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AN ABSTRACT OF THE THESIS OF Greta Krahn Stapleton for the Master of Science in Education presented July 28, 1986.

Title: Serving Primary Caregivers of Persons with Alzheimer's
Disease: An Integrated Service Delivery Model.

APPROVED BY MEMBERS OF THE THESIS COMMITTEE:

Phyllis S. Lee, Chair

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Alzheimer's disease (AD) is the most common form of nontreatable dementia, a syndrome which reflects a progressive and global impairment of memory, intellect, and other cognitive abilities. This devastating condition directly touches the lives of as many as 10 million Americans, including not only persons suffering from the

disease but their primary caregivers and other family members as well. At present the course of AD cannot be halted or reversed, and no cure is known. The problem, then, is how to most effectively respond to the psychosocial needs of primary caregivers in order to help them provide the best possible care for a loved one with AD.

Research into the pathology of AD suggests that three types of brain tissue lesions are related to development of the disease. Etiology is uncertain, but a variety of biochemical, viral, genetic, and toxic causes are being investigated. Diagnosis requires (a) an assessment of clinical symptoms and history; (b) cognitive testing; (c) a thorough medical examination; and (d) a review of psychosocial functioning. The focus is on identifying and treating reversible causes of dementia first, with diagnosis of AD only after other possible causes have been excluded. A one-dimensional view of AD as a medical condition for which no cause, treatment, or cure is known presents a grim prognosis. A more positive view suggests that while the biological aspects of AD are not currently treatable, the psychological and social aspects are often amenable to intervention.

Primary caregivers must often cope with tremendous stress and feelings of burden as they provide constant care to an elderly, chronically ill family member with AD. A variety of psychosocial intervention strategies have been used in recent years in an effort to help ease their stress and burdens. These include (a) individual and family counseling; (b) education and counseling groups;

(c) ongoing caregiver support groups; (d) caregiver respite services; and (e) self-help organizations and materials. Common elements of these approaches reflect the need for caregiver education, training, counseling, and support services. However, current services are generally reactive in that they focus on crisis intervention rather than on primary prevention.

The proposed Integrated Service Delivery Model responds to the need for an interdisciplinary approach to AD by offering a new conceptual framework for providing comprehensive services to primary caregivers. The medical care, psychoeducational, and social support service elements of the model reflect the assertion that AD is a biological, psychological and social phenomenon. They suggest a holistic approach to a complex problem, and take into consideration the many interdependent needs of primary caregivers and care receivers. The overall goals of the Integrated Service Delivery (ISD) Model are (a) integration of a variety of services for clients and (b) enhanced ability of clients to provide in-home care in an effort to delay or prevent institutionalization of persons with AD. The first goal is achieved through the coordination of interventions designed to meet the needs of AD caregivers and care receivers. The second goal is achieved as a result of coordination and integration, and results in the outcomes of reduced stress and burden and improved care management skills for primary caregivers.

Implementation of the Integrated Service Delivery Model is recommended. However, several factors must be considered including (a) an appropriate setting for such a system; (b) the costs involved

for both clients and the supporting organization; (c) problems of coordination without duplication of effort; (d) the time frame of service delivery; and (e) development of a holistic perspective to AD on the part of a broad range of service providers. Areas for future research suggest (a) testing of hypotheses inherent in the objectives of the ISD Model; (b) investigating strategies to implement early intervention with primary caregivers; and (c) considering the applicability of the ISD Model to primary caregivers and care receivers suffering from other chronic and terminal illnesses.

SERVING PRIMARY CAREGIVERS OF PERSONS WITH ALZHEIMER'S DISEASE:
AN INTEGRATED SERVICE DELIVERY MODEL

by

GRETA KRAHN STAPLETON

A thesis submitted in partial fulfillment of the
requirements for the degree of

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TO THE OFFICE OF GRADUATE STUDIES AND RESEARCH:

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Finally, I dedicate this thesis, with love and gratitude, to my parents--Madeline Krahn who is a primary caregiver, and Emil Krahn who has Alzheimer's disease.

TABLE OF CONTENTS

	PAGE
ACKNOWLEDGEMENTS	iii
LIST OF FIGURES	vi
CHAPTER	
I INTRODUCTION	1
Alzheimer's Disease	2
Primary Caregivers	4
Statement of the Problem	6
Purpose	9
Definition of Terms	10
II REVIEW OF THE LITERATURE	11
Pathology of Alzheimer's Disease	11
Etiology	15
The Process of Diagnosis	21
Patient and Caregiver Prognosis	29
III OVERVIEW OF CURRENT SERVICES FOR PRIMARY CAREGIVERS . .	34
Burdens of Primary Caregivers	34
Psychosocial Intervention Strategies	37
Individual and Family Counseling	
Education and Counseling Groups	
Ongoing Caregiver Support Groups	
Caregiver Respite Services	
Self-help for Caregivers	

CHAPTER	PAGE
Summary	52
IV THE INTEGRATED SERVICE DELIVERY MODEL	57
A Conceptual Framework	58
Biological Component	
Psychological Component	
Social Component	
Coordination	
Integration	
A Design for Service Delivery	64
Entry Into the Service Delivery System	
Utilization of Coordinated Services	
Outcomes of Service Delivery	
V RECOMMENDATIONS AND IMPLICATIONS	77
Implementation of the Integrated Service Delivery Model	78
Suggestions for Future Research	80
REFERENCES	83
APPENDIX	90

LIST OF FIGURES

FIGURE	PAGE
1. Clinical Features of Alzheimer's Disease	24
2. Tasks and Problems Common to AD Primary Caregivers	35
3. Integrated Service Delivery Model	55
4. A Design for the Delivery of Proactive, Integrated Intervention Services for Primary Caregivers	65
5. Suggested Questions to Obtain Historical Information about Dementia from Primary Caregivers	67

CHAPTER I

INTRODUCTION

America is aging. The number of persons age 65 or older has grown steadily since the beginning of the 20th century. In 1900, 3.1 million persons, or 4.1% of the total population, were in this age group. By 1940, over 9 million Americans (6.8%) were 65 years of age or older (Blake & Peterson, 1979; Siegel, 1972). The most recent data available (U.S. Bureau of Census, 1984) indicates that in 1983 this group totaled 27.4 million, or 11.7% of the total population, and census experts predict that an estimated 34.9 million Americans (13%) will be considered part of this older population by the year 2000.

In a survey conducted for the National Council on the Aging by Louis Harris and Associates, Inc. (1981), "poor health" was identified as a "somewhat serious" or "very serious" problem by 46% of the 1,837 persons age 65 and over who were surveyed. According to Woods, Niederehe, and Fruge (1985), dementia, or the progressive, debilitating decline of memory and other cognitive abilities, "is among the most feared disorders of later life" (p. 19). Many persons continue to believe that dementia is synonymous with being senile. To the contrary, Huyck and Hoyer (1982) define senescence as

the normal [emphasis added], age-related deteriorative processes that occur gradually within the organism at many levels. Disease processes [such as dementia] are distinct from, but may accelerate, the processes of senescence (p. 75).

Zarit and Zarit (1983) agree, and point out further that:

while there are notable differences in cognitive performance between older and younger persons, the vast majority of individuals over age 65 are able to live independently and to manage their daily lives in a competent way (p. 38).

Even so, the fact remains that an estimated 15% of persons age 65 or older have some degree of cognitive impairment which prevents them from living and managing their lives independently. Of this group, approximately one-third suffer from severe dementia (Aronson, 1982; Schneck, Reisberg, & Ferris, 1982; Teusink & Mahler, 1984). When these percentages are applied to population data presented above, a group of approximately 4.1 million older persons in the United States can be identified as suffering from cognitive impairment. The size of this group will increase as more people continue to live into old age (Aronson, 1984).

ALZHEIMER'S DISEASE

Dementia refers to a syndrome, or group of symptoms, which reflects a progressive and global impairment of memory and other cognitive abilities. It can have a variety of causes. Some are treatable, such as those brought on by delirium, depression, nonprogressive brain damage, toxic reactions, infection or fever, cardiovascular conditions, anemia, tumors, vitamin deficiencies, and

numerous metabolic disorders (Zarit, Orr, & Zarit, 1985; Zarit & Zarit, 1983). Mace and Rabins (1981), however, note that over 90% of dementing conditions are irreversible. Of these, over half fall into the diagnostic category of primary degenerative dementia (American Psychiatric Association, 1980), more commonly known as Alzheimer's disease.

Dr. Alois Alzheimer, a German physician, first identified the disorder bearing his name in 1907. The subtle onset and progressive nature of Alzheimer's disease (AD) may affect individuals differently, but some common changes in functioning have been observed. These most often include (a) a gradual, progressive decline in memory, learning, concentration, and judgement; (b) disorientation to time and place; (c) difficulties in use of language and communication; (d) confusion, especially with unfamiliar situations and people; and (e) changes in personality, mood, and behavior. On average, complete disablement occurs within seven to ten years following diagnosis. The person with AD then requires constant care and assistance with even minimal activities of daily living such as dressing, eating, grooming, and toileting (Aronson, 1984; Mace & Rabins, 1981; Powell & Courtice, 1983).

Dr. Alzheimer's original patient was a woman in her early 50s. Subsequent studies led him to believe that this was a dementing condition which occurred in people under age 55 (Mace & Rabins, 1981; Riesberg, 1981). More recently, researchers have determined that while the disease does occur in people as young as age 40, the

incidence of Alzheimer's-type dementia increases with advancing age, especially after age 70. It is the fourth leading cause of death in adults, accounting for at least 120,000 deaths each year (Aronson, 1984; Zarit et al., 1985).

PRIMARY CAREGIVERS

The identification of dementia as an organic condition has helped to dispel the common belief that loss of memory and intellect is an unavoidable condition of old age. Nevertheless, "a serious disruption of memory and intellect is extremely disabling for the afflicted individual, and can place tremendous burdens on relatives and friends" (Zarit & Zarit, 1983, p. 38). Until recent years, society in general believed that the best approach to caring for dementia patients was institutionalization (Silverstone & Bookin, 1982; Zarit & Zarit, 1983). While over half of the patients in nursing homes do have some degree of dementia, approximately 85% of all persons with dementia are cared for at home, by family members (Aronson, 1984; Aronson & Katzman, 1982; Zarit & Zarit, 1983). This refutes the assumption that families tend to provide little care for, or even ignore their elderly members. On the contrary, evidence suggests repeatedly that families do everything possible to delay or prevent nursing home placement for members with dementing illness (Hammond & Bonney, 1983; Mace & Rabins, 1981; Powell & Courtice, 1983; Zarit et al., 1985).

While several family members may assist with caregiving, the primary caregiver is the person who is directly involved in the ongoing, daily care for the person with AD. Most often the spouse assumes this role. If the spouse is no longer living, or is unable to provide daily care, the responsibility usually shifts to an adult child. In some families an adult sibling of the person with AD, a grandchild, or some other family member becomes the primary caregiver (Cantor, 1983; Ory et al., 1984).

The burdens of caregiving are often overwhelming. Zarit et al. (1985) refer to caregivers as the "hidden victims" of Alzheimer's disease. By the time diagnosis is made, the person with the disease may be unable to comprehend the full extent of present or future limitations. Primary caregivers are painfully aware of these limitations, however, and as the disease progresses they often suffer more than the person who has been diagnosed. Along with providing daily care for a disabled family member with AD, primary caregivers must also cope with conflicting emotions, and assume many of the roles and responsibilities of the impaired family member. Although each has its unique burdens, the common link among caregiving situations is the tremendous stress placed on caregivers (Mace & Rabins, 1981; New York City Alzheimer's Resource Center, 1985; Powell & Courtice, 1983; Teusink & Mahler, 1984; Zarit et al., 1985).

STATEMENT OF THE PROBLEM

When faced with the reality that the course of Alzheimer's disease cannot be halted or reversed, and that no cure is known, primary caregivers often experience feelings of hopelessness and despair. They want to provide the best possible care for a loved one who continues to deteriorate cognitively and emotionally, but the demands seem overwhelming when no resolution is in sight.

Several experts (Aronson & Katzman, 1982; Mace & Rabins, 1981; Powell & Courtice, 1983; Reifler, 1983; Woods et al., 1985; Zarit et al., 1985; Zimmer & Mellor, 1982) have discussed the needs of AD primary caregivers. They can be summarized as follows:

1. Information about the nature and prognosis of Alzheimer's disease.
2. Permission to acknowledge and express intense emotions such as grief, anger, fear, guilt, helplessness, and loneliness.
3. Approaches for managing problem behaviors displayed by the person with AD.
4. Personal stress reduction techniques and self-care strategies.
5. Assistance in locating and using support services and community resources.

Physicians and other health care providers often do not have the time or the expertise to help primary caregivers meet these needs (Barnes, Raskind, Scott, & Murphy, 1981; Hayter, 1982; National Institute on Aging [NIA], 1984; University of Michigan, Institute of

Gerontology, 1983; Zarit et al., 1985). Providing these necessary services is a task suggested for a team of trained professionals including physicians, nurses, counselors, social workers, health educators, and gerontology specialists.

From this perspective, the challenge for concerned professionals is how best to help primary caregivers meet these needs in order to insure optimal physical, mental, and social wellbeing both for themselves and their loved ones with AD. The literature on Alzheimer's disease emphasizes approaches which focus on caregiver education and support. Examples of successful education and support programs are discussed by several authors (Aronson, Levin, & Lipkowitz, 1984; Barnes et al., 1981; Glosser & Wexler, 1985; Lipkowitz, 1982; Pratt, Schmall, Wright, & Cleland, 1985; Schmidt & Keyes, 1985; Zarit et al., 1985).

A second approach discussed by some AD experts is integrated delivery of a broad range of services. Aronson and Katzman (1982) stress the necessity of "an interdisciplinary team approach in dealing with dementing illness" (p. 48), while Aronson and Lipkowitz (1981) state that

a broader conceptual model must be employed, whereby attention is paid to psychologic, social and economic factors affecting both patient and family, in addition to the biologic aspects of the disease process (p. 571).

Zarit et al. (1985) agree that AD is a biological, psychological, and social phenomenon, and support the need for a coordinated, multicomponent model. The lack of current information on such an

approach with AD primary caregivers suggests that it has not been widely implemented.

A third approach, taken from literature on chronic and terminal illness, stresses a proactive stance to help patients and caregivers. Emphasis is placed on caregiver training as soon as practicable after diagnosis in an effort to more successfully manage or prevent health care crises. Proactive, coordinated caregiver services are in place for such chronic and terminal conditions as: (a) kidney failure (Hassett, 1972; Peterson & Clark, 1984); (b) cancer (Cohen, 1982; Edstrom & Miller, 1981); (c) congestive heart failure (Higgins & Kashani, 1984); (d) stroke (Shadden, 1983); (e) chronic lung disease (McDonald, 1981); (f) hemophilia (Inagaki & Yamada, 1984); and (g) diabetes (Bernheimer & Clever, 1977). Lazarus and Weinberg (1982) also stress the need for a proactive approach with elderly psychiatric patients in an effort to prevent irreversibility and reduce hospital admissions. As with integration of services, AD specialists support the notion of proactive service delivery (Aronson & Lipkowitz, 1981; Reifler, 1983; Zarit et al., 1985), but no specific efforts to implement such an approach were found in the literature.

Although the efficacy of a proactive approach is apparent, and the call for integrated services has been issued, these two elements seem to be lacking in programs for AD primary caregivers. Existing approaches primarily offer crisis intervention services. As noted above, examples of proactive, coordinated services have been shown to

be effective for caregivers of persons with a variety of chronic diseases. This suggests that a similar model, which includes precrisis and ongoing medical care, education, training, and support, may also be effective for AD primary caregivers.

PURPOSE

This thesis proposes an Integrated Service Delivery Model to address the biological, psychological, and social aspects of AD. Three constructs--physical health, mental health, and social interaction--underlie the complex, interdependent needs of AD primary caregivers. They provide a conceptual framework for coordinating a broad range of precrisis and ongoing services for AD primary caregivers, and form the foundation for the proposed model.

A review of current literature focuses on the biological aspects of AD, covering pathology, etiology, diagnosis, and prognosis. This is followed by a discussion of the burdens of caregiving, and an overview of several psychosocial interventions used with primary caregivers. These include individual and family therapy, education and counseling groups, support groups, respite services, and self-help for caregivers. Next, the Integrated Service Delivery Model is proposed. Detailed presentation of the model focuses on both conceptual and practical integration of services for primary caregivers. Finally, a discussion of recommendations and implications considers implementation of the proposed Integrated Service Delivery Model and suggests areas for future research.

DEFINITION OF TERMS

Alzheimer's disease. The most frequent cause of irreversible dementia. Also known as primary degenerative dementia, organic brain syndrome, and senile dementia of the Alzheimer type (SDAT).

Dementia. From Latin de--away, and mentis--mind. A syndrome, or group of symptoms, which reflects a disease process involving progressive and global impairment of memory, other cognitive abilities, and behavior. Over 90% of dementing conditions are irreversible.

Integrated Service Delivery Model. A conceptual framework for providing coordinated, precrisis medical care, psychoeducational services, and social support services to AD primary caregivers.

Model. A conceptual framework which provides a form for presenting a group of related ideas.

Primary caregiver. The person directly responsible for day-to-day care of a family member with AD.

Proactive approach. A way of providing services which emphasizes crisis prevention and the development of more effective approaches to managing unavoidable crises.

Senile dementia. Brain failure occurring in old age, and caused by a specific disease process.

Senility. Old age. The sum of normal physical and mental changes occurring in advanced life. From the Latin root senex, verb form senescere--to grow old.

CHAPTER II

REVIEW OF THE LITERATURE

This chapter is designed to provide an overview of the nature of Alzheimer's disease, the process of diagnosis, and the prognosis for persons with the disease and for primary caregivers. It is not intended as an exhaustive review of literature.

PATHOLOGY OF ALZHEIMER'S DISEASE

Throughout history, persons who exhibited unexplained and bizarre changes in behavior were frequently thought to be possessed by evil spirits. This was probably true for persons with dementia (Schneck et al., 1982). Reisberg (1981) and Schneck et al. (1982) report that the first known medical description of dementia was in an 1838 French psychiatry textbook which discussed

"démence senile" as an illness in which there occurs a weakening of the memory for recent experiences and a loss of drive and willpower. The condition appears gradually and may be accompanied by emotional disturbances (Reisberg, 1981, p. 4).

At the end of the 19th century, Kraepelin, a German physician, reported that "insanity" in the elderly was marked by significant brain changes. He found cerebral infarcts attributable to arteriosclerosis in approximately 50 percent of the group he studied. He noted cortical atrophy but no significant

arteriosclerosis in the other half of the group. In 1899, Dr. Alois Alzheimer suggested that dementia patients with marked cortical atrophy were suffering from a vascular disease that involved the arterioles. A few years later, however, he reported the presence of neuritic plaques in cases of senile dementia (Schneck et al., 1982).

Dr. Alzheimer's early work, along with that of Dr. Kraepelin and Dr. Arnold Pick, helped lead to the identification of dementia as a disease process. For nearly 50 years afterward, however, the dominant view was that dementia in the elderly (i.e., senile dementia) was caused by arteriosclerosis. The assumptions were that (a) because changes in the walls and in the diameter of blood vessels do occur more frequently as people age, and (b) because these types of changes are strongly associated with myocardial infarction and heart disease, then (c) a similar process results in narrowing of cerebral vessels, causing a reduction of blood supply and oxygen to the brain (Schneck, et al., 1982). As a result of significant research in the last two decades, specialists now agree that cerebral arteriosclerotic disease, or "hardening of the arteries of the brain," is an appropriate diagnosis in only about 15 to 20 percent of senile dementia cases. The preferred diagnostic label for this condition is multi-infarct dementia (Jarvik, 1980; National Institute of Neurological and Communicative Disorders and Stroke [NINCDS], 1984; Schneck et al., 1982; Shelanski, 1975).

Alzheimer's disease is the most common form of dementia in the elderly, accounting for 50 to 60 percent of cases. The disease was

originally identified by Dr. Alzheimer as a presenile condition, but specialists generally agree that "the presenile and senile forms of Alzheimer type dementia are at present indistinguishable from one another, except by age at onset" (Jarvik, 1980).

The most obvious element of pathology in Alzheimer's disease is cerebral atrophy, or shrinkage of the brain, especially of the cortex. A computerized tomography (CT) scan is used to identify the degree and areas of atrophy, and is particularly useful in cases of presenile onset Alzheimer's disease. In the elderly, however, a CT scan may be less helpful as a diagnostic tool. The normal death of nerve cells in a healthy individual causes brain shrinkage of as much as 20% to 30% between the ages of 25 and 70. Therefore, even the brain of a mentally alert 70-year-old may appear distinctly atrophied (Butler & Emr, 1982; National Institute of Neurological and Communicative Disorders and Stroke [NINCDS], 1983; Schneck et al., 1982).

The most distinctive pathologic changes common to Alzheimer's disease are three types of brain tissue lesions which can only be identified microscopically. The first of these are neurofibrillary tangles. They are made up of long, hair-like strands of protein which twist themselves into abnormal spiraled configurations known as paired helical filaments (PHF). Masses of PHF bind tightly together to form tangled lesions, which are located within AD brain cells (Butler & Emr, 1982; NIA, 1984; NINCDS, 1984; Schneck et al., 1982; Selkoe, 1984). Neurofibrillary tangles are found primarily in the

frontal and temporal cortex, and in the hippocampus areas of the brain (Schneck et al., 1982; Shelanski, 1975; Zarit et al., 1985).

The second type of lesions common to AD are senile, or neuritic plaques, which lie adjacent to brain cells containing neurofibrillary tangles. Zarit et al. (1985) suggest that a normal neuron can be thought of as a tree, and that "tangles are like a disease from within, . . . [while] plaques are like a pest outside" (p. 12). Plaques are masses of degenerated cell matter which form around a nucleus of abnormal protein fibers known as amyloid, a substance not usually found in the brain (Butler & Emr, 1982; NINCDS, 1984; Shelanski, 1975). They also contain PHF, but Selkoe (1984) notes that the nature of the relationship between the PHF in neurofibrillary tangles and that in senile plaques is unknown. Plaques are found most often in cortical tissue of the frontal lobe, and in the hippocampus (Schneck et al., 1982; Shelanski, 1975).

Granulovacuolar bodies are the third type of lesion common to AD. These are pockets filled with fluid and granular debris that accumulate in cell bodies (Butler & Emr, 1982; Zarit et al., 1985). These lesions, which were not originally identified by Dr. Alzheimer but by researchers nearly 50 years later, seem to be concentrated in the hippocampus of persons with AD (Schneck et al., 1982).

While these three types of microscopic lesions are clearly related to Alzheimer-type dementia, a perplexing factor is that they are also present to some degree in elderly persons with no significant cognitive impairment. However, Butler and Emr (1982)

report on several studies in which researchers have concluded that the density and distribution of brain lesions in the elderly correlates with the degree of premorbid cognitive impairment. In Switzerland, another research team found that the more extensive the concentration of plaques and tangles in the hippocampus and the neocortex, the greater the memory loss (NINCDS, 1984).

All of these findings are helping to clarify the pathology of Alzheimer's disease. The confounding problem is that, because of the invasive nature and the dangers inherent in brain biopsy, positive identification of the disease can occur only after death. As a result, researchers must work either with autopsy tissue or with laboratory animals in their efforts to identify how the three types of lesions are formed. The hope is that once formation is understood, lesions may be prevented, reduced, or even eliminated (Butler & Emr, 1982; Jarvik & Kumar, 1984b; NINCDS, 1983; NINCDS, 1984; Shelanski, 1975).

ETIOLOGY

Researchers agree that the cause of Alzheimer's disease remains unknown (Butler & Emr, 1982; Jarvik & Kumar, 1984b; NIA, 1984; NINCDS, 1984; Rathmann & Conner, 1984; Zarit et al., 1985). A variety of biochemical, viral, genetic, and toxic causes are being investigated. Two related biochemical hypotheses show much promise. The first of these is the cholinergic theory which suggests that a possible cause of AD is related to marked deficiencies in choline

acetyltransferase (CAT) (Butler & Emr, 1982; Coyle, Price, & DeLong, 1983; NIA, 1984; NINCDS, 1984; Wurtman, 1985). This enzyme is an element in the manufacture of acetylcholine, an important neurotransmitter. The cholinergic system is involved in both memory and learning, and the majority of cholinergic neurons are located in the cerebral cortex and hippocampus. As noted previously, these areas of the brain show the greatest number of Alzheimer-type lesions. Butler and Emr (1982) and Coyle et al. (1983) also report the profound loss of neurons (as much as 80 percent) in the nucleus basalis. This is an area at the base of the brain, the cells of which produce acetylcholine and transmit it to the cerebral cortex. Research indicates that the significant loss of these acetylcholine-producing neurons is directly correlated to the reduction in cholinergic activity in the Alzheimer brain.

The second biochemical hypothesis being tested by researchers focuses on the abnormal protein structures evident in Alzheimer lesions (Wurtman, 1985). Research by Selkoe (1984) has focused on isolating and identifying the paired helical filaments (PHF) previously described. He has also attempted to break down the rigid chemical bonds in PHF in an effort to dissolve or restructure these apparently destructive proteins. This work relates to the cholinergic theory in that high concentrations of neurofibrillary tangles containing PHF are found in the degenerated acetylcholine-producing neurons of the nucleus basalis. Selkoe

(1984) suggests that decreased acetylcholine may result from PHF concentrations in neuritic plaques and neurofibrillary tangles.

The viral, or infectious-agent hypothesis suggests that Alzheimer's disease may be caused by a slow-acting virus (Butler & Emr, 1982; Jarvik, 1980; NIA, 1984; Prusiner, 1984; Schneck et al., 1982; Wurtman, 1985). Jarvik (1980) reports that a limited experimental study involved exposing cultured neurons from human fetal brain tissue to an extract of Alzheimer brain tissue. In this case the cultured tissue developed paired helical filaments which appeared the same or similar to those found in Alzheimer-type neurofibrillary tangles. Jarvik suggests caution in interpreting these results, however, because of the limited nature of the study.

More promising research involves the study of dementias related to AD. One example is the study of Kuru, a chronic, progressive neurologic disease found in certain tribes in New Guinea. It has been shown to be transmitted by a slow-acting virus, the incubation period of which may be several years (Schneck et al., 1982; Wurtman, 1985). Two other degenerative neurological disorders, the very rare Creutzfeldt-Jakob disease (CJD) in humans, and scrapie in sheep, have also been linked to slow infectious agents (NIA, 1984; Prusiner, 1984). Researchers have identified small, abnormal protein particles, or prions, which seem to be a causative element in both CJD and scrapie. Further research has shown that these prions form into long rods which resemble the abnormal-protein amyloid matter found in Alzheimer senile plaques (Prusiner, 1984). Abnormal protein

elements seem to be a common focus in much AD research, and since CJD and AD share many clinical and pathological features, researchers are continuing to pursue the infectious agent hypothesis.

Many case studies and descriptions of familial patterns of Alzheimer-type dementia suggest that a genetic hypothesis must be investigated in developing an etiology for AD. Several specialists (Butler & Emr, 1982; Matsuyama & Jarvik, 1982; NIA, 1981; Rathmann & Conner, 1984) discuss a classic Swedish study in which researchers determined that close relatives of persons with senile dementia have approximately a four times greater risk of developing the disease than the general population. Matsuyama and Jarvik (1982) reviewed literature on AD genetic factors and found that only 11 studies had been conducted between 1925 and 1981. Most of these focused on the risk of siblings or parents developing Alzheimer-type dementia. By combining data from these studies they derived a risk factor of approximately three times greater than the general population up to age 80. The one study of risk faced by children reported that for children of persons with presenile AD the risk was 1.6 %, and for children of persons with senile onset AD the risk was 2.2 %. The studies reviewed by Matsuyama and Jarvik (1982) seem to support increased familial incidence of AD, but no clear genetic etiology has been established.

One interesting genetic connection, however, is that nearly all persons with Down's syndrome who live to age 30 or 40 develop the clinical symptoms and pathologic changes of AD (Butler & Emr, 1982;

Rathmann & Conner, 1984). Heston and Mastri (1977) also noted a significantly increased incidence of Down's syndrome and certain chromosomally linked blood disorders in family members of persons with AD. Researchers continue to search for reliable genetic markers such as specific chromosome abnormalities, but fragmentation and loss of chromosomal material is common in the elderly. Some chromosomal changes which have been noted in persons with AD may also be the result of environmental factors. Jarvik and Kumar (1984b) and Matsuyama and Jarvik (1982) emphasize the need for longitudinal studies and adequately controlled research in pursuing answers raised by the genetic hypothesis.

The excess of trace metals in AD brain tissue, especially aluminum, has led to the hypothesis that a toxic agent may contribute to the development of the disease (Butler & Emr, 1982; Liss & Thornton, 1984; NIA, 1984; NINCDS, 1984; Schneck et al., 1982; Wurtman, 1985). Early research involved injecting laboratory animals with aluminum, which resulted in the subsequent formation of neurofibrillary tangles similar to those found in persons with AD. Later research reported that the aluminum levels in AD brain tissue were 10 to 30 times greater than in persons with no evidence of dementia. NIA (1984) notes that investigators working in Guam, and in parts of Japan and New Guinea, have all observed increased cases of parkinsonism-dementia, especially in areas where garden soil and drinking water samples have shown unusually high levels of aluminum. NINCDS (1984) and Wurtman (1985) also report that some persons who

have undergone long-term kidney dialysis with a solution high in aluminum have developed a form of irreversible dementia. Liss and Thornton (1984) caution that while much evidence supports increased aluminum in the brain as a factor in the formation of neurofibrillary tangles, the cause and effect relationship between aluminum levels and AD has not yet been determined.

One other area of etiological research should be mentioned. Some work is being done on possible immunological defects which may be related to the onset or progression of AD (NINCDS, 1983; Rathmann & Conner, 1984; Zarit et al., 1985). Several immune system abnormalities have been noted in persons with AD (Matsuyama & Jarvik, 1982). These seem to be related to chromosome malformations which may, in turn, cause biochemical responses to AD abnormal protein structures.

While a variety of hypotheses are being studied in an effort to identify causes of Alzheimer's disease, specialists emphasize the importance of considering all variables in the development of an etiology for such a complex disease (Jarvik, 1980; NINCDS, 1983; Wurtman, 1985; Zarit et al., 1985). The hypotheses presented are not distinct and separate. New evidence in favor of one hypothesis may also provide information pertinent to others. The common link among etiological research studies seems to be the attempt to answer two questions: (a) What causes certain brain cells to die prematurely and at a faster rate in persons with AD? and (b) Are the pathologic changes noted in AD causes or effects of the disease?

THE PROCESS OF DIAGNOSIS

The assessment and identification of Alzheimer's disease is confounded by many factors. First, confirmation of AD can be made only during autopsy. Even then it may be difficult if more than one disease condition could have caused dementia (Butler & Emr, 1982; Jarvik, 1980). Second, no current tests used to assess for dementia can definitively diagnose or rule out AD. Diagnostic information must be gathered from a variety of sources, and specialists suggest that the clinical diagnosis should be possible or probable Alzheimer's disease (Jarvik & Kumar, 1984a; Katzman, 1982; Zarit et al., 1985). Third, a variety of physical conditions often found in the elderly may result in dementia-like symptoms. These conditions include metabolic disorders, nutritional deficiencies, and cardiovascular disease. Confusion, delirium, or dementia is frequently a toxic reaction to medications used to treat such conditions (Jarvik & Kumar, 1984a; Katzman, 1982; NINCDS, 1984). Fourth, functional psychiatric conditions in the elderly, such as bipolar depression, paranoid and schizophrenic disorders, and anxiety states, can easily appear like dementia. Depression in older persons is especially difficult to separate from dementia, and has often been called pseudodementia (Jarvik, 1980; Jarvik & Kumar, 1984a; NINCDS, 1984; Zarit et al., 1985).

Another problem in diagnosing Alzheimer's disease is that in its early stages it may be difficult to distinguish from normal aging (Mace & Rabins, 1981; Zarit et al., 1985). Several gerontological

specialists (Alpaugh & Haney, 1985; Botwinick, 1977; Cohen & Wu, 1980; Craik, 1977; Huyck & Hoyer, 1982; Welford, 1977, Williams, 1980) have discussed age-related changes in memory, cognition, learning, and intellect, which are directly related to the diagnosis of AD. These specialists suggest that minor decline in ability occurs with age, but that the most significant changes occur in the way in which information is processed. For example, older adults are able to remember as well as younger adults but do not because of less motivation or interest, or because their environments and lifestyles require less structure and differentiation. Further, older persons remember different aspects of experience (i.e., more general information rather than specific details of an event). Recent research is beginning to consider these changes in processing, and to question earlier studies showing significant decline in the elderly. These early studies often used test instruments initially developed for younger populations and inherently biased against older persons. For example, lower scores on time-limited tests may have been related to increased reaction time in older persons. Time pressure may also have caused anxiety and fatigue, resulting in even lower scores. These early research results, accompanied by the persistent myth that forgetfulness is a normal part of aging, have compounded the problem of diagnosing Alzheimer's disease.

Because of the difficulty of diagnosis, AD specialists emphasize the use of a variety of diagnostic techniques (Jarvik, 1980; Jarvik & Kumar; 1984a; Katzman, 1982; NINCDS, 1984; Schneck et al., 1982;

Zarit & Zarit, 1983; Zarit et al., 1985). The approach used must attempt to identify and treat reversible causes of dementia first, with diagnosis of Alzheimer's disease only after other possible causes have been excluded. Four diagnostic areas are considered. The first is an assessment of clinical symptoms and history of the dementing condition (Zarit & Zarit, 1983; Zarit et al., 1985). The clinical features of AD are presented in Figure 1 on the following pages. Information needed to determine the degree of impairment is obtained through interviews with the patient and with close family members. In true cases of dementia the identified patient may deny or be unaware that memory and other abilities are impaired. If depression is the presenting problem the patient is likely to be able to give specific information about when the memory problems started, what things are forgotten, and how often forgetfulness occurs. In cases of delirium or focal brain damage the patient may or may not be aware of the degree of cognitive impairment.

Mace and Rabins (1981), Powell and Courtice (1983), and Zarit et al. (1985) generally agree that the typical history of AD includes the gradual onset and continuous progression of impairment described in Figure 1. By the time a diagnostic evaluation is conducted, family members often report that the problems have been increasing over a time period ranging from several months to several years. Little fluctuation in symptoms occurs, but ongoing daily problems may get worse toward evening. This is referred to as "sundowner's syndrome" (Mace and Rabins, 1981). In contrast, the onset of other

Mild Impairment	Moderate Impairment	Severe Impairment
<p><u>Memory</u>--Trouble remembering recent events, names, thoughts, words. Misplaces or loses familiar items. May forget appointments, get lost easily, lose sense of direction.</p> <p><u>Cognitive Ability</u>--Some difficulty with complex but familiar tasks (e.g., paying bills, balancing checkbook, making change, cooking, playing cards). Some trouble making decisions, planning, concentrating. May no longer be able to work.</p> <p><u>Coordination/Motor Skills</u>--Generally good coordination and motor skills. May have slowed reaction time. May be unsafe when driving.</p>	<p><u>Memory</u>--Increasingly unaware of recent events, experiences. Remembers more distant past. Significant difficulty forming new memories and learning new information.</p> <p><u>Cognitive Ability</u>--Significant difficulty making decisions, planning, concentrating. Loss of abstract thinking, learned behavior (e.g., manners, communication skills), sense of time, distance, temperature. Displays poor judgement. Unable to sequence events such as driving, cooking, dressing. Needs step-by-step instructions repeated frequently. May not know place, time, day. Begins to neglect health and hygiene.</p> <p><u>Coordination/Motor Skills</u>--Loses some coordination and balance. May have difficulty mentally controlling body, be unsteady, bump into things, fall easily, have difficulty walking. Loses ability to write legibly.</p>	<p><u>Memory</u>--No apparent recent memory. Remote memory also significantly impaired.</p> <p><u>Cognitive Ability</u>--Almost total loss of cognitive function. Impaired judgement. Unable to attach meaning to sensory stimuli. Complete disorientation to time and place. Unable to recognize familiar persons, family members, even self in mirror.</p> <p><u>Coordination/Motor Skills</u>--Significant difficulty coordinating body movements for eating, dressing, maintaining balance. Prominent shuffling gait. May lose ability to walk, sit up, swallow. In extreme cases may go into stupor or coma.</p>

Figure 1. Clinical features of Alzheimer's disease.

Mild Impairment	Moderate Impairment	Severe Impairment
<p><u>Mood and Behavior</u>--Mood swings. Frequently depressed. Socially withdrawn. Prefers familiar situations. Easily distracted. Shows less initiative, spontaneity. May deny or try to cover up forgetfulness, confusion.</p>	<p><u>Mood and Behavior</u>--Frequent and intense mood swings. Self-absorbed, insensitive to others, depressed, confused in unfamiliar surroundings. May pace, wander, become agitated, hostile, suspicious, paranoid, aggressive. May hide things and accuse others of stealing. Sleep pattern disturbances are common.</p>	<p><u>Mood and Behavior</u>--Almost total confusion. Usually maintains a general mood of either agitation (e.g., pacing, fidgeting, constant movement) or withdrawal (e.g., lack of affect, oblivious to environment and people). May have hallucinations or delusions.</p>
<p><u>Activities of Daily Living</u>--Little or no assistance needed with bathing, dressing, grooming, eating, toilet needs.</p>	<p><u>Activities of Daily Living</u>--Bathing, dressing, grooming, eating, and toileting become confusing, frightening, or are forgotten. May forget location of bathroom, where to find clothes, when, what, and how much to eat. Bladder or bowel incontinence may develop.</p>	<p><u>Activities of Daily Living</u>--Requires constant assistance with bathing, dressing, grooming, eating, toilet needs.</p>
<p><u>Language</u>--Speech is generally unaffected. May desire to communicate less. Slightly reduced vocabulary. May have difficulty finding correct word, be vague, or make irrelevant comments.</p>	<p><u>Language</u>--Talks less. Repeats words and phrases. Speech is slower and filled with pauses. Significantly reduced vocabulary. Seldom uses complete sentences. May use stereotyped phrases, invent words or use incorrect words.</p>	<p><u>Language</u>--Impossible to carry on conversation. Vocabulary limited to a few phrases or words. May repeat phrases or words but seldom understands meaning. Often does not understand what others say. May completely lose ability to talk.</p>

Adapted from: New York City Alzheimer's Resource Center (1985)

Figure 1 (cont.).

conditions such as delirium, depression, and focal brain damage can usually be linked with specific events. In delirium, the symptoms can become extreme within a few days to a few weeks of the event. They may also fluctuate widely over the course of a day. The person may be alert and rational at times, and a few hours later may be disoriented, agitated, and have hallucinations. Depression and focal brain damage are not usually progressive; however, depression is typically worse in the morning. A knowledge of these different symptoms is important in order to distinguish dementia from other similar conditions.

A second diagnostic area for AD involves cognitive testing (Katzman, 1982; NINCDS, 1984; Zarit & Zarit, 1983; Zarit et al., 1985). The primary assessment instrument is a routine mental status examination. This involves a series of approximately ten questions which are designed to test knowledge of such common information as the person's date of birth, the current day or date, the person's present location (i.e., the hospital or physician's office where testing is taking place), the person's address, the name of the President of the United States. Since this type of information is usually considered "overlearned," persons who make two or three errors are likely to have serious cognitive deficits (Lezak, 1983). A further test of memory, attention, and concentration may be to ask the person to remember three common words (e.g., cat, house, ball) and to repeat them several minutes later. Others may include simple words spelled backward, reversing numbers in a series, or counting

backward from 100 by sevens (serial sevens). Intellectual functions such as reasoning, judgement, and organization of thoughts may be assessed by asking the meaning of a few simple proverbs, by asking what the person would do in a threatening situation (e.g., What would you do if you smelled smoke in your house?), or by having the person copy a geometric design or draw a clock with the hands set at a specific time.

A second assessment instrument suggested as particularly reliable by Zarit et al. (1985) is the face-hand test, which is "a measure of the perception of double simultaneous stimulation" (p. 47). One side of the face and the back of one hand are touched at the same time and the patient is asked where the touch is felt. A series of 16 face-hand touch configurations are administered. Errors after the fourth trial suggest some degree of cognitive impairment. The greater the number of errors, the greater the impairment.

Some specialists support further neuropsychological assessment when reported symptoms and history suggest dementia which is not substantiated by mental status testing (Fuld, 1984; Katzman, 1982; Zarit & Zarit, 1983; Zarit et al., 1985). The Wechsler Adult Intelligence Scale (WAIS) and the Luria-Nebraska Neuropsychological Battery have both been used with some success. Low scores on the vocabulary and information subtests of the WAIS for a person who is well educated seem to support a hypothesis of dementia. Complex paper-and-pencil tests of this type are frequently stressful and confusing for elderly persons, however, and the usefulness of results

should be considered carefully. In addition, follow-up testing may be appropriate at approximately six-month intervals if early test results do not support described dementia symptoms.

The third diagnostic area for Alzheimer's disease is a thorough medical examination (Jarvik, 1980; Jarvik & Kumar, 1984a; Katzman, 1982; Mace & Rabins, 1981; Powell & Courtice, 1983; Zarit et al., 1985). The major purpose of the examination is to identify or rule out any possible treatable conditions which may cause dementia. An examination should include a complete blood count and urinalysis, metabolic tests of thyroid function, vitamin B₁₂, and folate levels, serologic test for syphilis (VDRL), chest x-ray, and a computerized tomography (CT) scan. In some cases certain other tests may be indicated such as electrocardiogram (EKG), electroencephalogram (EEG), spinal tap for examination of cerebro-spinal fluid, skull x-rays, or a brain scan.

The fourth area of AD assessment is a review of psychosocial functioning. A thorough assessment of this area focuses not only on the person suspected of having AD, but on the primary caregiver as well. Zarit et al. (1985) have developed two instruments designed to help identify psychosocial function and the burdens of caregiving. The first instrument is the Memory and Behavior Problems Checklist. It is a 30-item inventory administered to primary caregivers in the form of a structured interview. Each item briefly describes a problem behavior (e.g., asking the same question over and over) associated with AD. As each item is read, caregivers are asked to

respond on one Likert scale to indicate how often the behavior occurs, and on another to indicate how upset they get in response to the behavior. The second assessment instrument is the Burden Interview. It is a 22-item instrument designed "to evaluate the subjective impact of caregiving, . . . [and to] tap important dimensions of the stress experienced by caregivers" (p. 83). Caregivers are asked to indicate on a Likert scale how often they feel as described by the various statements on the inventory (e.g., Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?).

The diagnosis of Alzheimer's disease can be made only after reviewing the results of the four assessment areas described above, by identifying and treating dementia-like symptoms which are secondary to other conditions, and by ruling out all other possible causes. The diversity of the four assessment areas reflects the need for an interdisciplinary team approach to diagnosis and treatment of dementia and the related stress of primary caregiving (Aronson & Katzman, 1982; Aronson & Lipkowitz, 1981; Zarit et al., 1985). The Integrated Service Delivery Model presented in this paper will help to address this need.

PATIENT AND CAREGIVER PROGNOSIS

The probable course of Alzheimer's disease is reflected in the clinical features described in Figure 1 (p. 24). The onset is subtle and diagnosis may be difficult, especially in the early stages. The

degree of impairment increases gradually, but is particularly obvious to the primary caregiver. On average, a person with AD will die within seven to ten years after diagnosis (Mace & Rabins, 1981; Powell & Courtice, 1983). Much research is focused on AD. Numerous experimental treatments have been tried, but none have been successful in reversing the disease or slowing its progression. While some psychotropic drugs, social interventions, and psychotherapeutic techniques may help to treat a few symptoms, at present AD itself does not respond to treatment, and no cure is known (Jarvik, 1980; Jarvik & Kumar, 1984c; Katzman, 1982; Zarit et al., 1985).

The grim prognosis for AD often has profound effects on primary caregivers. Zarit et al. (1985) refer to them as the "hidden victims" of AD.

Few other disorders place so much stress on family members as dementia. Caregivers routinely report stress-related symptoms, such as anxiety, depression, or feelings of fatigue. They are often angry or resentful, feel guilty about not doing enough, even though they may spend 24 hours a day with the patient. The stresses they experience have many sources. Often they must take over tasks that the patient can no longer do, such as housekeeping or dressing the patient. They must keep vigilant watch over the patient; and often must cope with the patient's specific behavioral disturbances, such as wandering around or not sleeping at night. Moreover, caregivers often experience a great sense of personal and psychological loss as they see their relative gradually decline. Often, the care they must provide demands all of their time. They usually get little relief from the daily strain. They even may be criticized by other relatives (p. 69).

A one-dimensional view of AD as a medical condition for which no cause, treatment, or cure is known can leave both professionals and caregivers feeling hopeless and ineffective. Zarit et al. (1985) believe that

if the illness is viewed as a problem with many components, some of which can be solved while others cannot, it becomes reasonable to plan interventions. . . . Dementia [is] a "bio-psycho-social phenomenon," and while the biological aspects are not currently treatable as has been indicated, the psychological and social are often amenable to intervention (pp 1-2).

A variety of psychosocial approaches have been used in recent years to help primary caregivers. Individual and family counseling offer opportunities for primary caregivers and other family members to receive professional help in meeting the unique needs of their AD caregiving situation (Cutler, 1985; Haley, 1983; LaBarge, 1981; Pinkston & Linsk, 1984; Ware & Carper, 1982; Zarit et al., 1985). Time-limited educational and counseling groups provide training and support programs for AD caregivers facing similar problems (Aronson et al., 1984; Barnes et al., 1981; Cohen, 1983; Glosser & Wexler, 1985; Lipkowitz, 1982; Schmidt & Keyes, 1985). Ongoing support groups allow a regular time for caregivers to share their frustrations and successes, and to support one another in their efforts (Easterly, 1982; Mace & Rabins, 1981; Oktay, 1985; Powell & Courtice, 1983; Schmall, 1984; Weaver, 1982). Respite care and adult day care programs for persons with AD provide reliable alternatives which offer primary caregivers the opportunity to seek relief from the stress of constant care (Emick-Herring, 1983; Mace & Rabins,

1984; Sands & Suzuki, 1983). Several self-help books and caregiving guides offer information and practical suggestions for providing ongoing care to persons with AD (Long Beach Community Hospital, 1984; Mace & Rabins, 1981; New York City Alzheimer's Resource Center, 1985; Oregon State University Extension Service, 1985; Powell & Courtice, 1983). An overview of these psychosocial approaches will be presented in the following chapter.

The important efforts of the Alzheimer's Disease and Related Disorders Association (ADRDA) have served to catalyze the growing awareness and understanding of AD. Organized in 1979, this national, nonprofit advocacy organization conducts educational forums, supports research, assists in organizing support groups, advises government agencies and elected officials, and offers a broad range of information and support services to family members of persons with AD. In just six years ADRDA has grown from an original seven chapters to 147 chapters and affiliates throughout the United States. Total membership exceeds 150,000 persons (ADRDA, 1986; Stone, 1982).

While the growth of ADRDA and the expansion of psychosocial approaches reflect many of the service needs of AD primary caregivers, the majority of intervention strategies take a reactive approach and assume that caregivers will seek help for the stress and burdens of providing care. On the contrary, most caregivers cope until a behavior management crisis occurs, or until the burdens become so great that the stress itself is a crisis (Mace & Rabins,

1981; Zarit et al., 1985). Coordinated intervention strategies are needed in order to provide early and ongoing education, training, and support services to caregivers (Aronson & Lipkowitz, 1981; Reifler, 1983; Zarit et al., 1985). Such strategies support a proactive approach which will help caregivers prevent and more effectively manage the crises of providing care to a person with AD. The Integrated Service Delivery Model presented in this paper responds to both the need for a network of interdisciplinary services and for a proactive approach to serving AD primary caregivers.

CHAPTER III

OVERVIEW OF CURRENT SERVICES FOR PRIMARY CAREGIVERS

A variety of psychosocial intervention strategies have been used in recent years in an effort to help ease the burden of AD primary caregivers. This chapter presents a brief discussion of caregiver burdens followed by an overview of current intervention strategies. The Integrated Service Delivery Model is proposed as a more effective approach to serving the needs of primary caregivers.

BURDENS OF PRIMARY CAREGIVERS

Ory et al. (1984) define burden as "the impact of the changes in cognition and behavior of the Alzheimer patient on the family, and the patient's subsequent need for care and supervision" (p. 10). Gerontology specialists (Barnes et al., 1981; Brody, 1985; Cantor, 1983; Clark & Rakowski, 1983; Zarit, Reever, & Bach-Peterson, 1980) have documented the stress of providing constant care to an elderly, chronically ill family member. A variety of stressful caregiving tasks can contribute to a subjective sense of burden for caregivers. Two categories of AD caregiving tasks are identified in Figure 2. These categories outline both direct care tasks for the person with AD, and enabling tasks which support the caregiver's ability to provide care.

Direct care tasks:

1. Responding to repeated questions, demands, accusations.
2. Maintaining a calm atmosphere.
3. Providing structure and routine for daily activities.
4. Managing problem behaviors such as wandering, agitation, rapid mood swings, loss of social skills, lowered inhibitions.
5. Responding to catastrophic reactions when person is overwhelmed by a confusing or frustrating situation.
6. Communicating in the most effective way with a person who does not understand or remember.
7. Assuming roles and responsibilities such as managing money, driving, cooking, household tasks.
8. Performing basic activities of daily living such as bathing, grooming, dressing, feeding, toileting.

Enabling tasks:

1. Gaining knowledge about AD and its effects.
 2. Coping with intense emotions such as guilt, anger, helplessness, loneliness, frustration, fear.
 3. Readjusting personal routines to compensate for increased demands of caregiving.
 4. Avoiding severe drain on physical strength and health.
 5. Resolving uncertainty about caregiving skills.
 6. Facing financial, legal, and long-term care decisions.
 7. Maintaining contact with and accepting help from family, friends, community agencies, professionals.
 8. Making use of caregiving alternatives such as adult day care, respite care, short-term institutional care.
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Figure 2. Tasks and problems common to AD primary caregivers.

A logical correlation would suggest that the more difficult caregiving becomes, the more the sense of burden and stress increases. However, specialists have discovered that while the severity of AD is a significant factor, it alone does not correlate with the degree of burden experienced by caregivers (Ory et al., 1984; Pratt et al., 1985; Zarit et al., 1980; Zarit et al., 1985). These specialists generally agree that a variety of interacting factors contribute to caregiver stress and feelings of burden. Ory et al. (1984) identify these factors as follows:

1. The extent of personality and behavioral changes due to the disease;
2. Past history of family dynamics;
3. The caregiver's preexisting coping abilities and abilities to identify alternative ways of coping;
4. Social supports available for the caregiver;
5. The difference between caretaker's expectations for support and their perceptions of support received;
6. The caregiver's other responsibilities such as work; and
7. Sociodemographic characteristics of the patient and caregiver (i.e., sex, age, SES, cultural/ethnic background) (p. 9).

Pratt et al. (1985) note that stress is reduced if caregivers are confident about their problem-solving and caregiving skills, and are able to reframe or change the meaning of otherwise stressful circumstances. Zarit et al. (1985) suggest that "when the caregiver is flexible and tries out new approaches [for managing problems], the burden tends to be experienced as less stressful" (p. 72). Pratt et al., (1985) and Zarit et al. (1980) indicate that the degree of social support, especially support from other family members, correlates with feelings of burden. When immediate and extended family are supportive and involved in caregiving, even in limited

ways, the primary caregiver's burden seems to be reduced. Ory et al. (1984) and Zarit et al. (1985) suggest that the better the relationship between the caregiver and the care receiver prior to onset of AD, the less stressful the relationship will be as the disease progresses.

Pratt et al. (1985) note an unexpected finding. They found that the burdens and stress of providing care are not significantly reduced by institutionalization of the person with AD (Pratt et al., 1985). While placement in a long-term care facility may alleviate the stress of providing technical care, feelings of guilt connected with caregiver failure often continue for as long as the person with AD remains institutionalized (Brody, 1985; Smith & Bengston, 1979).

The interactive biological, psychological, and social aspects of AD all contribute to feelings of burden and stress experienced by primary caregivers. Since the biological aspects of AD cannot be treated, interventions most often focus on the psychological and social aspects of the disease. Elements of the following psychosocial intervention approaches seem useful in helping to alleviate stress and reduce feelings of burden for AD primary caregivers.

PSYCHOSOCIAL INTERVENTION STRATEGIES

Individual and Family Counseling

Counseling caregivers frequently involves working with both the primary caregiver and other members of the family. Three such

approaches are described. Zarit et al. (1985) have used a stress management model for working with primary caregivers. This model has three treatment components: (a) content input; (b) process; and (c) output. The first component involves providing information about AD so that caregivers will understand the disease process, and know better how to respond to changes and problem behaviors in the person with the disease. The second component is teaching a general problem-solving process which caregivers can apply to specific problems as they arise. Knowledge of why problems may occur, and application of a practical approach to solving problems will lead to the third component--being able to manage problem behaviors and increasing social supports.

Individual counseling and family meetings are important treatment modalities used with the stress management model. In both modalities the focus is on responding to the changes caused by AD. Zarit et al. (1985) recommend beginning with individual counseling because caregivers are often at a point of crisis and need personalized attention. It is important to develop an empathic, nonjudgemental therapeutic relationship in which the caregiver will feel supported and understood. With this foundation, successful learning of the problem-solving process and new insight about AD are most likely to occur.

After several individual sessions, a meeting of immediate and extended family members is held to address the tensions and imbalances created by the disabilities of the person with AD. The

purpose of the meeting is to implement the stress management model within the family so that (a) members better understand the condition of the person with AD, and (b) the family's problem-solving process is enhanced. While some attention is given to managing problem behavior, the overall goal of the family meeting is to increase family and social support for the primary caregiver. Family members typically are willing to participate in such meetings, and the outcome is usually more family involvement in caregiving responsibilities.

Cutler (1985) presents five aspects which she believes are important in counseling primary caregivers and their families. First, a thorough assessment of the caregiver's problems is conducted, and a treatment plan is developed which includes goals for the caregiver, the family, and the person with AD. Education about the patient's condition and about the course, symptoms, treatment, and medical management of AD is a second important aspect of counseling primary caregivers. Education also includes general information about the aging process, common family responses to caregiver stress, available community resources, and problem-solving skills. The author believes that caregiver participation in an ongoing support group is a third aspect of a complete counseling program. By the time caregivers seek help "they are often 'on the edge.' Support often holds them together while they mobilize the energy required to improve their situation" (p. 54).

A family systems perspective is a fourth important element in counseling caregivers. The ideal situation is to involve the primary caregiver and the family in counseling. In this way all concerned receive information and education about AD. In a counseling setting family members are also better able to recognize and resolve conflicts about caregiving issues. Finally, Cutler recommends that a fifth aspect is acknowledging and assisting caregivers to work through intense emotions, conflicting values, and intrapsychic issues which may be interfering with adaptation to the role of primary caregiver. The author cautions counselors to be sensitive to clients as individuals separate from the role of caregiver, and to assist them to maintain a sense of self when they feel as though they are being consumed by providing constant care for the person with AD.

A nontraditional service delivery system for reaching caregivers and families in need of counseling assistance is described by Tomine (1986). Outreach is conducted through nursing homes, community agencies, educational institutions, churches, and senior citizen organizations. Services are provided in a variety of settings in order to offer the most comfortable atmosphere for clients who are often reluctant to seek assistance. These settings include nursing homes, senior citizen centers, and client homes.

The author identifies her role as both an educator and a facilitator for primary caregivers. She uses an education/problem-solving model, similar to that described by Zarit et al.

(1985), when leading family groups and seminars. She also uses noncognitive approaches when working with individual clients. Examples include neurolinguistic programming, therapeutic hypnosis, sensory experiences, dreams, music, poetry, humor, and storytelling. These approaches help caregivers gain insight into previously unrecognized strengths and abilities which may be useful in alleviating the stress of caregiving.

Some common elements are evident in the three approaches described above. Each approach uses an educational component to provide information about AD and to help primary caregivers improve their problem-solving skills. Each also emphasizes working with both individuals and families in an effort to help them resolve conflicts and work together as a caregiving team. While all three approaches discuss elements which would seem to be useful for reducing caregiver stress and feelings of burden, it is noted that none of the three approaches contain an evaluation component.

Education and Counseling Groups

The success of education and counseling groups for AD primary caregivers has been reported by several specialists. These types of groups are usually limited in size and duration, and are led by trained facilitators. Barnes et al. (1981) describe a 16-week group program for AD primary caregivers conducted at the Seattle/American Lake Veterans Administration Geriatric Research, Education and Clinical Center (GRECC). The group consisted of 15 participants, and 90-minute sessions were held every two weeks. The general goal was

to provide information and support for primary caregivers of AD patients who were receiving clinical care through GRECC. The group leaders employed a supportive, empathic style which was relatively nondirective. In addition, they often functioned as educators by providing information about the course of AD and the character changes, intellectual limitations, and behavior problems associated with the disease.

At the end of the group, members reported that participation had a variety of beneficial effects. It increased their understanding of AD, resulting in more appropriate expectations and less guilt regarding the patient's behavior. It reduced their feelings of isolation and helped them to maintain a greater degree of self-identity in relation to the patient. It provided a setting in which they could share their feelings, and gain support and acceptance from others in similar circumstances. Finally, it offered a social outlet which helped caregivers recognize the importance of respite care so that they could continue personal and social activities.

In separate articles, Aronson et al., (1984) and Lipkowitz (1982) describe a patient/family group program for both caregivers and persons with AD conducted at the Gerontology Center of the Albert Einstein College of Medicine in New York City. Participants were outpatients and their primary caregivers. Group meetings were held weekly for 90 minutes. Details of group size and duration were not

given. Four therapeutic goals were established for these groups:

1. To develop a positive staff-participant relationship characterized by spontaneity, trust, and warmth.
2. To improve participants' recognition of the many health problems which existed in both the patients and family members (all of whom were elderly), and techniques for coping with them.
3. To provide information to help the participants in their activities of daily living and in their adjustment to the difficult process of deterioration.
4. To assist family members in planning for the future, in hope that this would provide them with more clear direction and a sense of control over their lives (Lipkowitz, 1982).

Each weekly group session began with approximately 30 minutes during which AD patient and caregiver groups were combined. This time was spent in reviewing activities of the past week (e.g., holidays, birthdays, special events), discussing plans for the current day's meeting, and gentle exercising to music. The groups were then separated for 45 minutes. While work with AD patients focused on sensory awareness training, reality orientation, resocialization, life review, and movement and activity therapies, a more cognitive approach was used with the caregiver group. Caregivers were allowed to observe the patient group which helped them recognize the realistic capacities of persons with AD. Staff were also able to model suitable activities and appropriate communication skills. Caregiving suggestions, coping strategies, decision-making skills, and adapting expectations to changes in the AD patient were discussed. Caregivers were invited to express intense emotions within the supportive atmosphere of the group, and were also encouraged to develop a support network (which often grows out of group participation). Caregivers and AD patients were brought

together for the final 15 minutes for refreshments and socialization.

Aronson et al. (1984) report that this patient/family group program seemed to be helpful for both primary caregivers and persons with AD. Attendance was nearly perfect and a high level of participation was achieved at group meetings. Family members noted that they had been able to resume some personal activities which had previously been given up because of the demands of caregiving. They also reported that AD patients seemed to enjoy the group activities, and that some positive carryover of social skills and daily living activities seemed apparent. Caregivers noted that the support of the group helped reduce their stress and enabled them to provide more loving and patient care.

Glosser and Wexler (1985) discuss another variation of the time-limited education and counseling group for AD primary caregivers. Eight-week sessions comprised of weekly two-hour meetings were offered three times each year. Groups were open to relatives of AD patients who had been diagnosed at the University of Massachusetts Medical Center in Worcester, MA. Group size ranged from 10 to 20 participants per session. Three group goals were identified:

1. To provide accurate information about Alzheimer's disease and other dementias in order to help family members understand the medical and behavioral aspects of the illness.
2. To teach family members skills for managing the behavioral, legal/financial, social and interpersonal problems associated with progressive dementia.

3. To offer family members an opportunity to share and receive validation and support for the feelings they experience as caregivers for a close relative with a progressive dementia (p. 233).

The general format of the group involved the coleaders or appropriate specialists providing information through structured, didactic presentations for approximately one hour, with the second hour reserved for discussion of personal experiences, problems, feelings, and questions.

A formal evaluation of this group program was conducted by the authors. Approximately 64% of persons completing the program over a two year period responded to evaluation questionnaires. Glosser and Wexler report that overall,

group meetings were very positively evaluated by participants. Despite the formal structure of the group meetings which emphasized education and didactic presentations about dementia, participants found the contact with other family members and the opportunity to share feelings, receive support, and learn from each other to be some of the most beneficial aspects of the group. It appears that dissemination of accurate information by professionals in a discussion group format has a direct positive effect on the attitudes and feelings of participants (1985, p. 235).

Based on evaluation data, education and counseling groups seem to be an effective approach for providing services to AD primary caregivers. As with individual and family counseling, much emphasis is placed on educating caregivers about the disease process and its effects on both patients and family members. Another common element seems to be training in decision-making, problem-solving, and more effective caregiving techniques. An important benefit of groups is the sense of support and acceptance from others in similar

circumstances. Barnes et al. (1981) and Glossesr and Wexler (1985) both report that caregivers wanted to continue meeting beyond the designated group termination date. Group participants were encouraged to continue meeting without facilitators, and in both cases formed their own ongoing, self-help support groups.

Ongoing Caregiver Support Groups

While numerous AD specialists (Aronson, 1982; Aronson et al., 1984; Glosser & Wexler, 1985; Mace & Rabins, 1981; Powell & Courtice, 1983; Pratt et al., 1985; Teusink & Mahler, 1984; Zarit et al., 1985) recommend caregiver participation in ongoing support groups, few examples of such groups are available in current literature. Schmall (1984) and Steuer (1984) discuss different support group models. In the educational model meetings are usually held in a class format, with professionals presenting information about AD, patient behavior and management, decision-making, and caregiver coping skills. The presentation is followed by questions and discussion. This model is often a safe first step for caregivers who may be threatened by sharing their problems and feelings with strangers. The mutual peer support model emphasizes interaction and sharing. Caregivers learn from each other about changes that accompany AD; they encourage one another to develop coping and problem-solving skills; and they support each other when faced with difficult caregiving decisions. The education/mutual support model combines both educational and peer support components. One approach to the combined model is to allow approximately half of each group meeting for an educational

presentation/discussion, and the other half for interaction, sharing, and mutual support. Another approach is to alternate educational meetings and interaction/sharing meetings.

These authors suggest that caregiver support groups are similar to education and counseling groups in that they provide a setting in which caregivers receive information about AD; share their problems, concerns, and feelings; and receive understanding and support from others in similar caregiving situations. They are different in that they are frequently initiated by caregivers themselves, and are seldom time-limited. Support groups are usually open to all caregivers and family members. However, in some cases group size may be restricted (optimum size seems to be 10 to 12 members), or membership may be limited to persons whose relationships are similar to the person with AD (e.g., only primary caregivers, or only adult children), in order to develop more group cohesiveness. They may be facilitated by professionals, but often an original organizer or a skillful group member assumes a leadership role. Schmall (1984) suggests that the most effective leadership may be cofacilitation by a professional and a group member.

While ongoing support groups appear to be a useful tool for AD primary caregivers, Lieberman (1985) notes that

empirical research on outcomes is limited and covers a narrow band of activities. Studies of behavioral deviations --alcoholism, overeating, and drug abuse--predominate. Studies of groups that deal with life transitions, crises, or diseases are rare (p. 46).

Because of similarities, perhaps some inferences about support group effectiveness can be made from previously presented evaluations of educational and counseling groups. Steuer (1984) suggests that support group effectiveness

may not be measurable on psychometric scales. For example, preliminary data in one study indicate that participants thought they benefited from the group, but no significant differences were found on an observer-rated scale of depression (p. 57).

Self-reports by participating caregivers suggest that the most beneficial aspects of Alzheimer support groups are: (a) insight and understanding; (b) a sense of belonging; (c) finding others with similar problems; and (d) that these persons were coping and surviving.

Caregiver Respite Services

Adult day care and in-home respite care are examples of respite services for AD primary caregivers. Sands and Suzuki (1983) report on an adult day care program which had been operating for two years at the Harbor Area Adult Day Care Center in Costa Mesa, CA. The center limited its services to providing day care for persons with dementia, and average participation was 20 clients per day. Staffing ratio was one staff member for every four or five clients. Program goals were: (a) to provide respite for AD primary caregivers; (b) to meet client needs for stability, structure, orientation, constancy in personnel, and assistance in communication; and (c) to respond to client needs for recognition, self-esteem, meaningful relationships

and activities, and personal space. A monthly support meeting, individual counseling, and referral services were also available for primary caregivers. Feedback from caregivers consistently indicated they gained relief as a result of having a care alternative for their family member with AD. They also reported having gained insight and emotional support from other caregivers and program staff. In some cases caregivers even reported what they believed were improvements in cognitive and emotional functioning of the person with AD.

Mace and Rabins (1984) discuss the results of a nationwide survey of 346 adult day care programs providing services for elderly persons with dementia. They report that these programs serve approximately 7,000 persons per day, and that 20% of those served are persons with dementia. Survey results indicated that most adult day care centers were willing to accept clients with dementia, and that many were operating under capacity. This suggests that adult day care is being underutilized as a respite service by AD primary caregivers. Some persons with AD may be unable to adjust to adult day care depending on the severity of their impairment. For those who can adjust, however,

centers are willing to go to considerable lengths to assist clients and families and clients may show improved behavior and peer friendships. Some centers serve very impaired people--many until close to their death. These centers have developed excellent skills in the care and management of these clients (p. 44).

The Multidisciplinary Center on Gerontology at the University of Kentucky in Lexington, KY developed a volunteer training program for

persons willing to provide in-home respite care for persons with AD (Bell, 1984). Twenty-eight of the volunteers who completed the training program agreed to provide two to three hours of in-home respite once a week to allow AD primary caregivers time away from the constant demands of caregiving. Some volunteers occasionally provided longer periods of respite. For example, one stayed full-time in the home while the primary caregiver had surgery. Volunteers were trained to offer supportive social activities for persons with AD. These included having refreshments, reminiscing, looking at old family pictures, looking at picture books or magazines, taking walks, and playing familiar games (but not necessarily by conventional rules). Respite care volunteers frequently telephoned primary caregivers between visits as a way of providing additional support. No formal evaluation of the program was reported, but caregiver comments suggested that the program was effective in offering support and caregiving assistance, thus reducing feelings of stress.

As with participation in a support group, many AD specialists (Aronson, 1982; Cantor, 1983; Mace & Rabins, 1981; Ory et al., 1984; Powell & Courtice, 1983;) advocate the use of respite services to help reduce the stress and feelings of burden experienced by primary caregivers. However, caregivers often resist seeking respite help. This may be due to feelings of guilt which are often very strong when caregivers realize they are no longer able to provide care without

help. More thorough evaluation of respite services may help to reveal why they seem to be underutilized by primary caregivers.

Self-help for Caregivers

The Alzheimer's Disease and Related Disorders Association, discussed in chapter 2, is a national self-help organization open to anyone interested in AD. Membership and participation in such an organization often gives caregivers and family members a feeling that they are doing something worthwhile to help themselves and others (Stone, 1982). Easterly (1982) describes a local self-help organization in the Seattle area. The Alzheimer Support Information Service Team (ASIST) was formed in 1978 by family, friends, and professionals involved with AD. The organization fosters public awareness of AD, is involved in research efforts, and sponsors caregiver and family support groups throughout Washington state. They also provide telephone outreach services, and offer in-home visits for primary caregivers and families of persons recently diagnosed with AD.

A variety of self-help books and manuals are available to help primary caregivers, family members, and other persons interested in learning about AD and the type of care needed by persons with the disease (see Appendix). These are practical guides which are easy to read and understand. They cover such topics as causes of dementia, managing behavior and personality changes, creating an appropriate caregiving atmosphere, responding to special problems, making

financial, legal, and caregiving decisions, and self-care for caregivers.

As with many other psychosocial intervention approaches for AD primary caregivers, the effectiveness of using self-help materials and of participating in self-help organizations has not been evaluated. Lieberman (1985) suggests that self-help materials and groups

are useful, on pragmatic grounds. They offer an alternative to professional service. The issue is not which is better but rather the value of encouraging diversity in service (p. 48).

SUMMARY

Psychosocial intervention approaches available for AD primary caregivers seem to reflect some common elements. These include:

1. Education about AD to help caregivers understand the medical and behavioral aspects of the disease.
2. Training to improve caregiving, coping, problem-solving, and decision-making skills.
3. Counseling and support to acknowledge intense emotions, reduce feelings of isolation, and provide opportunities to share the problems of caregiving with others in similar situations.

Another common element among approaches is that they are generally reactive and crisis oriented. Interventions such as education and counseling groups, support groups, and respite services are often developed in reaction to several primary caregivers seeking help for similar crises. In other cases counseling, education, and support may be available, but caregivers do not take advantage of such

services until they reach a point of crisis. Caregivers seeking help in a time of crisis often become frustrated and discouraged when they must contact several different providers in an effort to obtain the services they need (Aronson et al., 1984; Aronson & Lipkowitz, 1981; Barnes et al., 1981; Mace & Rabins, 1981; Powell & Courtice, 1983; Schmall, 1985; Tomine, 1986; Zarit et al., 1985).

Most services for AD primary caregivers have only been available since the late 1970s. Important efforts have been made toward providing appropriate psychosocial interventions, but little empirical data are available to support their effectiveness. AD specialists (Aronson & Katzman, 1982; Aronson & Lipkowitz, 1981; Ory et al., 1984; Pratt et al., 1985; Zarit et al., 1980; Zarit et al., 1985) encourage further evaluation of intervention strategies, and have called for a comprehensive approach to service delivery.

A broader conceptual model must be employed, whereby attention is paid to psychologic, social and economic factors affecting both patient and family, in addition to the biologic aspects of the disease process. Continuous management must be provided rather than sporadic "crisis intervention." In the provision of appropriate care, an interdisciplinary approach becomes essential. . . .

In short, what is required for the [AD] patient is a comprehensive long-term care strategy. This should consist of a network of services which involves the social service and health care networks, and which addresses the needs of both the [AD] patient and the "significant others" who are involved in his/her care. The continuum of care developed to accommodate the changing needs throughout the course of this disease should include acute- and chronic-care components, both medical and psychosocial (Aronson & Lipkowitz, 1981, p. 571).

The literature on other chronic diseases such as kidney failure, cancer, congestive heart failure, stroke, chronic lung disease,

hemophilia, and diabetes documents the efficacy of proactive, integrated education, training, and support service programs for primary caregivers (Bernheimer & Clever, 1977; Cohen, 1982; Edstrom & Miller, 1981; Hassett, 1982; Higgins & Kashani, 1984; Inagaki & Yamada, 1984; McDonald, 1981; Peterson & Clark, 1984; Shadden, 1983). These programs increase caregivers' abilities to provide in-home care for the chronically ill, and help to delay or prevent admission to a hospital or long-term care facility. This same goal is repeated frequently in the AD literature (Aronson & Katzman, 1982; Aronson & Lipkowitz, 1981; Mace & Rabins, 1981; Ory et al., 1984; Powell & Courtice, 1983; Silverstone & Bookin, 1982; Zarit et al., 1985). In order to achieve this goal, AD primary caregivers must be offered preventive, integrated services similar to those available to caregivers of persons with other chronic diseases.

The Integrated Service Delivery Model is proposed as the type of broader theoretical model called for by AD specialists. It offers a conceptual framework for providing comprehensive, proactive services to primary caregivers. Figure 3 identifies the elements of the Integrated Service Delivery (ISD) Model. These elements respond to the assertion that AD is a biological, psychological, and social phenomenon (Aronson & Lipkowitz, 1981; Zarit et al., 1985). They suggest a holistic approach to a complex problem by considering the many interdependent needs of AD primary caregivers.

Medical care services, psychoeducational services, and social support services are the major service components of the ISD Model.

Figure 3. Integrated Service Delivery Model.

They reflect the constructs upon which its framework is built. Medical care supports the physical health of caregivers and persons with AD. While diagnosis and monitoring of the AD patient's condition is important, primary caregivers must maintain their physical health in order to be able to provide necessary care. They must also strive to maintain their mental health in the face of tremendous stress and feelings of burden associated with caregiving. Psychoeducational services support the mental health of caregivers. Finally, the demands of providing constant care often leave caregivers feeling isolated and unsupported. A network of interpersonal and institutional social services can help them maintain needed social interaction with family, friends, and the community. These constructs--physical health, mental health, and social interaction--and their supporting services have been identified as essential elements of an integrated program for primary caregivers, based on information drawn from the literature on AD and other chronic diseases. The ISD Model is outlined in detail in Chapter 4.

CHAPTER IV

THE INTEGRATED SERVICE DELIVERY MODEL

The purpose of the Integrated Service Delivery Model is to offer both a conceptual framework and a design for the delivery of proactive, coordinated intervention services for primary caregivers of persons with Alzheimer's disease. One goal of the model is the integration of a variety of services for clients of such a system. A second goal is to enhance the ability of system clients to provide in-home care in an effort to delay or prevent institutionalization of the person with AD.

The foundation of the ISD Model is the belief that AD is a biological, psychological, and social condition. The biological aspect can be defined as the degree of physical health retained as AD progresses. Physical health for both the person with the disease and the primary caregiver are included in this definition. The psychological aspect refers to maintenance of mental health for the primary caregiver as the patient's mental and physical health deteriorate. Support of interpersonal and community social interaction for primary caregivers responds to the social aspect of AD. As the person with the disease loses the desire and ability to interact with others, caregivers need to reach out to family, friends, and the community for social contact. Thus, in order for

primary caregivers to provide ongoing care, their physical health, mental health, and social interactions must be enhanced at the same time that these conditions deteriorate in the person with AD.

A CONCEPTUAL FRAMEWORK

Biological Component

The biological nature of AD is such that the disease-related decline of a patient's physical health cannot be prevented. However, some changes in physical condition may be unrelated to the disease, and care for all treatable conditions is important. Equally important is the physical health of the primary caregiver. Mace and Rabins (1981) and Powell and Courtice (1983) note that the stress of caregiving can be detrimental to a caregiver's physical wellbeing. If a caregiver becomes ill or is hospitalized, alternative care for the dementia patient will be necessary. Being cared for in a strange place or by an unfamiliar person, and the concomitant change in routine often generates catastrophic reactions in the person with AD. Therefore, primary caregivers must care for their own health at the same time as they care for the dementia patient.

In order for caregivers and persons with the disease to maintain optimal physical health, medical care services have been identified as an essential element of the ISD Model. These services include diagnosis and monitoring of the person with AD. This involves care for treatable conditions unrelated to dementia, as well as the judicious prescription of medications to help manage personality and

behavior problems associated with AD. Medical care services also include routine and specific care for the caregiver, proper diet and exercise for both caregivers and care receivers, and the availability of home health services. The broad range of identified medical care needs involves a variety of service providers such as physicians (both general practitioners and specialists), nurses, dietitians, and home health aides. Coordination of these services suggests a treatment team approach so that all health care providers understand the special problems and needs faced by primary caregivers and persons with AD.

Psychological Component

A second essential element of the ISD Model is psychoeducational services. These services respond to the mental health needs of primary caregivers. A principle characteristic of AD is the decline of the patient's mental health through the progressive and global impairment of memory and other cognitive abilities. The process cannot be prevented, and watching this slow disabling of a loved one can have profound effects on primary caregivers. Personality changes are also common as the disease progresses. Mood swings marked by anger, hostility, accusations, belligerence, or withdrawal are frequent expressions of the frustration, fear, and confusion experienced by AD patients. These expressions are most often directed toward the primary person who is attempting to provide loving and patient care.

Not surprisingly, depression is a frequent condition among primary caregivers. They often experience feelings of helplessness, hopelessness, grief, anger, and frustration. They may know little about AD, and be confused about the personality and behavior changes evident in the person with the disease. They may feel burdened by having to assume many of the patient's roles and responsibilities, and overwhelmed by the prospect of increased caregiving demands as the patient becomes progressively more impaired. They may feel unsure of their caregiving skills and their ability to respond to problem behaviors (Mace & Rabins, 1981; Powell & Courtice, 1983; Zarit et al., 1985).

Knowledge about AD, training in caregiving skills, and emotional understanding can help enhance the mental health of primary caregivers. Therefore, psychoeducational services are an essential element of the ISD Model. Mental health professionals, health educators, and gerontology specialists can offer caregivers such services as individual and family counseling; educational information about AD; training in decision-making, problem-solving, coping, and self-care skills; and individual and family values clarification regarding care of an elderly, chronically ill family member. Professionals providing psychoeducational activities also become a part of the treatment team in order to facilitate the coordination of services within the ISD Model.

Social Component

The third essential element of the ISD Model is social support services to increase primary caregivers' social interactions. The social aspect of AD relates to the time demands of caregiving and the accompanying reduction in social contacts for primary caregivers. As AD progresses, more and more caregiver time is needed to assist the care receiver with activities of daily living. The management of problem behaviors and concern about safety can make caregiving seem like a task which requires a "36-hour day" (Mace & Rabins, 1981). Social contacts may also be limited because of inappropriate behaviors displayed by the person with AD. Such behaviors can cause embarrassment for caregivers and feelings of uneasiness for other persons. As a result, many caregivers decide it is easier to avoid social situations, thus isolating the person with AD and themselves at the same time.

The social aspect of AD also relates to societal myths, expectations, and rules regarding appropriate care for elderly persons with dementia. First, a general stereotype is that to be ill and elderly is to be mentally deficient. This stereotype combined with the reality of dementia supports the myth that families reject their ill elderly, placing them in nursing homes to receive the care which could be provided by family members. Conflicting with this myth is an expectation that persons with mental illness should be institutionalized so they will not be a nuisance to society. Finally, the traditional health care system, and government

regulations regarding financial reimbursement for services often present tremendous barriers to families of persons with AD who can no longer provide in-home care. Many nursing homes will not accept patients with AD. Even when a competent care facility is found, Medicare and other insurance providers will not cover the cost of long-term custodial care for chronic conditions such as dementia (Aronson, 1984; Brody, 1985; Silverstone & Bookin, 1982).

As a result of time demands, conflicting myths and expectations, and policy barriers, primary caregivers often feel isolated from social interactions, and from society in general. Therefore, the availability of interpersonal and community social support services is an important component of the ISD Model. Examples of services include peer support groups, self-help organizations, respite care, public social service agencies, legal and financial planning, and spiritual support. Social workers, gerontology specialists, representatives of self-help organizations and public agencies, legal and financial consultants, and members of the clergy provide these types of services. Coordination of social support services suggests that these service providers be included in the AD treatment team, or available to consult with and advise the team.

Coordination

The purpose of coordination is twofold. First, it provides for entry into the service delivery system. It is a central component through which outreach to, and referral of caregivers takes place. Coordination offers a single point of entry for caregivers into the

ISD system, thereby eliminating the frustration of having to make several contacts to obtain services. Second, coordination facilitates caregiver utilization of available medical care, psychoeducational, and social support services. It insures that caregivers' needs are assessed and evaluated, and that they are referred to services based on identified needs.

An effective approach to coordination is the establishment of treatment teams (Aronson & Lipkowitz, 1981; Zarit et al., 1985). This involves a team leader and appropriate specialists from each of the three service areas working together to respond to the unique needs of each caregiver and care receiver. By working together service providers can share their knowledge and expertise thereby allowing all to be more responsive to the needs of primary caregivers and persons with AD. The team leader becomes the single contact person for caregivers as they utilize services. The treatment team works with the caregiver to develop an individualized treatment plan and to recommend appropriate referrals. The team leader can support and encourage the caregiver to take advantage of recommended services, and can conduct follow-up to evaluate changing caregiving demands and service delivery needs. Based on these changes the treatment plan can be revised and other services recommended, if appropriate.

Integration

Integration is the outcome of coordination. It is a holistic response to the complex, interdependent needs of AD primary

caregivers and care receivers. The ISD approach combines services to insure primary caregivers ongoing, easy access to a network of professionals, peers, and organizations committed to helping them meet their special needs. Service providers work together to counsel, educate, support, and care for clients within an organized, unified service delivery system. Integration facilitates a proactive approach to the utilization of services within the ISD Model.

A DESIGN FOR SERVICE DELIVERY

In addition to presenting a conceptual framework, the ISD Model also offers a dynamic design for service delivery (Figure 4). Elements of the model and their related activities are directed by two objectives derived from the previously identified goal of enhanced caregiving. These objectives are:

1. To alleviate the stress and burdens experienced by primary caregivers.
2. To increase caregivers' skills in managing the physical, psychological, and social problems associated with AD.

A proactive approach to the utilization of services is the underlying attitude which drives the model. The focus is on prevention of potential caregiving crises, and the development of attitudes, skills, and support systems for more effective management of those crises which are unpredictable and unavoidable. The service delivery model is described on the following pages.

Integrated Service Delivery Model

Figure 4. A design for the delivery of proactive, integrated intervention services for primary caregivers.

Entry Into the Service Delivery System

Identification of clients. Primary caregivers are the intended client population of the ISD Model. A proactive, crisis-prevention approach suggests the need to identify and bring primary caregivers into the service delivery system as early as possible. This may be when a care receiver is showing early signs of impairment, but prior to medical evaluation and diagnosis of AD. Mildly impaired persons and their families often are concerned about forgetfulness, behavior changes, and other early symptoms of dementia. They have many questions, and outreach activities designed to increase public awareness of AD can encourage concerned families to seek assistance and answers. Examples of outreach activities include newspaper articles, radio and television presentations, public information forums, inservice training for social service agencies, community health education classes, and presentations to church groups, volunteer organizations, senior centers and senior citizen associations. Such activities invite potential clients to make contact with the integrated service delivery system, and also urge agencies to make appropriate referrals.

Assessment and evaluation. Once primary caregivers make contact with the system, an initial assessment helps to determine the type and level of services needed. Figure 5 suggests questions which are helpful in eliciting historical information from the primary caregiver about the dementia. If dementia has not been diagnosed, or if diagnosis is uncertain, the patient would be referred for a

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1. How long ago did you first notice changes in the patient?
 2. What were the first signs?
 3. What happened next and when?
 4. Would you describe the onset as gradual or sudden?
 5. When was it first diagnosed by a doctor?
 6. What was the diagnosis?
 7. Do you remember what tests were done and their findings?
 8. What drugs have been prescribed for this condition?
 9. What are the current medications the patient is taking?
 10. Has the course of the disease been gradual or stepwise?
 11. Has the patient had any surgeries in recent years?
 12. Has the patient had any head injuries in recent years?
 13. Has anyone else in the patient's family had a problem like this?
-

Figure 5. Suggested questions to obtain historical information about dementia from primary caregivers.

medical and psychiatric examination as soon as possible. Initial assessment would also include interviewing the primary caregiver to determine the dementia patient's functional level, as well as the stress level and feelings of burden experienced by the caregiver. The Memory and Behavior Problems Checklist and the Burden Interview (Zarit et al., 1985) discussed in chapter 2 are examples of useful assessment instruments. Interview information can also help to reveal the caregiver's (a) knowledge of AD and other forms of

dementia, (b) current caregiving and coping strategies, (c) problem-solving and decision-making skills, and (d) family and social supports.

Treatment planning. Based on responses to the initial assessment and evaluation, a preliminary treatment plan is developed. The treatment plan responds to needs of both the primary caregiver and the person with dementia. As indicated, diagnosis of the presenting problem is the initial step in the treatment plan. If the problem is a reversible form of dementia, proper medical care will help to alleviate it. If diagnosis reveals Alzheimer's disease, the patient and the primary caregiver will be best served through a variety of integrated services. The treatment plan provides an outline of recommended services for the caregiver and the care receiver.

Referral. Primary caregivers and persons with AD are referred to services based on identified needs and recommendations in the individualized treatment plan. Initial recommendations may include referral to a qualified physician for diagnosis of dementia, and individual counseling for the primary caregiver. Other appropriate early interventions include caregiver education about AD, family counseling, and caregiving conferences. The level and types of services required depend on factors such as the degree of AD impairment, caregivers' and care receivers' physical and mental health, feelings of stress and burden, and quality of social

support. Utilization of services is monitored; further referrals are based on changing caregiving demands and concomitant service needs.

Coordination. Ongoing coordination of services (a) offers a single point of entry into the integrated service delivery system, (b) provides regular review and revision of the individualized treatment plan, and (c) insures appropriate referral as caregiving demands and related service needs change. This occurs in the context of a treatment team approach to planning and intervention with primary caregivers and care receivers. The key member of the treatment team is the team leader, who would most likely be a mental health professional, social worker, or gerontology specialist. The team leader becomes the main contact person for the caregiver, conducts the initial assessment and evaluation, and is primarily responsible for carrying out coordination activities. The team consists of the leader and professionals from each of the three service areas. The leader may be one of those professionals. Together with the primary caregiver, they develop the initial treatment plan. The team leader discusses available services with the primary caregiver, and makes referrals based on recommendations in the treatment plan. Follow-up by the team leader can help to reveal caregivers' and care receivers' changing service needs. The treatment plan may be revised and additional referrals made if appropriate.

Utilization of Coordinated Services

Medical care services. The first step in providing appropriate medical care for persons with dementia and primary caregivers is the diagnosis of dementia. This process is described in chapter 2. Diagnosis of Alzheimer's disease must be supported by thorough psychiatric and medical testing. If AD is diagnosed, medical care then focuses on monitoring the progression of the disease, and on maintaining the person's physical health for as long as possible. AD itself cannot be treated, but as it progresses the management of certain personality and behavior changes may be facilitated by the careful use of medications. These may be appropriate for clinical depression accompanying AD, and for severe behavior problems such as belligerence, hostility, and aggression. Often medications for such conditions will have an opposite effect of that intended when taken by a person with dementia (Jarvik, 1980; Zarit et al., 1985). Knowledgeable physicians will prescribe them with caution and limit their use.

Physical conditions unrelated to AD must also be treated in order to help maintain the patient's physical health. Illness, hospitalization, and especially surgery are traumatic events which can bring about a marked deterioration in a person with AD. In later stages of the disease the effect of such events can be permanent. It may mean that care can no longer be provided at home, and placement of the AD patient in a long-term care facility may be necessary. The treatment team physician who specializes in AD can consult with those

treating other conditions in order to advise them about dementia. Together they can decide on appropriate treatment approaches which will support the AD patient's physical health without exacerbating symptoms of dementia.

In order to have the physical stamina to care for a person with AD, primary caregivers must attend to their own health. The stress of caregiving can leave them vulnerable to illness. In addition, any number of physical problems can be exacerbated by stress. Serious illness or hospitalization of the caregiver, and the accompanying temporary or permanent changes in caregiving are often confusing and frightening for the person with AD. Helping caregivers maintain physical health is an important element within a network of integrated services for AD. Caregivers of elderly dementia patients are usually their elderly spouses. Medical care services are especially needed by these older caregivers who may be physically less able to withstand the stress of caregiving. Information available from the treatment team can assist the caregiver's primary physician in understanding special difficulties associated with caregiving. Regular physical examinations and appropriate treatment are part of a proactive, preventive approach to health care.

Other elements of medical care are important for both caregivers and care receivers. If either (or both) is physically frail, in-home nursing services may be prescribed by the treatment team. Regular visits and care from a visiting nurse or home health aide may mean the difference between continued care at home for the AD patient or

placement in a long-term care facility. Two preventive measures--proper diet and regular exercise--can help to maintain physical health. A dietitian working with the treatment team can provide suggestions and recommendations, and can help to develop special diets if necessary. Regular exercise can help in reducing stress, and in maintaining cardiovascular activity and muscle tone.

A variety of health care providers can be involved in working with the treatment team. A physician specializing in psychiatry or neurological disorders may be the appropriate AD specialist. Other possible medical treatment team members include nurses, home health care providers, and dietitians. The treatment team approach helps to insure that ISD system clients receive coordinated medical services which address their identified health care needs.

Psychoeducational services. The purpose of psychoeducational services is to meet the mental health needs of primary caregivers, and to help them regain a sense of control over certain aspects of a disease which, from a biological perspective, cannot be controlled. The needs of caregivers summarized in chapter 1 suggest that they would benefit from knowledge about AD, improved skills in decision-making, problem-solving, coping and self care, and support for intense emotions and difficult caregiving decisions. These elements can be provided through a variety of intervention services, many of which were discussed in chapter 3.

Individual counseling provides a setting in which caregivers can be acknowledged as individuals apart from their role as caregiver.

Some education about AD and skill training may be appropriate within this context. Family counseling is another intervention approach available to caregivers within the ISD Model. This approach can help family members recognize changes within the family system as a result of the illness of one member. Training in problem-solving and decision-making can facilitate family members' working together when faced with difficult caregiving decisions. An outcome of such counseling is often increased family involvement in caregiving and a reduced sense of burden for the primary caregiver.

A third approach available to caregivers is education and training to increase knowledge about AD and to improve caregiving skills. A group format allows interaction among caregivers and helps them recognize that they are not isolated and alone as they face the stress and burdens of caregiving. Several examples of educational groups are available in the literature (see chapter 3). Meeting content includes education about AD and the nature of cognitive and behavioral changes resulting from the disease; training to improve caregiving, including problem-solving, decision-making, coping, and self-care skills; and information about support services and community resources.

The integrated service delivery system allows primary caregivers to be referred to a variety of psychoeducational services based on the ongoing review of needs. Counselors, psychotherapists, health educators, and gerontology specialists are likely to be involved in evaluation of need. As education and training increase knowledge and

skills, caregivers often regain a sense of control over managing problems, making decisions, and caring for their own needs.

Social support services. The availability of community and social support is another important link in the network of services available to primary caregivers through the ISD Model. An overview of many of these services was presented in chapter 3. Participation in an ongoing caregiver support group can provide a sense of belonging and understanding common among persons with similar problems, and can also help to reduce feelings of isolation frequently experienced by caregivers. Membership in a self-help organization such as the Alzheimer's Disease and Related Disorders Association can often give caregivers a feeling that they are combining their efforts with others in similar situations to advocate for continued AD research, expanded caregiver services, and policy changes to reduce health care barriers for persons with AD.

Support services available to help relieve the daily burdens of caregiving include adult day care and in-home respite care. Both offer reliable alternatives so that primary caregivers can have time away from the constant demands of providing care. Legal and financial concerns can often be stressful for caregivers. Knowledgeable consultants can answer complicated questions and help caregivers make necessary decisions as early as possible in order to prevent crises as the care receiver becomes progressively more impaired. Many times elderly persons with AD and their primary caregivers have limited income. In such cases they are often

eligible for government assistance and services such as social work case management, hot meal programs, home health services, and medical care. Information about these services, and often the services themselves, are available through local senior centers and area agencies on aging. Finally, many caregivers have strong spiritual values and find a great sense of relief in being able to share their burdens within a religious context. Often the caregiver can turn for help, both practical and spiritual, to caring members of the clergy and to friends who share common values and beliefs.

The types of social support services described above are provided by social workers, gerontology specialists, agency staff members, legal and financial consultants, caring volunteers, and members of the clergy. Coordination of social support services also involves working with agencies and programs external to the ISD system. As with medical care and psychoeducational services, ongoing evaluation of needs will help to determine the most appropriate social service referrals for primary caregivers.

Outcomes of Service Delivery

The first outcome of the Integrated Service Delivery Model is reduced stress and burdens for primary caregivers. Caregiver entry into the service delivery system initiates assessment and evaluation of needs, development of a treatment plan, and referral to a broad range of services designed to meet identified needs. Caregivers receive information, counseling, and support which help them recognize that while AD is a chronic, degenerative physical

condition, they are able to manage some of the psychological and social elements of the disease. As they learn about AD, receive support from other caregivers, and develop more effective caregiving skills they regain a sense of control. This renewed sense of control often reverses feelings of victimization, and results in reduced stress and burdens for primary caregivers.

The second outcome of the ISD Model is increased caregiver skills in the management of physical, psychological, and social problems associated with AD. The medical care component of the service delivery model offers caregivers help in managing their own physical health. The psychoeducational component provides training in problem-solving, decision-making, coping, and self-care skills. The social services component provides opportunities for caregivers to interact with and learn from others in similar circumstances. Coordination of these services reinforces a proactive approach to caregiving and supports AD caregivers as they work to prevent crises and constructively manage those which do occur.

A positive inverse relationship between these two outcomes is suggested. As caregivers' management skills increase, feelings of stress and burden are likely to decrease. Lowered stress and burden may enhance management skills. The web of integrated services available within the ISD Model serves as a safety net for caregivers. Ongoing access to services provides them with assurance that help is available and that they are not alone as they continue to provide care for a family member with Alzheimer's disease.

CHAPTER V

RECOMMENDATIONS AND IMPLICATIONS

Statistics suggest that Alzheimer's disease is a condition which directly touches the lives of as many as 10 million Americans (Aronson, 1982). This figure includes not only persons suffering from the disease, but their primary caregivers and other family members as well. The problem of providing ongoing care for a person with AD is exacerbated by (a) caregiver stress and feelings of burden; (b) lack of knowledge and skills for effective management of caregiving problems; and (c) current service approaches which focus on crisis intervention rather than on primary prevention. Because AD is a biological, psychological, and social phenomenon, specialists have called for a service delivery approach which responds to problems presented by all three aspects of the disease (Aronson & Katzman, 1982; Aronson & Lipkowitz, 1981; Zarit et al., 1985).

The Integrated Service Delivery Model presented in this paper contributes a new conceptual framework for the delivery of a network of AD services in response to the problems identified above. It is a holistic model in that it takes into consideration the interdependent physical health, mental health, and social interaction needs of primary caregivers. While it does not address such AD needs as medical research and advocacy for health care policy changes, it does

offer a proactive, coordinated approach to service delivery leading to the outcomes of reduced stress and burden, and improved care management skills for primary caregivers. Achievement of these outcomes suggests that primary caregivers will be better able to provide long term in-home care and thus delay or prevent institutionalization of persons with AD.

IMPLEMENTATION OF THE INTEGRATED SERVICE DELIVERY MODEL

The primary recommendation of this thesis is the implementation of the proposed Integrated Service Delivery Model. Several factors must be considered. The first question is in what type of setting could such a model be most effectively implemented. Health maintenance organizations (HMOs) often consider health care from a holistic perspective. They support education and preventive services as ways to improve physical and mental health. Several of the types of services proposed in the ISD Model may be available through an HMO. Implementation of a coordinated services delivery model may be accomplished most easily in such a setting, and could be mutually beneficial for both the HMO and for families of persons with AD.

Another consideration is the cost of an integrated service delivery system. Implementing the model as an independent program or agency would mean having to bear the cost of organizing, developing, and providing the entire range of services outlined in the model. The cost would be prohibitive. If the model were implemented in a setting where some services and an administrative structure already

exist, the cost would be substantially less. Another cost factor is the charge to clients for such services. The broad range of ISD Model services could become expensive. In addition, Medicare and other insurances cover few services related to Alzheimer's disease. A benefit of implementation within an HMO could mean that the cost for such services would be covered in membership fees, thus limiting the additional expenses for clients.

A third consideration of implementation relates to coordination. The number of potential service providers and their diverse professional backgrounds may present decision-making problems when determining client treatment priorities. Depending on the service needs of caregivers and care receivers, some treatment teams may have several members. The larger a team the more likely coordination problems may occur. Further, some resources may exist outside of the service delivery system. Duplication of effort is discouraged, but coordination with resources external to the system could also be problematic.

The time frame of service delivery is a fourth consideration. The demands of caregiving often mean that caregivers have a limited amount of time available to take advantage of services intended to help them in their caregiving role. Services may need to be time limited and concentrated in such a way that meeting with a counselor or attending an education and training group does not become another burden for caregivers. Two-hour blocks of time each week are suggested. The two-hour design allows sufficient time for content

delivery and discussion, while weekly contact provides for continuity and support. The availability of both day and evening services is recommended. Providing respite care or supervised social activities for AD patients may also help to encourage caregivers' utilization of services.

A final consideration is the development of a new attitude on the part of service providers. Many potential service providers have been trained to view such conditions as AD from a single biologic, psychologic, or social perspective. Interaction and sharing of expertise among treatment team members can help to promote the broader concept of AD as a bio-psycho-social phenomenon. Such a view will allow service providers to acknowledge that offering a broad range of services will best meet the diverse needs of AD caregivers and care receivers.

SUGGESTIONS FOR FUTURE RESEARCH

Implementation of the ISD Model implies areas for future research which lead to further improvement of services for persons with AD and their primary caregivers. One research focus is the testing of hypotheses inherent in the objectives of the model:

1. That utilization of ISD Model services reduces stress and burdens experienced by primary caregivers.
2. That utilization of ISD Model services increases caregivers' skills in managing physical, psychological, and social problems associated with AD.

Investigation could center on the relationship between caregivers' management skills and feelings of stress and burden. A second area of inquiry could compare the ISD Model with traditional models of service delivery. Past AD services have been primarily reactive. The ISD Model proposes an approach which is holistic and proactive.

Another research question might investigate strategies to implement early intervention with primary caregivers. Identification of potential clients, as suggested in chapter 4, includes outreach in an effort to bring AD primary caregivers and care receivers into the ISD system prior to a time of crisis. However, AD specialists note that many caregivers do not take advantage of available services until a caregiving crisis occurs (Aronson et al., 1984; Mace & Rabins, 1981; Powell & Courtice, 1983; Zarit et al., 1985). In addition, Waxman, Carner, and Klein (1984) report on significant underutilization of mental health services by the elderly. Schmall (1985) suggests that services for AD caregivers be prescriptive in nature. If physicians prescribe certain interventions for primary caregivers the credibility of such services is often enhanced. In addition, insurance coverage may be more likely. These are clearly complex questions, and answers may be elusive.

An ultimate research consideration may be the applicability of the ISD Model to primary caregivers and care receivers suffering from other chronic and terminal illnesses. Some concepts included in the ISD Model were taken from reports on similar models which had been effective with other diseases (see chapters 1 and 3). One advantage

of the model is that implementation can utilize existing services in a new way. Another advantage is that a proactive approach to service delivery is often more cost effective than direct, crisis-oriented services (Shadden, 1983). Finally, most chronic illnesses can be regarded as bio-psycho-social conditions, as is Alzheimer's disease. The holistic philosophy of the ISD Model supports integrated services and treatment of those aspects of a disease which are amenable to change. As a result, the Integrated Service Delivery Model proposed in this paper may be an effective approach to service delivery across a broad range of chronic conditions.

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APPENDIX

SELECTED BIBLIOGRAPHY OF SELF-HELP MATERIALS FOR PRIMARY CAREGIVERS

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