughts of institutionalization for Maria and has a very negative perception of what they would have to offer. Tony is also not aware of what is available and how those institutions might be a resource to him. Many of the respondents to the questionnaire had negative feelings towards nursing homes (41.4%) while others (37.9%) had no opinion. This would indicate that caregivers and families do not view institutions as being a desirable support alternative. Most of the families were not aware of any existing services which existed in the community and, as a result, did not take advantage of them. Others who knew of them felt that they could not afford the services and did not utilize them.

As a result of this study, it is the opinion of this researcher that most of these families and patients are not receiving appropriate services and interventions needed in the management of Alzheimer's Disease.

Another area which needs to be addressed and which affects both the patient and their family is the often controversial issue of an individual's right to know that he or she is suffering from a terminal illness. Without this knowledge, the Alzheimer's patient is not given the opportunity to make decisions that will affect him or her in the later stages of the disease when cognitive functioning is lost. These decisions include how he or she will be cared for, by whom, where they will be cared for, and what efforts
should be made to prolong life when that becomes an issue that loved ones are left to face. There are also decisions that must be made concerning the future of one's family and the distribution of assets. Many people are not able to face the prospect of their own death. This is especially true when a diagnosis of a terminal illness has been made. Each individual, however, should have the right to know that they are suffering from an illness that will ultimately take their lives.\textsuperscript{24} The results of the questionnaire indicated that opinion was equally divided on this question. Almost half of the respondents felt that the patient had the right to know that the illness was terminal and the other half felt that they should not be told.

\textbf{Recommendations}

The main focus of this study is to assess the ability of caregivers and family members to cope with the psycho-social impacts of Alzheimer's Disease. These psychological and social factors were examined in twenty-nine questionnaires and three case studies. Although this research cannot be generalized to a larger population because of the limitations of this study, the following recommendations are being made based on the study findings:

1. Early Diagnosis

\textsuperscript{24}Dubler Neveloff, Nancy, \textit{A Legal View: The Patient's And Family's Right to Know}, Generations, Western Gerontological Society, Vol. VII. No. 1, Fall 1982, p. 11.
In spite of the many factors involved in the diagnosis of Alzheimer's Disease and the difficulty of making a definitive diagnoses, more simplified methods of diagnosing patients have been developed through the use of various medical procedures. Early diagnosis is needed to give patients the opportunity to make their future plans and wishes known. This could help to relieve the tremendous guilt and anxiety experienced by family members when they are later forced to make difficult and painful decisions for the patient. Families suffer a great deal when they must resort to custodial care or institutionalization for the patient. They must bear the burden of these decisions; frequently without knowing the wishes of the patient.

2. Patients have "a right to know."

Even when diagnosis is made at an early stage of the disease, patients are often not informed about the seriousness of their illness. Unfortunately, this effort to "protect" the patient by avoiding the pain of dealing with the problem, robs them of the basic human right of self-determination. The patient should understand the ramifications of this illness and be allowed to participate in planning for his or her future care while cognitive abilities are still in tact.

3. Case management.

Coordination of in-home support services through case management and networking of service providers is very
important. Case management should be geared to the specific stages of the disease and the needs of the family, particularly the caregiver. Through case management, social workers and other helping professionals would be able to better assist the family in their efforts to cope with the progression of Alzheimer's Disease.

4. In-home support services.

As indicated in this study, the family is the primary caregiver — many times this falls on the shoulders of one family member. As a result, there is a need for the availability of more adequate in-home support services through our health care systems, both public and private. Service providers must be trained and be sensitive to the needs of the Alzheimer patient, the caregiver, and other family members. This would provide needed relief and support to the caregiver and make it possible to keep the Alzheimer patient at home for a longer period of time. This would also help to reduce the high costs of early or unnecessary institutionalization; and the trauma it causes the family and the patient. Caregivers must be given support through adequate funding for in-home health care and support services rather than having to resort to institutionalization. It is further recommended that community agencies meet these needs through greater awareness, funding, networking, and coordinated program implementation.

"Formal community attempts to cope with Alzheimer related problems, beyond meeting non-psychiatric
medical needs, emanate to a large extent from the mental health and social service systems, and the aging services network. While each of these systems purports to serve the Alzheimer patient, little in the way of care is actually provided. Where help is given, it is fragmented. The complex needs of the patient and family do not mesh with the services being offered.25

As a result of this study, it is the recommendation of this researcher that social policies be focused on the support of the family in addition to the maintenance of the patient.

5. Respite Care

a. Availability of more Day Care Centers with trained staff to care for Alzheimer’s patients on an hourly or daily basis is needed. This would give caregivers needed relief from the stress of daily caregiving.

b. The establishment of more Board and Care Homes which are licensed and staffed by well trained workers and paraprofessionals skilled in the care of the Alzheimer patient, are similarly needed. This would prevent over utilization of nursing homes and improve the public’s opinion of these kinds of facilities.

c. Skilled care facilities need to offer more to family members. In advanced stages of the disease, if the family can no longer care for the patient, skilled nursing care may often be required. These nursing homes

25 Silverstone, Barbara, Bookin, Deborah, Alzheimer’s Disease: Changes In the Community Perspective, Generations, Western Gerontological Society, Vol. VII., No. 1, p. 29.
must also be staffed with well trained employees who are skilled and educated in the care of the Alzheimer patient and sensitive to the needs of family members. It is also recommended that close family members be permitted to take part in the care of the patient to whatever extent they can and wish to participate. It is further recommended that spouses of Alzheimer patients be permitted to share accommodations with the Alzheimer patient, when desired. This would help to relieve feelings of helplessness, guilt and loneliness.


a. Family support systems are a vital part of the treatment of this disease and it is strongly recommended that they be encouraged and reinforced.

b. Greater utilization of self-help groups as a coping mechanism is vital to the caregiver. One method of achieving this would be to expand existing self-help groups to more communities. Another would be to have existing groups provide more frequent meetings which are specifically focused on the emotional support and needs of caregivers and close family members. More outreach is needed on the part of existing self-help groups to minority populations who are not presently being reached. This study indicated, for instance, that Hispanics, Blacks, and Southeast Asian populations are, for the most part, not utilizing the services of the self-help group that was involved in this
study. Yet, Hispanics and Southeast Asian populations are quite large in this area, and many Black families also live in the community and surrounding areas. This outreach can be accomplished by contacting representatives of minority communities. It is necessary to focus on minority populations to determine the prevalence of Alzheimer’s Disease among these groups. Once this is accomplished, existing self-help groups can offer their assistance by expanding their network to include the participation of minority populations. Advisory groups should also be developed to help meet the language and cultural needs of minority populations.

7. Education

a. Emphasis on educating the public as to the prevalence of Alzheimer’s Disease and its potential impact on both individuals and on society must be continuously advocated by self-help groups.

b. More emphasis on educating professionals (e.g., social workers, health care professionals, and other helping professionals) needs to be stressed. This would enable professionals of many disciplines to identify and intervene appropriately with the Alzheimer patient, caregivers, and families. This will help prevent inappropriate interventions which only add to the families suffering and guilt.

8. Research
a. More funding is required for research into the etiology and cure of Alzheimer’s Disease.

b. There is also a need for more research into the psychosocial impact of Alzheimer’s Disease on caregivers and families and its impact on society. Once the enormity of this disease is examined and its impact understood, it will be more likely that caregivers and families will be provided with the financial, physical, and emotional support which they need.

c. Studies should be initiated into the numbers of Alzheimer’s patients found in all ethnic groups. This would give service providers the opportunity to plan programs which are culturally relevant to minority population groups. Interventions that conflict with the cultural norms of various ethnic groups are ineffective and should be avoided.

Once research has established the cause of this disease, and hopefully a cure is found, perhaps it will no longer be necessary to be concerned about Alzheimer’s patients, their families and how they manage. Until that time comes, however, attention must be given to those members of society who continue to suffer from the psychosocial impact of Alzheimer’s Disease.
APPENDIX
Alzheimer's Disease

QUESTIONNAIRE

1. Are you the caregiver (person taking care of the patient): Yes __ No __

2. Your age: __

3. Your sex: Male __ Female __

4. Patient's age: __

5. Patient's sex: Male __ Female __

6. Your relationship to the patient: ______________ (husband, wife, child)

7. How long has the patient had Alzheimer's disease: Months __ or Years __

8. How would you describe your health status: Good __ Fair __ Poor __

9. Your work status: Homemaker __ Retired __ Employed __ Unemployed __ Disabled __

10. Your income: Under $12,500 __ $12,500 to $25,000 __ Over $25,000 __

11. Your ethnic group: White __ Black __ Hispanic __ Asian __ Other __________

12. Is the patient in an institution, such as, a nursing home: Yes __ No __

13. If yes, how long has the patient been confined: Months __ or Years __

14. If in an institution, how many hours/day did you spend caregiving: __

15. If the patient is at home, how many hours/day do you spend caregiving: __

16. Overall, how long have you spent as a caregiver: Months ___ or Years ___

17. Who physically helps you in your caregiver role (Check all which apply):
   - Visiting Nurse __ Housekeeper __ Family __ Friends __ Physical Therapist __
   - Day Care Center __ Other (write in) ____________ ____________ No One __

18. How often is this help provided: hours/day __ or hours/week __

19. Is your medical insurance adequate: Yes __ No __ It covers (Check all which apply):
   a) Prescription drugs __ b) Home health care __ c) Long term convalescent care __

20. The Alzheimer's Disease & Related Disorders Assoc. (ADRA) support group helps you by (Check all which apply):
   a) Increasing your ability to cope __ b) Providing educational information __
   c) Providing contacts for needed help __ d) Other ________________
21. To indicate the extent to which you agree or disagree with the following statements, check the appropriate response for each: SA (strongly agree), A (agree), D (disagree), or SD (strongly disagree).

<table>
<thead>
<tr>
<th>Statement</th>
<th>SA</th>
<th>A</th>
<th>D</th>
<th>SD</th>
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<tbody>
<tr>
<td>A. I feel guilty because I cannot do more for the patient.</td>
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<tr>
<td>B. Families with Cancer patients suffer more than we do.</td>
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<td>C. Patients should be told their illness is terminal.</td>
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<td>D. I often feel alone.</td>
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<td>E. Doctors are patient and understanding.</td>
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<td>F. I feel the patient manipulates me.</td>
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<td>G. I have little time for myself.</td>
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<td>H. Alzheimer’s disease is hereditary.</td>
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<td>I. I often feel depressed.</td>
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<td>J. I often take something to calm my nerves.</td>
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<td>K. I get frustrated trying to communicate with the patient.</td>
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<td>L. Nursing homes provide good care &amp; services.</td>
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<td>M. I feel that my family avoids me.</td>
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<td>N. I can afford all necessary patient care &amp; services.</td>
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<td>O. The costs for care have depleted my financial resources.</td>
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<tr>
<td>P. The costs for care will deplete my financial resources.</td>
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<td>Q. It is easy to lose your temper with the patient.</td>
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<td>R. This illness puts a severe strain on family relationships.</td>
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<td>S. I feel that my friends avoid me.</td>
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<td>T. People think I exaggerate about the patient’s condition.</td>
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</table>

Look over your answers to make sure you have answered all the questions. After you’ve completed the questionnaire, deposit it in the box at the front of the room. Thank you for your cooperation.

Marlene Brickner, BSW, MSW Candidate
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