A profile of Georgia caregivers to Alzheimer's disease & related disorder victims

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ABSTRACT

The profile of caregivers to Alzheimer's disease victims in Georgia was examined. The sample population consisted of 377 caregivers (20% of the registered members of the 16 Alzheimer's Support Groups across the state). The findings revealed that, the majority of the caregivers are between the ages of 45 and 74 years old, they tend to be the spouse of the victim, live on a fixed income, and is experiencing emotional, physical and financial stress. The findings were analyzed utilizing tables and percent comparisons.
A PROFILE OF GEORGIA CAREGIVERS
TO
ALZHEIMER'S DISEASE & RELATED DISORDER VICTIMS

A Theses Submitted In Partial Fulfillment of the Requirements For
The Degree of Master of Social Work

By
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# TABLE OF CONTENTS

Abstract ........................................................................................................... ii  
Acknowledgements ......................................................................................... iii  
List of Tables ................................................................................................... iv  
List of Figures .................................................................................................... v  

## CHAPTER

I. **INTRODUCTION** ................................................................. 1  
   Rationale  
   Purpose of Study  
   Summary  

II. **REVIEW OF THE LITERATURE** ................................. 6  
   Introduction  
   Caregivers  
   The Black Aged  
   Support Services for Caregivers  
   The Aspects of Dementia  
   Limitations To Study  
   Summary  

III. **THEORETICAL FRAMEWORK** ............................... 24  
   Introduction  
   General Systems Theory  
   Societal & Individual Determinants of Medical & Social Care Utilization  
   Statement of Purpose  
   Basic Assumptions  

IV. **RESEARCH METHODS & PROCEDURES** ............... 30  
   Research Design  
   Subjects of the Study  
   Selection Procedure  
   Instrumentation
Research Procedure
Analysis

V. RESULTS..................................................33
   Introduction
   Descriptive Analysis
   Summary & Implications

VI. APPENDICES.............................................52
   Appendix A--Causes of Dementia
   Appendix B--State-wide Support Groups
   Appendix C--Instrument
   Appendix D--Glossary

VII. BIBLIOGRAPHY..............................68
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LIST OF TABLES

1. Victim's Sex By Age.................................................. 34
2. Age & Sex of Victim By Age of Caregiver............................ 35
3. Frequency & Percentage Distribution of Caregivers Age............. 36
4. Income of Caregiver By Age........................................ 38
5. Cost of Care By Caregiver Income.................................. 39
6. Relation of Caregiver By Age........................................ 40
7. Location & Race of Victim........................................... 41
8. Family Assistance to Caregivers By Age............................. 42
9. Caregiver Assistance From Family.................................. 43
10. Problems Facing Caregivers......................................... 44
11. Service Needs of Persons with Alzheimer's Disease & Their Caregivers.................................................. 45
12. Support Service Utilization........................................ 46
13. Causes of Dementia.................................................... 53
LIST OF FIGURES

1. Frequency Polygon of Age Distribution in Table 3..........................37
CHAPTER I

INTRODUCTION

The population growth in the United States among the elderly age 65 and over has increased from approximately 3.1 million people in 1900 to 26 million in 1980. This is an increase from 4.1 to 11.3 per-cent of the total population. It has been projected by the United States Bureau of the Census that the number of persons over age 65 will reach 33.5 million to 36.6 million (13%) by the year 2000, and approximately 58.5 million (20%) by the year 2025. The United States Bureau of the Census estimated that in 1978 there were 2.8 million black Americans age 60 and older, and they represented 8% of the total population. As the 65 and over population increases, so will the number of older black men and women. The Bureau of Census has projected that by the year 2000 there will be 3 million blacks 65 years and older in the United States. These statistics suggests that persons will live longer due to the advancements being made in medical science.

In Georgia, the 1970 Census indicated that 70% of the population age 65 and over were white. Elderly blacks represented
10% of this age cohort in Georgia. In 1980, 22% of the population in Georgia age 60 and over was reported as black while, 77.3% of the population were white. As the population growth of the elderly in Georgia rises, both blacks and whites will live out their lives independently at home. However, there will be a significant minority that will experience chronic diseases. These diseases will impair their ability to care for themselves, resulting in their total dependence on others for daily activities for living.

The major diseases from which most older people suffer and die include cardiovascular disease, cancer and stroke. The fourth major killer of the elderly is not as familiar to us due to the assumption that to become old is to automatically become senile. The fourth major killer of the elderly population is known as dementia.1

In 1982, an estimated 5% of persons over the age of 65 and an estimated 20% of persons over the age of 80, were afflicted with a dementing disease, impairing over 1.5 million older adults. As our population ages over the next fifty years, an estimated 4 million family members and friends will

participate in the suffering. 1 Dementia not only afflicts the victim, it places enormous stress on the family and friends of the victim.

The National Institute of Aging (8/85) estimated that 7% of the 65 and over population has serious dementia; four percent (4%) of the 65-74 population; 13% of the 75-84 population; and 25% of the 85 and over population.

There are no precise figures available as to the incidence and prevalence of dementing diseases. However, it is estimated that fifteen percent (15%) of the elderly in the community and at least fifty (50%) of those residing in long term care facilities suffer from moderate to severe mental impairment. Although this represents a small proportion of the total aged population, the problems they present to their families are others who assume responsibility for their care are formidable. 2

Rationale

Every year several hundred thousand Americans begin to lose their ability to remember whether they have turned off the stove or locked the front door. It becomes hard for them to name


familiar objects, find the right word or balance a checkbook. They continue to look well, and they exhibit no overt neurological deficit. Gradually, they will be unable to speak, think or care for themselves, and in time they will become bedridden and die of some other complication.¹

The effect of Alzheimer’s disease on family and friends is devastating. Most public and private resources available to assist individuals and families afflicted with other diseases are not available to Alzheimer's patients. Federal coverage under Medicare and Veteran's Administration health programs is minimal; private assistance through supplemental and other health insurance policies is almost non-existent; and Medicaid alone of the public programs provides significant assistance, if the individual meets the income criteria and needs nursing home care. As a result of the limitations inherent in the current structure of the public programs, family members are the caregivers for Alzheimer's disease patients. This role is enormously taxing, consuming and almost relentless in its demands.

The present and future demographic trends (i.e. high unemployment rates, extended life patterns of the elderly due to medical technologies, smaller number of offspring among the 45+…

age cohorts, migration of children etc.) may greatly impact upon the future of family care for the elderly.

Purpose of the Study

The purpose of this study is to describe the profile of the caregiver of Alzheimer's disease patient in Georgia. Little is known about the caregiver in Georgia. The study attempted to address the following questions. Who are the caregivers? What are their needs? Are caregivers most likely to take care of the patient at home or place the patient in a nursing home? How expensive is it to care for an Alzheimer's disease victim?

It is important that possible gaps in support services be identified, so that the caregiver's burdens may be eased or at least, service providers may begin to address the needs of the caregiver to better provide effective care for the elderly person afflicted with Alzheimer's disease.
CHAPTER II

REVIEW OF THE LITERATURE

Introduction

This chapter contains a review of research which covers four major areas pertinent to this study. They include:

1. Caregivers;
2. The Black Aged;
3. Support Services for Caregivers;
4. The Aspects of Dementia.

Caregivers

The majority of caregivers of elderly persons are women (Cantor, 1983, Safford, 1980, Johnson and Catalano, 1983). As with the young, caregiving to the elderly appears to be a women's issue. In addition to them being women they are often age-peers. (Cantor, 1980). C. L. Johnson (1983) indicated in her study that, in serial order, the spouse functions as the primary caregiver, in the absence of the spouse, a child assumes the role; and in the absence of offspring, another family member is responsible. Shanas, (1979, a. and 1979 b.) helped to dispel the myth of family abandonment. Cantor (1980) indicated that the primary caregivers tend to fulfill the role with little assistance from others even though they may suffer themselves
from age-related physical, financial, and social limitations.

Fengler and Goodrich, (1979) and Crossman et al., (1981) indicated in their studies that elderly wives caring for disabled husbands have special needs and problems. Through interviews, they discovered that morale scores of disabled husbands and their wives were associated. Even though morale was generally low, it was possible to dichotomize the wives into high and low morale groups. Wives with low morale scores were particularly in need of support if institutionalization of the husband was to be minimized. Isolation, loneliness, economic hardship and role overload were the most frequently mentioned problems of the low morale wife.

The home or community care of persons with one of the dementias places a major burden on the primary caregivers as well as other family members. In a study by Zarit et al., (1980) the majority of the caregivers were identified as women. One of the major findings of this study was that, the extent of burden reported by primary caregivers of persons with dementia was not related to the behavior problems caused by the illness, but was associated with the lack of available social support systems.

In a study by Mace and Rabins and the Institute of Gerontology (1980), the need for getting help outside of the family was discussed. It was noted that in a majority of the
cases, the family, for a variety of reasons, did not seek nor use outside help. The researchers suggested, that the real reason for not seeking outside help may be the inherent desire of most families to provide care for their disabled members for as long as possible.

Summary

The researchers suggest that the caregivers have been left out of the support service mechanisms. In addition, the decision of caregivers not to use outside resources, may worsen the situation for both the caregiver and the victim, in spite of their efforts to care for the family member by themselves.

The Black Aged

This section will cover family assistance and help seeking patterns among black families.

The urbanization, industrialization and socialization of blacks has made an impact on the caregivers of elderly blacks in American society. A cross-cultural study by Mindel (1980) concluded that blacks have large and cohesive family systems that provide a great deal of help, entertainment and emotional support to their elderly relatives. However, rather than serving as an alternate support system, the role of the black family is that of providing supplementary assistance to elderly members in need.
An investigation by Jackson (1980) on the type of social support exchanged between the elderly and their children and grandchildren revealed that gifts, assistance when ill and transportation were the most frequent instrumental aid that the black elderly received.

A study by Taylor (1984), examining the impact of family and demographic factors on the frequency of support from family members, concluded that the black elderly are active participants in family networks. In addition, a hierarchy of preferred support resources was determined. The elderly in this study preferred receiving help from a particular group and will seek aid from others only if the preferred group is unwilling or unable to assist. Children are viewed as the most appropriate source of support followed by other kin, non-kin, and lastly, formal organizations.

Evans and Northwood (1978) in their study of minority elderly, concluded that informal support systems of friends and neighbors in a black community in Seattle acts as a supplement to the existing family structure.

A study examining the knowledge and use of social services among the black elderly was completed by Rao and Rao (1981). The study concluded that family background and interaction variables appear to be the most powerful factors
explaining the knowledge and use of social services. In addition, the researchers noted that family related variables explaining females and males knowledge of social services were not the same. Talking with siblings and children, intergenerational help given to children/grandchildren and seeing grandchildren were the most powerful variables in explaining black females' knowledge of services. By contrast, sex of the nearest child, intergenerational help received from children children/grandchildren, seeing children, and last seen relatives were the strongest variables explaining the males' knowledge of services. There was only one family related variable--intergenerational help given--was common to both males and females.

In a study by Ralston (1984), it was determined that socio-demographic characteristics of black elderly indicate that attenders of the senior centers will primarily be female, widowed, in the young old age group and from lower socio-economic backgrounds.

Summary

It is suggested by the research that there are many low-income black elderly in tightly woven extended family networks; there are other low-income black elderly who are isolated by family members; and there are some middle-income
black elderly who are rarely not grouped in the analysis of data on black elderly so that we have little knowledge other than speculation in regard to family relationships in this subgroup.

The myth that black families are a homogenous group has been refuted and policy makers; program directors/developers, public and private agencies need to recognize the different social and cultural factors which affect the knowledge and use of social services by elderly blacks.

Support Services for Caregivers

Several researchers indicate that family support is an important part of appropriate intervention programs. They tend to increase informal social supports which may be effective with a caregiver. (Safford, 1980; Stuerer, 1984; Gwyther and Matteson, 1983; Fuller et al., 1979; Zarit et al., 1980 and Glosser & Wexler, 1985) This service maybe provided by social workers, nurses, counselors, and physicians, and often forms a supportive counseling relationship with involved family members.

Pasamanic et al., (1967) reported that home visits made by public health nurses to families of schizophrenics had a beneficial effect on patient outcome. The public health nurse listening to clients and their families and their offering of some counseling aided in the success of home care programs for schizophrenics.
Several studies promote the use of group meetings for the caregivers of older people with senile dementia (Glosser & Wexler, 1985; Steurer, 1984; Gwyther & Matteson, 1983; and Fuller et al., 1979). These groups give members an opportunity to share concerns, clarify problems and roles, and develop skills for problems solving and coping. In addition it is a means to provide caregivers with information and education on dementia and community resources that maybe useful.

Another type of intervention was described by Garrison and Howe (1976). The entire natural support network of the person with dementia is involved in providing assistance to the primary caregiver. The goal of network therapy is to use affective and instrumental resources present within the natural support network to promote coping with problem behavior. By helping the entire natural support network to share in the supportive care of the older person, the responsibilities on the primary caregiver are reduced, thus, burden may be lessened.

A program developed by Florence Safford, (1980) was designed with the premise, that the needs of the mentally impaired elderly in present and future times can best be served by the sharing of responsibilities for their care by the family and appropriate formal organizations. The major focus and purpose of the program is to serve as a linkage mechanism to
achieve a better balance in the shared functions of primary caregivers and formal organizations in meeting the needs of the mentally impaired adults and their families.

The research suggests, that to enhance the informal support network of the older person with dementia and providing intervention appropriate with the needs of the caregiver, may reduce the overwhelming burdens experienced by the caregiver. In addition, the networking approach may prevent the breakdown of the family system, thus reducing the rate of institutionalization of mentally impaired elderly.

Aspects of Dementia

Words like presenile, senile and senility help to perpetuate the myth, that aging means mental decline. Negative feelings about aging, compounded with the fear and shame so often associated with brain disease, have made it difficult for laymen and health professionals to deal with problems posed by the dementias.1

Dementia may be caused by many diseases (Mace & Rabins, 1983 and the U.S. Dept. of Health and Human Services, 1981). (See Appendix A). The research indicates that approximately 50-75 percent of the causes of dementia are caused by Alzheimer's

disease (Wurtman, 1985; Dept. of HHS, 1981 and Mace & Rabins, 1983). Alzheimer's disease was first described in 1907 by a German physician Alois Alzheimer. Now as it was then, the cause of the disease is unknown and there is no effective standard medical treatment.

**Stages of Dementia of the Alzheimer's Type**

The research describes three distinct stages, time frame and symptoms (Hayter, 1974; Mace & Rabins, 1981; Gwyther, 1982; and Gwyther & Matteson, 1983).

**Stage 1**

A period of usually two or more years. The patient is often described as less spontaneous, with less initiative, energy, or willingness to try new things. There is a difficulty with recent memory, finding words, finishing thoughts, doing routine chores, learning new things and responds out of character when confronted with tasks beyond present capability. The patient maintains a social facade that is often deceptive to casual acquaintances and physicians. Families and close friends find themselves denying and excusing the performance deficiencies, often attributing the difficulties to stress. Spouses and children may cover up for the patient out of fear for their interdependent
futures. Many well meaning friends and family members encourage the patient to try harder or seek cures from health food stores and megavitamin therapy.

Stage 2

After diagnosis, families note more behavioral, mood and sleep problems associated with the memory loss. These problems require increasing supervision and protection from risks. The patient needs frequent repetition and reassurance, becomes more confused about identities and time, and has more difficulty expressing thoughts and feelings. Caregivers find themselves increasingly fatigued, impatient, and with less time for themselves and other career or family responsibilities. The family becomes increasingly isolated from friends, fully absorbed in reducing environmental risks and taking over the role tasks of the patient. Many close family members describe a period of preliminary grief as they see the patient becoming not the woman (man) I married or the mother (father) I knew. This is the longest stage and usually involves arranging concurrent multiple persons to share the burden for in-home care.

Stage 3

The final or terminal stage of the disease is usually
shorter. The patient becomes weak, loses weight, may be incontinent, needs total help with personal care, may not communicate at all or recognize anyone, and may become susceptible to multiple infections and generalized physical deterioration. The family must make the most difficult decisions to date regarding terminal care and life support. Many families agonize over the need for institutional care, handling their own guilt and grief, while searching for new supportive kin roles to play with the non-responsive patient. Spouses of recently institutionalized patients experience a "limbo" status, a need to re-orient themselves and time to their futures beyond the caregiving role.¹

**Etiology Models of Dementia of the Alzheimer's Type**

Most of the persons afflicted with Alzheimer's disease are elderly, however, their symptoms are not the result of "aging" as such. They have a specific sickness, Alzheimer's disease. The diagnosis can only be inferred during the patient's lifetime; no unique pattern of behavioral abnormalities has been established and there is no satisfactory laboratory test short of a brain biopsy. An autopsy show highly characteristics

pathologic changes that have taken place within the brain.¹

Several researchers have attempted to describe dementia of the Alzheimer's Type so that it is understood and treatable. Wurtman, 1985, identified six models in his article which support most research on Alzheimer's Disease. The models have been supported by some observational or experimental evidence.

The Genetic Model

There are families in which the incidence of Alzheimer's disease is unusually high. A typical genetic disease stems from an inform error of metabolism (an abnormality in the genetic material, DNA, impairs the ability of cells to make a particular protein. It is suggested by this model that the disease is governed by several genes being either mild or severe. This model is supported by the fact that nearly all people with Down's Syndrome, a known genetic disorder, develop Alzheimer's disease by the age of 40.

An argument against the model, is that no one has yet to identify a functionally abnormal protein or an abnormal chromosome in Alzheimer's disease.

The Abnormal-Protein Model

Alzheimer's disease is associated with abnormal protein structures. Its three major pathologic signs are the neurofibrillary tangles within neurons, the amyloid that surrounds and invades cerebral blood vessels and the amyloid-rich plaques that replace degenerating nerve terminals. Each of these reflects an accumulation of proteins not normally found in the brain.

The bundles of fibrous proteins known as neurofibrillary neurofibrillary tangles are found in neuronal cell bodies in the hippocampus and the cerebral cortex. They are particularly abundant in brainstem neurons that release transmitters (acetylcholine) found to be deficient in Alzheimer's disease.

The second sign referred to as amyloid (starchlike) is applied to pathological accumulations within tissues of a protein-rich mass notable mainly for its staining properties. When amyloid is stained with a dye called Congo red and viewed under polarized light, it emits a greenish yellow glow. The nature of the protein in amyloid can vary, depending on what precursor proteins are available in a particular disease state.

The third sign is the cerebrovascular amyloid. This is the most common finding in Alzheimer's disease. These proteins in the blood of a patient maybe converted, by an enzyme in
of Alzheimer's disease. Such salts are present in drinking water, maybe added to foods and drugs and maybe released from aluminum cans and utensils.

It is possible that aluminum cannot by itself give rise to the clinical and pathologic indicators of the disease but that its presence contributes to their appearance in people exposed to another causative factor.

The Blood-Flow Model

For many years, most adult dementia was blamed on poor circulation or hardening of the arteries. This type of dementia has been correlated not with evidence of atherosclerosis or small strokes, but with acetylcholine deficit and the tangles, plaques and cerebrovascular amyloid of Alzheimer's disease. The disease is associated with a reduction in the amount of blood delivered to the brain, in the amount of oxygen and glucose extracted from this blood and in the energy generated from the oxygen glucose.

There is a parallel decline in the rate at which the brain consumes glucose, its major source of energy. It is true that a decrease in the number of cells consuming oxygen an glucose would be expected to diminish the brain's demand for blood.
The Acetylcholine Model

The first clear biochemical abnormality associated with Alzheimer's disease was reported in 1976 by Peter Davies of the University of Edinburgh Faculty of Medicine and David Bowen of the Institute of Neurology in London. In the hippocampus and the cerebral cortex of patients, they found, the level of the enzyme choline acetyl transferase (CAT) could be reduced by as much as 90 percent.

The reported investigations by other researchers has confirmed the same results. As a result, many researchers consider this the clue most likely to point to the cause of Alzheimer's disease. In addition, it explains the loss of memory noted in Alzheimer's disease victims.

The Acetylcholine Model has attracted the most attention and interest of researchers. It has provided the researcher with a possible treatment for the disease.

Summary

This section of review not only describes how the disease affects the victim, but also, how the disease affects the caregiver. The caregiver experiences stages of Alzheimer's disease as well as the victim. These stages deal primarily with the emotional impact of the disease upon the caregiver. They include: (1) denial, (2) fear, (3) anger and (4) guilt.
The etiological models further help the caregiver have a clearer understanding of what Alzheimer's disease is not. The research investigations of the acetylcholine model, gives some hope that the onset of the disease may be postponed or even greatly reduced in the near future.

Limitations to Study

The limitations for this study were the limited information on characteristics of black caregivers, their demographic characteristics, use of social services and the incidence of Alzheimer's disease among elderly blacks. Just as information about the middle-class black has been eliminated from research, here again blacks have been eliminated from a very pertinent area. Census suggests that the proportionate number of elderly blacks to young blacks is steadily rising, thus information on this cohort group is most important for the provision of adequate services.

We can only speculate about the characteristics and social support patterns of black caregivers to Alzheimer's disease victims. Thus, a vast area of knowledge is still unknown about elderly blacks and their caregivers.

Summary

The review of the literature covered the many aspects
of the caregiver, and the impact of dementia upon the family. However, nowhere in the review of the literature does it suggest that Alzheimer's disease is particular to any one race or ethnic group. The disease seemingly crosses all racial boundaries, and socio-economic statuses. One thing is clear, and that is the elderly is most likely to become afflicted with the disease.
CHAPTER III

THEORETICAL FRAMEWORK

Introduction

The literature review strongly suggested that there is a need for the provision of appropriate care for the mentally impaired, as well as, adequate knowledge, understanding and acceptance of the nature of the condition by the caregiver. The literature review supported the need for appropriate intervention for primary caregivers. In addition, emphasis is placed on the multi-disciplinary approach toward intervention and the use of social services.

The theories that best support the issues raised in this study include (1) The General Systems Theory and (2) The Societal and Individual Determinants of Medical and Social Care Utilization.

General Systems Theory

The best way to attempt to support the multiple disciplinary approach is that of General Systems Theory. This theory has proven to be stimulating and integrative for the tasks
of planning, managing, and evaluating community-wide service delivery systems.¹

General Systems theory is based on the assumption that there are general principles identical across all levels and types of systems, living and non-living. The writer will restrict the analysis to the levels of individuals and organizations. These systems will consider how efforts of human service organizations might be focused for primary prevention and service integration for individuals.

Berger and Federico, (1982) discuss the characteristics of systems as the whole is more than the sum of its parts. The system has characteristics and activities of the components. The unity of the system derives from the roles and functions of the components. Miller, (1972) states further that a system is a set of interacting units with relationships among them. The word "set" implies that the units have some common properties, which is essential if they are to interact or have relationships. The state of each unit is constrained by, or dependent of the state of the other units.

Anthony Browkowski (1983) suggest that the units referred to by Miller, generally referred to as subsystems, are linked as well as separated in various ways. Every system has a

boundary that is more or less open to the environment. Every system must import matter and energy across its boundary to maintain itself as an organized structure and to carry out its productive processes. Organizations responsible for a community should consider the make-up of the community and or geographic areas most affecting factors which promote stress. The information shared between the two systems interconnects and thus becomes the whole.

Societal & Individual Determinants of Medical & Social Care Utilization

Researchers suggest that the average age of the primary caregivers to mentally aged elderly are more often age peers who are often women. Further, the review indicates that the determinants for utilization of services maybe best supported by the Medical and Social Service Utilization Theory developed by Anderson & Newman (1973). The framework takes into account both societal and individual determinants. It suggests that the main societal determinants of service utilization are technology and norms. The health care system structures the provision of formal health care goods and services in society. This system consists of two major dimensions, resources and organization. The individual determinants that affect medical and social care utilization includes: (1) the predisposition of the individual to use services, (2) their ability to secure services and (3) the
degree of the illness.

Coulton & Frost (1982) expands Anderson & Newman's theory. They address three groups of variables. They include: (1) need factors, which comprise both subjective perceptions and objective judgments. Perceived need refers to an individual's own judgement about the necessity or benefits of a particular service; in this instance, physical, mental, personal care and social impairments. Secondly, enabling factors include circumstances or individual characteristics that either hinder or facilitate the use of an appropriate service, once a need has been recognized. Financial resources, knowledge of services, insurance coverage and ability to locate and travel to services are examples of enabling factors. Thirdly, the predisposing factors are individual characteristics that may affect need recognition or service utilization. The individual's sex, ethnicity, and level of social support, and psychological distress are predisposing variables that have also been linked to utilization.

An individual's need is viewed as a combination of the actual impairment and the person's belief in the necessity and potential benefit of a particular service. This belief may be the product of both level of impairment and predisposing factors that reflect attitudes toward particular services or a general
predilection to seek help. The degree of impairment is suggested to be a partial determinant of an elderly person's perceived need for a service, this study implies that the assessment maybe confirmed by a professional or a significant other. However, whomever makes the assessment, the observed systems or level of impairment, or both are critical factors in determining the use of a given service.

Summary

The theoretical constructs, used in this study supports the researcher's beliefs that, program developers have to concern themselves primarily at the community's responsibility to provide care for individuals within the community regardless of the individuals race, age, financial status or dysfunction.

Statement of The Problem

The most prevalent form of dementing illness is Alzheimer's Disease. Currently, Alzheimer's disease is unable to be treated. There is no known cure nor causes. The disease can only be managed and the emotional burden of managing victims of dementia falls heavily on the family. Since dementia cannot be treated and the mental deterioration is progressive, this places great psychological and economic strain on the caregiver. The provision of appropriate care for the mental impaired calls for knowledge, understanding, and the acceptance of the nature of the
Basic Assumptions

The researcher assumes that the caregiver will be a spouse, on a fixed income and experiencing a great deal of stress, related to the caring of the Alzheimer's disease victim. It was also assumed, that through a description of the caregiver, the researcher, would be able to develop insights, ideas, answer questions and develop hypothesis for future study.
CHAPTER IV

RESEARCH METHODS & PROCEDURES

Introduction

Chapter I discusses the issue of dementia and relates it to the steady growth population among the elderly in our society. The steady growth of the elderly population in Georgia and the tendency of Alzheimer's disease to afflict the elderly population gives notice to the need for information of the caregivers to this population.

Research Design

The hypothetical-developmental (exploratory) design was used in this study. A needs assessment was employed on a cross sectional study design. This allowed for the description of the profile of the caregivers to Alzheimer's victims. (independent variable) and their utilization of support services (dependent variable).

Subjects of the Study

The subjects are all registered with one of the sixteen (16) Alzheimer's support groups across the state of Georgia (See Appendix B). They are either primary or secondary caregivers.
(For the purpose of this study, both primary and secondary caregivers were aggregated as the caregiver.)

Selection Procedure

The study subjects were purposively selected rather than randomly selected. The non-availability of a data-base to randomly select the subjects, limited the researcher to systematically select the sample population.

Instrumentation

Survey research provides a means for greater assurance of anonymity, it limits interviewer bias, and provides accessibility to larger numbers of persons. The feasibility of survey research is that it is used to increase the knowledge about problems that affect a wide variety of people.

The survey used in this study is a 32 item questionnaire designed to measure the demographic characteristics of caregivers as well as measuring their needs and their frequency of service utilization (See Appendix C).

Research Procedures

One-thousand, seven hundred and ninety-nine (1,799) persons; identified as caregivers through their registration with one of the sixteen (16) state-wide support groups; were mailed a survey.
Analysis

Based upon the survey instrument, both quantitative and qualitative methods will be used. Data will be presented in the form of tables using percent comparisons.
CHAPTER V

RESULTS

Introduction

This chapter contains the presentation and discussion of the research findings. The chapter is divided into two sections: (1) descriptive analysis of findings from the survey instrument; and (2) Conclusion and Implications.

Descriptive Analysis

The survey respondents consisted of three hundred and seventy-seven (377) caregivers. They were heterogenous with respect to age, socio-economic status, and available family support systems.

The data for this method of study consisted of the median scores and the frequency distribution for the responses to the mailed caregiver survey. From the 1799 surveys mailed, 456 (25%) caregivers responded. From this population a total of 377 caregiver surveys were complete or usable. Out of the 377 surveys, 200 were from the Atlanta area. The 377 usable surveys represented 20% of all the caregivers registered with an
Alzheimer's Disease and Related Disorder support group in Georgia. All of the data described below relates to this surveyed population.

Age and Sex of Alzheimer's Victim

The surveyed caregivers were questioned regarding the age and sex of the Alzheimer's disease victim. This is presented in Table 1.

TABLE I

VICTIM SEX BY AGE

(N=377)

<table>
<thead>
<tr>
<th>Age</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>55-64</td>
<td>30</td>
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<td>65-74</td>
<td>53</td>
<td>42.1</td>
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<td>75+</td>
<td>43</td>
<td>34.1</td>
</tr>
<tr>
<td>N = 100%</td>
<td>126</td>
<td>33.4</td>
</tr>
</tbody>
</table>

The number of males being cared for represented 33.4% of this population. The age range most frequently cited for the male victims was located between the ages of 65-74, which represented 42.1% of this group. The number of females being cared for
represented 66.6%, and the most frequent age-range of female Alzheimer's victims was located at age 75 years old and above. This represented 52.6% of this population.

In addition to the distribution of the sex and age of the Alzheimer's victim, Table 2, represents the distribution of age and sex of the Alzheimer's victim by the age of the caregiver.

**TABLE 2**

AGE & SEX OF VICTIM BY AGE OF CAREGIVER
(N=377)

<table>
<thead>
<tr>
<th>Age of Caregiver</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>AGE</td>
<td>AGE</td>
</tr>
<tr>
<td></td>
<td>50-</td>
<td>60-</td>
</tr>
<tr>
<td></td>
<td>59</td>
<td>69</td>
</tr>
<tr>
<td>25-34</td>
<td>6.6</td>
<td>....</td>
</tr>
<tr>
<td>35-44</td>
<td>13.3</td>
<td>19.3</td>
</tr>
<tr>
<td>45-54</td>
<td>40.0</td>
<td>3.2</td>
</tr>
<tr>
<td>55-64</td>
<td>40.0</td>
<td>48.3</td>
</tr>
<tr>
<td>65-74</td>
<td>...</td>
<td>29.0</td>
</tr>
<tr>
<td>75+</td>
<td>...</td>
<td>.....</td>
</tr>
<tr>
<td>N=100%</td>
<td>4.0</td>
<td>8.2</td>
</tr>
</tbody>
</table>
The findings suggest that the caregiver is between the ages of 45 and 64 years old for both male and female victims. They tend to be spouses of the victim, when the victim is a male and between the ages of 60-69. The caregiver of the female victim tends to be the spouse, if the victim is between the ages of 50-59.

**Age of the Caregiver**

The respondents were questioned on their ages. The median age of the caregiver to an Alzheimer's disease victim is 55.6. The data suggests that the most frequent cited age range for the caregiver is between the ages of 45-54 years old, representing 49% of the population (See Table 3).

<table>
<thead>
<tr>
<th>Age</th>
<th>(F)</th>
<th>(CF)</th>
<th>(%)</th>
<th>(C%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>25-34</td>
<td>26</td>
<td>26</td>
<td>6.9</td>
<td>6.9</td>
</tr>
<tr>
<td>35-44</td>
<td>64</td>
<td>90</td>
<td>17.0</td>
<td>23.9</td>
</tr>
<tr>
<td>45-54</td>
<td>95</td>
<td>185</td>
<td>25.2</td>
<td>49.1</td>
</tr>
<tr>
<td>55-64</td>
<td>84</td>
<td>269</td>
<td>22.3</td>
<td>71.4</td>
</tr>
<tr>
<td>65-74</td>
<td>77</td>
<td>346</td>
<td>20.4</td>
<td>91.8</td>
</tr>
<tr>
<td>75+</td>
<td>31</td>
<td>377</td>
<td>8.2</td>
<td>100</td>
</tr>
</tbody>
</table>
Upon closer examination of the data, Figure 3.1 presents the age distribution of the caregiver across all ages. The curve peaks between the ages of 45 and 74 (See Figure 3.1).

In addition to age, respondents were questioned regarding their individual income and the cost of care of the
Alzheimer's victims. The income range ($40-49 thousand) with the highest frequency level represented 40.7% of the population (See Table 4.)

**TABLE 4**

INCOME OF CAREGIVER BY AGE
(N=377)

% Per Thousand Dollars

<table>
<thead>
<tr>
<th>Age</th>
<th>&lt;$10</th>
<th>$10-19</th>
<th>$20-29</th>
<th>$30-39</th>
<th>$40-49</th>
<th>$50+</th>
</tr>
</thead>
<tbody>
<tr>
<td>25-34.....</td>
<td>11.4</td>
<td>8.1</td>
<td>4.2</td>
<td>4.5</td>
<td>....</td>
<td>4.5</td>
</tr>
<tr>
<td>35-44.....</td>
<td>10.2</td>
<td>15.3</td>
<td>15.3</td>
<td>18.2</td>
<td>40.7</td>
<td>27.3</td>
</tr>
<tr>
<td>45-54.....</td>
<td>27.3</td>
<td>21.0</td>
<td>25.0</td>
<td>34.1</td>
<td>22.2</td>
<td>27.3</td>
</tr>
<tr>
<td>55-64.....</td>
<td>27.3</td>
<td>18.5</td>
<td>31.9</td>
<td>18.2</td>
<td>7.4</td>
<td>18.2</td>
</tr>
<tr>
<td>65-74.....</td>
<td>17.0</td>
<td>28.2</td>
<td>16.7</td>
<td>13.6</td>
<td>22.2</td>
<td>13.6</td>
</tr>
<tr>
<td>75+.......</td>
<td>6.8</td>
<td>8.9</td>
<td>6.9</td>
<td>11.4</td>
<td>7.4</td>
<td>9.1</td>
</tr>
<tr>
<td>N=100%....</td>
<td>23.3</td>
<td>32.9</td>
<td>19.0</td>
<td>11.7</td>
<td>7.2</td>
<td>5.8</td>
</tr>
</tbody>
</table>

In addition to income Table 4, presents the income and age of the caregiver. Whereas, Table 3 presents the age of the caregiver between the ages of 45-74, Table 4 indicates that 34% of the caregivers between the ages of 45-54 earn $30-39 thousand dollars per year, and 31.9% of the caregivers between ages 55-64 earn $20-29 thousand dollars per year.

The distribution of the cost of care of the Alzheimer's
disease victim is located in Table 5.

### TABLE 5

**COST OF CARE BY CAREGIVER INCOME**

(N=377)

% per thousand dollars

<table>
<thead>
<tr>
<th>Annual Income of Caregiver</th>
<th>Annual Cost of Care</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>&lt;$1</td>
</tr>
<tr>
<td>&lt; $10...........</td>
<td>34.5</td>
</tr>
<tr>
<td>10-19...........</td>
<td>36.2</td>
</tr>
<tr>
<td>20-29...........</td>
<td>14.6</td>
</tr>
<tr>
<td>30-39...........</td>
<td>3.5</td>
</tr>
<tr>
<td>40-49...........</td>
<td>7.1</td>
</tr>
<tr>
<td>50+...........</td>
<td>3.5</td>
</tr>
<tr>
<td>N=100%...........</td>
<td>30.0</td>
</tr>
</tbody>
</table>

The data reflected that the largest group (31%) of all the caregivers spend between $10-19 thousand dollars for the care of Alzheimer's victims, per year; 30% spend less than $1,000 and 27% spend between $1-9 thousand. Only 4% of the population spend $30 thousand or more for care of the victim. However, it is indicated by the data (Table 5) that the caregiver who earns between $20-29 thousand dollars per year may spend between $0-30 thousand dollars per year for care of the victim.
Relationships

With respect to the relationship of the caregiver to the Alzheimer's disease victim, 59.4% of the respondents were identified as children, other relatives or friends; 39.3% were noted to be spouses, and 1.3% of the population were identified as siblings (See Table 6). In general, those caregivers over 55 were spouses, under 55, children/and other friends and relatives.

<table>
<thead>
<tr>
<th>Age of the Caregiver</th>
<th>Spouse</th>
<th>Relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Children/other relatives-friend</td>
</tr>
<tr>
<td>25-34</td>
<td>......</td>
<td>11.2</td>
</tr>
<tr>
<td>35-44</td>
<td>1.3</td>
<td>27.7</td>
</tr>
<tr>
<td>45-54</td>
<td>7.4</td>
<td>37.5</td>
</tr>
<tr>
<td>55-64</td>
<td>26.3</td>
<td>19.6</td>
</tr>
<tr>
<td>65-74</td>
<td>44.6</td>
<td>4.0</td>
</tr>
<tr>
<td>75+</td>
<td>20.2</td>
<td>......</td>
</tr>
<tr>
<td>N=100%</td>
<td>39.3</td>
<td>59.4</td>
</tr>
</tbody>
</table>

Location

The respondents were questioned regarding the location
of the Alzheimer's disease victim. The number of Alzheimer's disease victims located within the community (non-institutionalized) represented 58% of the sample population (See Table 7).

**TABLE 7**

<table>
<thead>
<tr>
<th>Location and Race of Victim</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing Home</td>
<td></td>
<td></td>
</tr>
<tr>
<td>white</td>
<td>155</td>
<td>98.0</td>
</tr>
<tr>
<td>non-white</td>
<td>3</td>
<td>1.9</td>
</tr>
<tr>
<td>Non-Nursing Home</td>
<td></td>
<td></td>
</tr>
<tr>
<td>white</td>
<td>197</td>
<td>90.0</td>
</tr>
<tr>
<td>non-white</td>
<td>22</td>
<td>10.0</td>
</tr>
</tbody>
</table>

In addition to the distribution of the location of the Alzheimer's disease victim, Table 7, also presents the distribution of victim located by race. The data indicates that non-whites also, tend to care for their family members at home.

**Assistance From Family and or Friends**

The number of respondents who receive assistance from other family members or friends represented 58.4% of the population (See Table 8).
TABLE 8

FAMILY ASSISTANCE TO CAREGIVER BY AGE

(N=377)

<table>
<thead>
<tr>
<th>Age of Caregiver</th>
<th>Family Assistance</th>
<th>No Family Assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>25-34</td>
<td>9.1</td>
<td>2.5</td>
</tr>
<tr>
<td>35-44</td>
<td>20.4</td>
<td>14.0</td>
</tr>
<tr>
<td>45-54</td>
<td>28.2</td>
<td>17.8</td>
</tr>
<tr>
<td>55-64</td>
<td>18.6</td>
<td>22.9</td>
</tr>
<tr>
<td>65-74</td>
<td>18.2</td>
<td>31.9</td>
</tr>
<tr>
<td>75+</td>
<td>5.4</td>
<td>10.9</td>
</tr>
<tr>
<td>N=100%</td>
<td>58.4</td>
<td>41</td>
</tr>
</tbody>
</table>

The age-range which identified the highest frequency of assistance was represented between ages 45-54. This represented 28.2% of the population. The age-range which represented the highest frequency with no assistance was between the ages 65-74. This represented 31.9% of the no-assistance group.

The assistance from family and friends by race is located in Table 9. (See Table 9.)
Table 9 indicates that non-white respondents are just as likely to keep their family members at home. However, the sample of non-whites is so small a generalization cannot be made from the data.

Problems and Needed Services

The respondents were questioned regarding the biggest problems facing caregivers of Alzheimer's disease victims. The majority of the respondents identified the biggest problems facing the caregiver as the emotional and social impact upon the caregiver. Since the respondents could identify more than one response to this question, the results are placed in rank order. (See Table 10.)
TABLE 10
RANK ORDER OF
PROBLEMS FACING CAREGIVERS

<table>
<thead>
<tr>
<th>PROBLEMS</th>
<th>%</th>
<th>RANK</th>
</tr>
</thead>
<tbody>
<tr>
<td>The emotional and social impact on the caregiver</td>
<td>72.9</td>
<td>1</td>
</tr>
<tr>
<td>Lack of financial assistance</td>
<td>59.7</td>
<td>2</td>
</tr>
<tr>
<td>Lack of quality affordable services to keep persons at home</td>
<td>46.4</td>
<td>3</td>
</tr>
<tr>
<td>Lack of understanding and support by professionals and the community</td>
<td>41.1</td>
<td>4</td>
</tr>
<tr>
<td>Lack of quality affordable specialized long-term care</td>
<td>37.7</td>
<td>5</td>
</tr>
<tr>
<td>Physical impact of disease on caregiver</td>
<td>35.8</td>
<td>6</td>
</tr>
</tbody>
</table>

Services Needed Most By Persons & Families of Persons With Alzheimer's Disease

The respondents gave top priority to services which would give respite care and relief to family members. The ranking of the services needed most by persons and families of persons with Alzheimer's disease is located in Table 11. (Respondents could identify more than one service, see Table 11.)
## TABLE 11

### SERVICE NEEDS

<table>
<thead>
<tr>
<th>SERVICES NEEDED FOR PERSONS WITH ALZHEIMER'S DISEASE</th>
<th>%</th>
<th>RANK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day-care centers and other forms of respite care</td>
<td>67.4</td>
<td>1</td>
</tr>
<tr>
<td>Activities, personal care and supportive services for Alzheimer's disease patients in the home</td>
<td>57.5</td>
<td>2</td>
</tr>
<tr>
<td>Specialized long-term care facilities</td>
<td>46.4</td>
<td>3</td>
</tr>
<tr>
<td>Qualified health care providers and trained caregivers</td>
<td>42.4</td>
<td>4</td>
</tr>
<tr>
<td>Research and financial assistance</td>
<td>25.7</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SERVICES NEEDED BY CAREGIVERS OF PERSONS WITH ALZHEIMER'S DISEASE</th>
<th>%</th>
<th>RANK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respite care of all types (i.e. in-home, day-care, institutional)</td>
<td>66.9</td>
<td>1</td>
</tr>
<tr>
<td>Support groups and informed community</td>
<td>65.5</td>
<td>2</td>
</tr>
<tr>
<td>Financial support</td>
<td>51.8</td>
<td>3</td>
</tr>
<tr>
<td>Counseling and legal advise</td>
<td>49.6</td>
<td>4</td>
</tr>
<tr>
<td>Education and training on dealing with Alzheimer's disease victims</td>
<td>46.4</td>
<td>5</td>
</tr>
</tbody>
</table>
Utilization of Support Services

The distribution of the support services most frequently utilized by the caregivers are presented in Table 12. The top ten services was also presented in rank order, due to the multiple answers that a respondent may give. (See Table 12.)

**TABLE 12**

**RANK ORDER OF FREQUENT SUPPORT SERVICES UTILIZED BY CAREGIVERS**

<table>
<thead>
<tr>
<th>SERVICES</th>
<th>%</th>
<th>RANK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support Group</td>
<td>61.9</td>
<td>1</td>
</tr>
<tr>
<td>Part-time or Occasional Paid Help</td>
<td>33.2</td>
<td>2</td>
</tr>
<tr>
<td>Nursing Home</td>
<td>33.1</td>
<td>3</td>
</tr>
<tr>
<td>Legal Aid</td>
<td>29.0</td>
<td>4</td>
</tr>
<tr>
<td>Counseling</td>
<td>28.2</td>
<td>5</td>
</tr>
<tr>
<td>Hospital (Acute Care)</td>
<td>22.8</td>
<td>6</td>
</tr>
<tr>
<td>Companion or Sitter Service</td>
<td>14.1</td>
<td>7</td>
</tr>
<tr>
<td>Adult Day Care</td>
<td>14.1</td>
<td>8</td>
</tr>
<tr>
<td>Home Health Care</td>
<td>12.9</td>
<td>9</td>
</tr>
<tr>
<td>Personal Care Home</td>
<td>12.6</td>
<td>10</td>
</tr>
</tbody>
</table>

**Conclusion**

The results of the study suggests that caring for the
person with Alzheimer's Disease and Related Disorders is a unique situation. The analysis of the participants biggest problems and needed services provides the following conclusions: (1) The biggest impact of caring for an Alzheimer's disease victim is the emotional and social impact of the disease upon the caregiver. A few of these emotions can best be stated in the words of the respondents themselves.

* "The helplessness and sadness at watching a loved one deteriorate or watching the person slowly fade away".

* "The inability of accepting the finality of the disease".

* "My biggest problem is worrying about his well-being. Being there for him whenever he needs me. Knowing he is well cared for means everything to me."

* "Understanding what is happening to your loved one. Unable to continue contact with the outside world. Learning to be patient and give necessary care."

* "Not knowing how to deal with your own personal feelings and what to expect from the relative with the illness."

* "The grief and heartbreak. Constant worry and
stress about his future. My future. The stress
has hurt my own health. It's so tragic!

Many of the respondents indicated that the physical ex-
hauston of caring for the Alzheimer's disease victim can often
times be overwhelming, especially if there's no assistance. As
indicated in the descriptive analysis, the percentage of respon-
dents who did not have assistance was almost one-half of the
population surveyed and their ages fell between the 55-74 age
cohort.

Secondly, the social factors such as isolation and
confinement to the home, the day to day care needed by the
victim, the lack of personal free time and the total exasperation
from caring for the victim all day and most of the night was
sited by the majority of the respondents. One respondent's
comment further exemplifies the social and emotional impact of
caring for the Alzheimer's disease victim. "We are prisnors in
our own homes. Every family member's waking hours are taken up--
our nerves always on edge."

It is suggested that the caregiver of an Alzheimer's
disease victim is middle aged, on a fixed income, maintains the
victim in the community and is heavily stressed. The Support
services most used by the caregivers was identified as the sup-
port group. The low percentage of utilization of the other sup-
services, suggest either lack of knowledge of the available services, or, the cost is too expensive for the caregiver to obtain the service.

Summary and Implications

In this study the profile of the caregiver of the Alzheimer's disease victim was examined. The researcher felt that the most important area to investigate was that of the responses to the open-ended questions. These questions allowed the respondents to express in their own words the true impact of caring for an Alzheimer's disease victim.

The study used the mailed survey data collection method. The findings suggested that the caregivers of Alzheimer's disease victims in Georgia are in need of emotional and financial assistance.

The rationale for pursuing this particular study was that there are gaps in both the private and public sectors in addressing the needs/problems of caregivers to Alzheimer's disease victims. The gaps indicate that providers have failed to account for who actually provides the care, and well-being of the patient, as well as, the cost associated with caring for a non-physically disabled person.

Georgia is just beginning to investigate the profile of
the caregiver. It is hoped that the findings from this study will continue to provide social service administrators and legislators with supportive data regarding the implementation of needed programs and services. In addition, it is hoped that these findings will assist in revolting some of the myths that the impaired elderly are hidden away in nursing homes, and that elderly persons have extensive bank accounts.

The findings should have significant implications for social workers, physicians, nurses, and counselors regarding the development of effective programs and management technics to enhance the life of the Alzheimer's victim, as well as the caregiver.

The study promotes the notion that families of Alzheimer's disease victims; especially in stages one and two; consider it to be more beneficial to the patient, to be kept at home than be placed in a nursing home. Therefore, the recommendations resulting from this study include:

1) Public fund for respite care services.
2) Training programs for caregivers on how to care for an Alzheimer's victim.
3) Training programs for service providers on care of Alzheimer's victims.
4) The development of support groups in each Georgia
51

county.

5) Tax benefits for caregivers who care for the elderly at home.

The development of base-line data on caregivers of Alzheimer's disease victims will enable researchers to continue to add to the information of this population. In addition, researchers need to identify the type of support services which are utilized by those persons who are not involved with a support group. Also, the impact of stress upon other family members and friends who provide some assistance to the caregiver. Other, areas of needed research is the examination of possible factors which differentiate blacks and whites in the management of caregiver stress, examination of the difference in the management of stress and the size of the family and finally, is cost a factor or the lack of knowledge of a support service which determines utilization by a caregiver.
APPENDIX A

CAUSES OF DEMENTIA
TABLE 13
CAUSES OF DEMENTIA

Metabolic disorders

Thyroid, parathyroid, or adrenal gland dysfunction
Liver or kidney dysfunction
Certain vitamin deficiencies, such as vitamin B-12 deficiency

Structural problems of the brain.

Normal pressure hydrocephalus (abnormal flow of spinal fluid)

Brain tumors

Subdural hematoma (bleeding beneath the skull which results in collections of blood which press on the brain)
Trauma (injuries to the brain)
Hypoxia and anoxia (insufficient oxygen)

Infections

Tuberculosis
Syphilis
Fungal, bacterial, and viral infections of the brain, such as meningitis or encephalitis

Toxins (poisons)

Carbon monoxide
Drugs
Metal poisoning
Alcohol

Degenerative diseases

Alzheimer's disease
Friedreich's disease
Huntington's disease
Parkinson's disease
Pick's disease
Progressive supranuclear palsy
Wilson's disease
Vascular (blood-vessel) disease

   Stroke or multi-infarct disease

Autoimmune disease

   Temporal arteritis  
   Lupus erythematosus

Psychiatric diseases

   Depression  
   Schizophrenia

Multiple sclerosis
APPENDIX B

STATE-WIDE SUPPORT GROUPS
The Alzheimer's Disease and Related Disorders Association, Inc. (ADRDA), is a voluntary, non-profit organization devoted to information, education, family support and research on Alzheimer's Disease. Chapters offer educational opportunities for professionals and families, support groups, and up-to-date information on the disease. Georgia chapters are part of a national network of more than 120 affiliated groups.

Other Alzheimer's Family Support Groups (by PSA)

**Altamaha-Georgia Southern**

Baxley Alzheimer's Support Group  
(Counties of Appling, Jeff Davis, Toombs and Wayne)  
Evans County Alzheimer's Support Group  
(Counties of Bulloch, Candler, Evans and Tatnall)  
c/o Linda Sellers  
Altamaha-Georgia Southern APDC  
P. O. Box 328  
Baxley, Georgia 31513  
(912) 367-3648

*Atlanta Regional Commission* - (See Atlanta Area Chapter, ADRDA, above)

*CSRA* - (See Augusta Area Chapter, ADRDA, above)

**Chattahoochee-Flint**

LaGrange Alzheimer's Support Group  
c/o Carol Bowen  
Florence Hand Nursing Home  
1514 Vernon Road  
LaGrange, Georgia 30240  
(404) 884-6131

Newnan-Coweta Alzheimer's Support Group  
c/o Helen Holt  
Newnan-Coweta Senior Center  
39 Greenville Street  
Newnan, Georgia 30263  
(404) 253-8660
Coastal

Glynn Co. Alzheimer's Support Group
c/o Jessica Walter
Coastal APDC, P. O. Drawer 1917
Brunswick, Georgia 31521
(912) 264-7363, GIST 365-7363

Savannah Alzheimer's Support Group
c/o Nellie Chodkiewicz
Tidelands Mental Health Center
P. O. Box 23407
Savannah, Georgia 31403-3407
(912) 944-2283

Coosa Valley

Rome Area Alzheimer's Support Group
c/o Jean Angel, R.N.
Floyd Medical Center
Turner-McCall Boulevard
Rome, Georgia 30161
(404) 291-2577

Georgia Mountains

Gainesville Alzheimer's Support Group
c/o Rev. T. Richard Davis
First Baptist Church
751 Green Street, N. W.
Gainesville, Georgia 30505
(404) 534-7354

Heart of Georgia - (Nothing at this time)

Lower Chattahoochee

Columbus Alzheimer's Support Group
c/o Helen Ross
P. O. Box 1651
Columbus, Georgia 31902
(404) 327-5208

McIntosh Trail

Griffin Area
(Counties of Butts, Henry, Pike and Spalding)
c/o Jan Jones
Griffin-Spalding Home Health Agency
600 South 8th Street
Griffin, Georgia 30223
(404) 229-4962
Middle Flint — (Nothing at this time)

Middle Georgia

Macon Alzheimer's Support Group
c/o Rosalind McMillan
The Medical Center
Box 13, 777 Hemlock Streete
Macon, Georgia 31201
(912) 744-1267

North Georgia

Dalton Alzheimer's Support Group
c/o Ruth Lamb
1700 Daffodill Drive
Dalton, Georgia 30720
(404) 226-1499

Northeast Georgia

Athens Area Alzheimer's Support Group
c/o Kathy Gratzeck
N. E. Georgia Community Mental Health Center
1247 Prince Avenue
Athens, Georgia 30606
(404) 542-8656, Ext. 244

Oconee — (Nothing at this time)

South Georgia — (Nothing at this time)

Southeast Georgia

Bacon County Alzheimer's Support Group
c/o Karla Altman
Concerted Services, Inc.
P. O. Box 1965, 201 State Street
Waycross, Georgia 31501
(912) 285-6142, GIST 368-6030

Southwest Georgia (SOWEGA)

Albany Alzheimer's Family Caregiver's Support Group
c/o Virginia Griffin
SOWEGA Council of Aging, Inc.
309 Pine Avenue
Albany, Georgia 31701
(912) 432-1124

Note: All the above are in various stages of organization.
Indicates the location of Alzheimer's Disease and Related Disorder Support Groups throughout the state of Georgia.
APPENDIX C

INSTRUMENT
SURVEY OF FAMILY MEMBERS AND FRIENDS OF
ALZHEIMER'S DISEASE AND RELATED DISORDERS VICTIMS

1. Does someone in your immediate family have Alzheimer's Disease?
   Yes _____  No _____ (Go to question 9)

2. Please indicate the age, sex and race of the family member with Alzheimer's Disease?
   Age: _____  Sex: Male  Female  Race: _____

3. Are you the primary caregiver to the person with Alzheimer's Disease?
   No _____  Yes _____ (see below)
   A. Do you have children, other relatives or friends who assist you in caregiving?
      No _____  Yes _____

   B. What is your age? _____

   C. What is your current employment status?
      employed full time  employed part time
      unemployed  retired

4. What is your relationship to the person with Alzheimer's Disease?
   ____ Spouse (Husband or Wife)  ____ Friend
   ____ Parent  ____ Grandchild
   ____ Sibling (brother or sister)  ____ Paid Helper
   ____ Other (Specify ________________)

5. Where does this person with Alzheimer's Disease live?
   ____ Alone  ____ With a paid helper  ____ With a friend
   ____ With me  ____ With another relative
   ____ In a nursing home or other facility (Please specify type)
       ________________ and how many years _____________

6. Is this person with Alzheimer's Disease currently living in Georgia?
   Yes _____  No _____
7. Please estimate the annual expense incurred by you or your family in providing care for this person with Alzheimer's Disease. (Include home care, medical expenses, nursing home fees, etc.)

- No Cost
- Less than $1,000
- $15,000 - $19,999
- $25,000 - $29,999
- More than $35,000 (Specify ________________)

8. Please estimate the annual gross income of the family of this person with Alzheimer's Disease (Include income only of persons who contribute to the costs of this person's care).

- Less than $10,000
- $15,000 - $19,999
- $30,000 - $39,999
- $50,000 - $59,999
- Greater than $60,000 (Please specify ________________)

9. What do you think are the biggest problems facing caregivers of persons with Alzheimer's Disease?

________________________________________________________________________

________________________________________________________________________

10. What services do you think are needed most by:

A) Persons with Alzheimer's Disease? ________________

B) Families of persons with Alzheimer's Disease? ________________

**Persons who answered NO to questions #1 or 6 should stop here.**

Please return completed survey form to:

Margaret Counts
Department of Human Resources
Office of Aging
878 Peachtree Street, N.E.
Suite 632
Atlanta, Georgia 30309

If you have any questions concerning this survey please contact Margaret Counts at (404) 894-2084.
11. This last question covers three areas: I) use of services, II) reason for non-use and III) knowledge about obtaining services. First, in Column I, indicate how often each service was used by the person with Alzheimer's Disease or their primary care giver within the past 12 months. For each service not regularly used, indicate in Column II the reason why, using the lists of reasons below:

**REASONS**

A - Unable to Afford  
B - Service available but not suited to needs  
C - Service not available or not conveniently located  
D - Restrictive admission policies  
F - Do not know how to obtain services  
G - Do not need service  
* - Other - Be Specific

<table>
<thead>
<tr>
<th>SERVICE</th>
<th>I USE OF SERVICES IN PAST 12 MONTHS</th>
<th>II REASONS FOR NON USE OTHER (SPECIFY)</th>
<th>III KNOWLEDGE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never</td>
<td>A B C D E F G</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Occasionally</td>
<td>A B C D E F G</td>
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<tr>
<td></td>
<td>Regularly</td>
<td>A B C D E F G</td>
<td></td>
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<tr>
<td>Companion or sitter service through an Agency</td>
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<td>A B C D E F G</td>
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<tr>
<td>Adult day care services</td>
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<td>A B C D E F G</td>
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<tr>
<td>Part-time or occasional paid helper</td>
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<td>A B C D E F G</td>
<td></td>
</tr>
<tr>
<td>Paid live-in companion or helper</td>
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<td></td>
</tr>
<tr>
<td>Respite services in a nursing home</td>
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<td>A B C D E F G</td>
<td></td>
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<tr>
<td>Counseling</td>
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<td>A B C D E F G</td>
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<tr>
<td>Legal advice</td>
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<td>A B C D E F G</td>
<td></td>
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<tr>
<td>Home health care (from Home Health Agency)</td>
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<td>A B C D E F G</td>
<td></td>
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<tr>
<td>Congregate meals (from Senior Center)</td>
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<td>A B C D E F G</td>
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<tr>
<td>Home delivered meals</td>
<td></td>
<td>A B C D E F G</td>
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<tr>
<td>Transportation</td>
<td></td>
<td>A B C D E F G</td>
<td></td>
</tr>
<tr>
<td>Homemaker/chore services</td>
<td></td>
<td>A B C D E F G</td>
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<tr>
<td>Mental Health services</td>
<td></td>
<td>A B C D E F G</td>
<td></td>
</tr>
</tbody>
</table>
### REASONS

A - Unable to Afford  
B - Service available but not suited to needs  
C - Service not available or not conveniently located 
D - Restrictive admission policies  
E - Do not know how to obtain services 
F - Do not need service  
* Other - Be Specific

<table>
<thead>
<tr>
<th>SERVICE</th>
<th>I USE OF SERVICES</th>
<th>II REASONS FOR NON USE</th>
<th>III KNOWLEDGE</th>
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</thead>
<tbody>
<tr>
<td>Support Group</td>
<td>Never</td>
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<tr>
<td>Protective Services</td>
<td>Occasionally</td>
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<tr>
<td>Hospital (Acute Care)</td>
<td>Regularly</td>
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<td>V. A. Hospital</td>
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<tr>
<td>Hospice</td>
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<tr>
<td>Other Community Service</td>
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<td>(Specify)</td>
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<td></td>
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<td>Nursing Home</td>
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<td>Psychiatric Hospital</td>
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</tr>
<tr>
<td>Personal Care Home</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

*Other - Be Specific*
APPENDIX D

GLOSSARY
GLOSSARY

Caregiver: Refers to the individual who is responsible for providing or coordinating the resources required by the persons with dementia, such as housekeeping, financial help, personal hygiene, and shopping.

Dementia: Refers to a person who is deprived of the use of parts of the brain associated with a range of intellectual skills and activities unique to human beings. The irreversible progressive loss of mental faculties, often beginning with memory, learning, attention, and judgement.

Need: Refers to an individual's own judgement about the necessity or benefits of a particular service.

Support Service: Refers to a formal community program designed to contribute to the emotional, physical and economic welfare of persons who provide care to impaired elderly at home.

Utilization: Refers to the frequency of use of a particular support service.
BIBLIOGRAPHY


Evans, R. L. & L. K. Northwood, "The Utility of Locality-Based Social Networks", Journal of Minority Aging 3 1978:


Moore, Joan W. "Situational Factors Affecting Minority Aging". 


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72


