

/ FAMILY SUPPORT CONSIDERATIONS
IN ALZHEIMER'S DISEASE TREATMENT

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MJW

Introduction

Recently, there has been growing concern about the disorder termed Alzheimer's disease. In terms of its impact and severity Alzheimer's disease certainly can hold its own when compared to other major disorders. The characteristics of Alzheimer's disease can be profoundly disturbing to victims, their relatives, and other concerned persons.

Alzheimer's disease (AD) is a neurological disorder characterized by an irreversible deterioration of cognitive and motor skills. Also called Senile Dementia of the Alzheimer's type, this disorder is terminal. The disease course can range from three to fifteen years or more (Mace & Rabins, 1981; Cohen & Eisdorfer, 1986). During the course of the disease, memory and reasoning abilities gradually become impaired. These impairments eventually become severe enough to interfere with daily tasks and functions. In the latter stages of the disease, victims usually lose the capacity to speak and to recognize others. AD victims often lose mobility and become incontinent in the late stages. The symptoms noted above do not occur among most older adults. For AD victims, institutional care or informal care by relatives is necessary throughout the disease course.

Since AD can strike adults of any age, there is a wide variation in the ways that families care for disease victims. However, because AD is most likely to affect adults over the age of sixty years (Heston & White, 1983),

AD victims' spouses or adult children are usually the primary caregivers. Other relatives such as siblings, grandchildren, or nieces and nephews sometimes are primary caregivers but usually are secondary caregivers if they are involved in that respect (O'Quin & McGraw, 1985). Some families do find it necessary to place members with AD in nursing homes, but it is estimated that three times as many persons with dementia live with relatives than reside in nursing homes (Kahan et al., 1985). Families with AD victims living at home face substantial challenges in caring for members with AD and in maintaining optimal family functioning.

The onset of AD can be especially stressful for families. The insidiousness of symptom development can create ambiguity which engenders problems in family interaction. Conflict may increase if family members disagree about the need for evaluation of the AD victim's behavioral changes. Even after the disease is diagnosed, family members may respond differently. Some family members may deny that the disease is evident or may seek to minimize the presence of AD. Family communication problems are illustrated in the following excerpt from a letter written by the adult son of an AD victim to the adult son's sister:

"Mom has changed so much in the past several months. She sits in the house most of the day and cries alot. She talks, or at least strings words together, but they seldom

make sense. However, Dad seems to know what she is saying most of the time. I guess it comes from their fifty years together.

Dad would not use the words Alzheimer's disease in front of her. He also would not allow me to talk about Alzheimer's while I was visiting. However, she knows she has a problem. Several times during the day, usually at meals, she asks him, 'What's wrong with me?' His reply is always the same: 'Your memory is not what it used to be, dear. Don't worry.' It took all my strength not to get angry with him. After all, he is the one living with her and taking care of her all of the time..." (Cohen & Eisdorfer, 1986, p. 114).

As the excerpt above shows, conflict may be subterranean in some families. Conflict may tend to be more overt in other families. Not only do family members respond uniquely to the presence of AD, but families have different coping styles in confronting the disease. Many families have cohesive and functional coping styles; meanwhile, some families have excessively conflicted or detached styles of coping (Scott et al., 1986). Factors such as pile-up of stressors and family resources also influence families' adjustments to the crises and transitions brought about by AD (Famighetti, 1986; McCubbin & Patterson, 1983).

Families impacted by AD typically deal with multiple crises. Crises may develop due to critical incidents such as diagnosis of the disease and the need for hospitalization or institutionalization of the member with AD. Some families need little or no formal support in confronting these crises. However, some families do need formal support and turn to various community resources such as AD support groups, individual counseling, or family therapy.

The AD support group is the most common source of formal support for relatives of AD victims (Wasow, 1986; Ory et al., 1985). Personal experiences and feelings can be shared among members of the group. In some cases, this support option is inadequate or inappropriate, and other forms of intervention are preferable.

Issues related to the use of the helping options noted above comprise the primary focus of this report. It is posited here that the critical importance of family interaction factors in the AD coping process necessitates the use of appropriate family support or intervention. It may be that the prominent use of AD support groups and, to a lesser extent, individual counseling is misguided in some cases. Family meetings and family therapy may be preferable options of support and intervention for families affected by AD. In particular, periodic family meetings may be valuable for families that are having problems coping with AD but are not in need of therapy per se. It is also important to

consider the timing of formal support or intervention and the likely stages of the family coping process when implementing a continuum of support for these families.

An adequate continuum of support for families impacted by AD can take form only if there is coordination among formal support providers and between these and informal support providers. Collaboration between professionals and families is needed in order to promote an effective coordination of services. These items will also be addressed in this report.

There are four major sections in this report. The first section includes more background information about this intriguing disorder known as Alzheimer's disease - named after the German physician who first identified it. The second section deals with family interaction and family role differentiation factors which need to be considered when assessing and helping families impacted by AD. The third section involves a description of the support and intervention options currently available for these families. The final section concerns the integration and coordination of support services for families confronting AD. It is hoped that this report provides a comprehensive review and analysis of the impact Alzheimer's disease can have on families.

Background on Alzheimer's Disease

Alzheimer's disease is a complex and intriguing disorder. It is necessary to understand what is known and not known about certain dimensions of this disease. The following is a review of four dimensions of research on Alzheimer's disease: symptomatology, epidemiology, etiology, and medical treatment.

Symptomatology of AD

It seems that a plethora of disease processes and factors must be ruled out before the diagnosis of Alzheimer's disease can be made. The differential diagnosis of AD is complex and sometimes results in substantial errors (Hollander et al., 1986). A definitive diagnosis cannot be made until the afflicted person has passed away (Olson, 1989). Clinicians need to rely on the presence of certain signs and symptoms.

The most important clinical marker for the diagnosis of AD is the widespread presence of neurofibrillary tangles and neuritic plaques in the neocortical and hippocampal regions of the brain (Hardy et al., 1986). Tangles and plaques are microscopic structures sometimes evident in the brains of older persons with no signs of AD; however, there are many more plaques and tangles in the brains of those with AD. Tangles and plaques cannot be identified without an autopsy or biopsy, though certain imaging techniques can be used to

assess aspects of the cortical area of the brain where some of the tangles and plaques are located (Olson, 1989).

It appears that imaging techniques are also helpful in the assessment of another major indicator of AD: a lack of cholinergic neurons in the cortex and subcortex of the brain (Hardy et al., 1986). Loss of these neurons leads to a deficiency in the production of acetylcholine, a neurotransmitter that may be critical in the memory process. Imaging techniques are capable of analyzing metabolic processes in the brain and soon may be able to aid in assessing the cholinergic system with precision. This would be valuable since it now appears that degeneration of cholinergic neurons is related to the formation of neuritic plaques in the neocortex and hippocampus (Hollander et al., 1986).

There also seem to be abnormalities affecting neurotransmitters other than acetylcholine. Somatostatin is a neurotransmitter that has been found consistently deficient among AD victims (Delfs, 1985). The significance of somatostatin deficiency has yet to be determined, although it has been shown that acetylcholine is a potent releaser of somatostatin (Robbins et al., 1982). Serotonin and norepinephrine levels also have been found deficient (Hollander et al., 1986; Adolfsson et al., 1979). These findings are important because they suggest that multiple forms of treatment of AD might be necessary rather than a

focus on moderating levels of a specific neurotransmitter. (The treatment of AD will be reviewed shortly). Also, they point to the complexity of diagnosis since other disorders share many of these abnormalities.

The diagnosis of AD is additionally complicated by the fact that there are several diseases with symptom formation similar to AD. For example, multi-infarct dementia and micro-infarct dementia involve much of the symptomatology of AD but follow a more variable, less progressive course. Cerebrovascular disease is a distinguishing feature of multi-infarct and micro-infarct dementia and not of AD, but one of these vascular dementias may coexist with AD (Cohen and Eisdorfer, 1986). In addition, several disorders including Creutzfeldt-Jakob's disease, Parkinson's disease, subdural hematoma, normal-pressure hydrocephalus, and hypothyroidism all share features similar to AD and must be ruled out before a diagnosis of AD can be given, according to DSM-III (1980) criteria. Also, Pick's disease is very similar to AD; these two diseases can be distinguished only with biopsy or autopsy (Heston and White, 1983). Finally, clinical depression and depressive pseudodementia are disorders that also must be ruled out (Merriam et al., 1988; Hollander et al., 1986). These disorders are reversible, but they can coexist with AD as well.

Given that the disorders above (and many others) are ruled out, one can begin to focus on the likelihood of

Alzheimer's disease. A primary symptom of AD is the progressive loss of memory. Initially, short-term memory is far more affected than long-term memory (Mace and Rabins, 1981). A pattern of forgetfulness emerges in which the person with AD begins to misplace items, to forget statements just made by self or others, or to forget events occurring in recent hours or days. The onset of this memory loss is frequently insidious and is often mistaken for or dismissed as a "normal" sign of senescence. Sometimes victims understandably attempt to mask the memory deficits by using cues such as notes or signs as reminders (Powell and Courtice, 1983). Eventually, these cues become ineffective as well. There is cause for concern, therefore, when the memory loss begins to interfere with routine daily activities.

Although memory loss is the foremost symptom of AD, the disease features numerous other symptoms. One of these is the impairment of intellectual judgment. This may include difficulties in performing simple mathematical tasks or in recognizing potentially dangerous situations. Needless to say, the potential for major incidents and accidents increases as a result of impaired judgment. For example, a victim may begin to stack papers on a gas stove or leave the door of an unattended car wide open. Another symptom is a decrement in lucidity. There is a loss of ability to comprehend and attend to events occurring in the

person's environment. In the early stages of the disease, the person's capacity to converse with others may be diminished little or not at all. However, the ability to verbally communicate deteriorates in the later stages (Cohen and Eisdorfer, 1986). Also, perceptual skills and eye-to-hand coordination are eventually affected, and complex tasks such as driving a car become very difficult (and unwise) to perform.

The symptoms noted above lead to behaviors that have become known all too well by relatives of AD victims. For example, many persons with AD frequently wander off and about. This is especially problematic if the wandering behavior occurs at night. The person can easily become disoriented and lost. It would be convenient to conclude that most wandering behavior is aimless. However, Shomaker (1987) and Snyder (1978) have presented evidence that the wandering is usually goal-directed but inappropriate. An example is the situation in which the person who once worked nights begins to leave the house at night in order to work. It is obvious that special precautions need to be taken in order to manage such behavior. Also, hypersexuality may become a problem, although diminished sexual functioning is more common. Another more common problem involves repetitive behavior. For example, the person with AD may ask the same question over and over within a brief period (Mace and Rabins, 1981). Although there is no timetable for

these problem behaviors, they tend to occur more frequently during evening hours than during morning hours. This pattern is nearly reversed for depressed persons with no signs of dementia (Heston and White, 1983).

A contrast of the diurnal aspects of behavior exhibited by persons with AD and persons with depression is hindered by the fact that some AD victims are also clinically depressed. It is estimated that about 25% of persons with AD are mildly or severely depressed (Powell et al., 1983). The depression can be due to the dementia itself, to physical reasons other than the dementia such as thyroid problems and reactions to medication, or to psychosocial factors, among other determinants (Cohen et al., 1986). Persons with AD and depression are typically apathetic and withdrawn. Agitation and sleep disturbances are quite common as well. Depression arising early in the course of AD is treatable either through therapy or antidepressant medication (Merriam et al., 1988). Severe depression is less responsive to treatment than mild or moderate depression.

Unfortunately, more severe psychological symptoms are sometimes evident in AD. In one large study of AD victims living in the community, nearly 30% reportedly experienced auditory or visual hallucinations (Merriam et al., 1988). Paranoid ideation is believed to be even more frequent. The paranoia sometimes takes root early in the disease when the

person with AD and those close to her or him are coming to grips with the victim's memory problems and other behavior changes. Once the paranoid ideation sets in, it can become difficult to deal with because of the restricted cognitive capacity of the person with AD. However, it seems that in many cases, the paranoid aspect is relatively transitory and not highly elaborate (Zarit et al., 1985). With regard to hallucinations, additional factors often need to be considered. Brain injury, delirium, and drug toxicity are among the factors that can increase the risk of hallucinations, and these factors are sometimes superimposed upon the dementia (Mace and Rabins, 1981).

Like many other older adults, persons with AD may suffer from a variety of health problems. Some of these problems may be attributed to the onset of AD while others may not. In the early stages of the disease, the AD victim may be quite healthy; problems such as arthritis and musculoskeletal disorders may be no more common among AD victims than among other persons the same age. However, the AD victim does eventually experience increased muscle rigidity and problems with mobility. Behaviors such as feeding oneself become more difficult or simply not possible. Also, incontinence is usually not likely in the early stages but is present in the late stages of the disease (Cohen and Eisdorfer, 1986). Weight loss is also common late in the course of the disease (Heston and White, 1983).

Needless to say, the late stages of the disease can be extremely difficult for the victim and those who care for her or him. In addition to the physical impairments noted above, the person with AD may become unable to recognize close relatives. Also, she or he eventually becomes aphasic and seemingly unresponsive to others' verbal messages. Although facial expressions become diminished, there is evidence that the victim usually can and does respond nonverbally to the messages of others. Hoffman et al. (1985) have found that persons in the late stages of the disease are especially sensitive and responsive to the emotional undertones of others' messages. Posture, head adjustment, and smiling can convey the victim's messages, although there tends to be a brief delay before they do respond. Unfortunately, communication can be adversely affected by problems with eyesight, which tends to deteriorate rather significantly for many persons with AD (Olson, 1989; Hutton, 1985). Even so, limited communication with the AD victim is possible and is important to help ease the burden of victims and their caregivers.

Epidemiology of AD

Alzheimer's disease appears to be a growing public health problem. This trend is expected to continue in future years. This will be described in a brief overview of the following aspects concerning the epidemiology of AD:

prevalence, incidence, sex comparisons, race comparisons, and mortality.

Prevalence. Estimates of AD's prevalence rate vary from study to study. For instance, Mortimer and Hutton (1985) estimated the number of cases in the U.S. at about one million. More recent estimates are that as many as 2.5 million Americans have the disease (Merriam et al., 1988). These estimates appear to be the lowest and highest, respectively. Problems related to accurate diagnosis may account for some of the variability of estimates. Nevertheless, prevalence of AD appears to be increasing and is expected to continue increasing in future decades.

If no cure for AD is found, it is expected that there will be a gradual increase in prevalence of AD through the year of 2020 or so. At that point, estimates are that 3.3 million Americans will have the disease. By the year 2040, it is projected that about 7.3 million Americans will be AD victims. The main reason for the sharp increase in cases expected to occur between the years of 2020 and 2040 is the maturation of the "baby boom generation" (Congress of U.S. Office of Technology Assessment, 1987). These projections point to the importance of considering age-specific prevalence rates.

For persons under the age of 65, the estimated current prevalence rate is 1 per 1000. However, the rate is about 2.5% for those at age 70 and about 25% for those at age 90

or so (Mortimer & Hutton, 1985; Heston & White, 1983). The risk of AD onset increases geometrically with age. However, the risk for specific age groups (e.g. 80-90) is not expected to rise in the future (Goldman, 1984). This means that the continued rise in prevalence of AD will primarily be a function of the increased number of older persons.

Incidence. The incidence of AD appears to parallel the incidence of other forms of senile dementia. The incidence rate of a disease is the number of cases occurring in a set period of time (usually a year) divided by the number of persons in the population at risk (Mortimer et al., 1985). The incidence of the senile dementias appears to follow a curious pattern. Among others, Hagnell et al. (1981) have found a sharp rise in the incidence of dementia for those persons in their 70s and 80s. However, there is a rather sharp decline in the incidence of dementia for those aged 90 or over. This suggests that due to hereditary and (or) environmental influences, some individuals are resistant to dementia.

Sex comparisons. More women than men suffer from senile dementia. The primary reason for this is assumed to be that more women than men reach older age (Goldman, 1984). However, there are some indications that given an equal number of women and men reaching older age, more women than men still would develop dementia. Age-specific prevalence

studies and incidence studies both have shown higher rates among women than men (Kokman et al., 1984; Kay et al., 1970; Schoenberg et al., 1981; Hagnell et al., 1981). The reasons for this are unknown; more studies seem warranted in order to explain this difference.

Race comparisons. Studies conducted in the U.S. and other countries seem to show that AD is universal in its presence, although there may be minor differences in prevalence rates. Incidence and prevalence rates have been consistently similar in Scandinavian, Japanese, and Israeli studies (Larsson et al., 1963; Kaneko, 1975; Treves et al., 1986). A U.S. study by Schoenberg et al. (1981) has shown slightly higher prevalence rates among blacks than among whites in a Mississippi county. One of the few exceptions to the consistency of findings is a 1984 study by Wang et al. in China (Mortimer et al., 1985). This research group has found an unusually low rate of senile dementia among Beijing residents. Cultural factors may be involved in this finding. Nevertheless, it does seem evident that senile dementia is prevalent worldwide.

Mortality. Although AD is rarely implicated as a direct cause of death, it is probable that the disease plays a substantive role in accelerating mortality. The survival time of AD varies but is most often in the five to ten year range (Cohen et al., 1986 Heston & White, 1983). Among

younger AD victims, survival time can be as brief as two or three years (Goldman, 1984). It cannot be determined with certainty whether AD is a direct cause of death; the primary cause of death is usually recorded as pneumonia or stroke, for example. Even so, researchers such as Siegel (1980) estimate that AD is the fourth leading cause of death among persons over 75 years of age. Because of the lack of definitive data, estimates such as this cannot be extended to include all age groups but do serve as rough indicators of AD's role in affecting mortality.

In sum, the data from epidemiological studies indicate that AD is gradually becoming more prevalent. This increase in prevalence is expected to accelerate early in the 21st century unless causes of and cure for the disease are found.

Etiology of AD

The etiology of Alzheimer's disease remains unclear. Although the last decade has been a period of obvious advances in the search for causes of the disease, it could be stated that more questions have been raised than answered. Among others, Gaitz (1985) has noted the tremendous complexity and contradictory evidence permeating etiology and treatment research. Nevertheless, several processes and agents have been implicated as possible factors in the development of AD. Among these factors are: the role of genetics, the role of the blood-brain barrier,

the role of the immune system, acetylcholine deficiency, head trauma, viruses, aluminum intake, nutrition, and stress. Before these factors are discussed, it should be noted that many researchers favor models of multiple causality which typically emphasize certain factors.

Role of genetics. It appears that there may be a genetic component to the onset of AD. There is a substantial increase in risk of developing the disease if a person has more than one first degree relative with AD (Davies, 1986; Heston, 1985). However, autosomal dominance, in which offspring have a 50% chance of inheriting the disease given an affected parent, is prevalent in only a few families (Cohen et al., 1986). This suggests that the genetic aspect may be important but not as prominent as it is in other disorders such as Huntington's chorea and Down's syndrome.

There is an important link, however, between Down's syndrome and AD. Nearly all Down's syndrome victims who live longer than 35 years develop the hallmark tangles and plaques of AD (Whalley, 1982). Since it is known that the gene for Down's syndrome is on the chromosome numbered 21, researchers have been studying the DNA of this particular chromosome as a possible determinant of AD. So far, the results of this research have been equivocal (Joseph, 1989). There does seem to be increasing evidence that the genetic role is significant among those who develop AD before the

age of sixty or so; this group experiences especially severe symptoms and shortened survival (Winblad et al., 1986).

Blood-brain barrier. Recently, there also has been growing evidence suggesting that the blood-brain barrier plays an important role in the onset of AD. Glenner (1985) has found that the structure of protein in the neuritic plaques of AD victims is similar to that of protein in the cerebral vessels. This points to a defect in the blood-brain barriers of AD victims. Hardy et al. (1986) have hypothesized that the loss of nerve cells in critical areas of the brain leads to blood-brain barrier damage and the development of neurofibrillary tangles and plaques. These researchers suggest that the blood-brain barrier defect is a prerequisite for the development of AD. However, since the loss of brain cells supposedly precedes barrier damage and is an age-related process, barrier damage may be relative or may be affected by the presence of toxic substances (Banks & Kastin, 1986). Certain toxic substances (e.g. aluminum) appear to be present in abnormally high amounts in the cerebrovascular systems of AD victims. Therefore, although it does appear that the blood-brain barrier is involved in the pathogenesis of AD, it is not clear whether barrier damage is a precursor or byproduct of AD development.

Immune system. The blood-brain barrier has been linked to another possible factor in AD onset: immune system

dysfunction. The aging process and autoimmune disorders are thought to be related to immune system deterioration (Nandy, 1978). With regard to senile dementia, Fillit et al. (1985) have found evidence of increased antibrain antibodies in the cerebral vessels of AD victims. These antibodies are believed to inhibit cholinergic activity. Increased permeability of the blood-brain barrier may serve to facilitate the role of these antibodies. Although there is not enough evidence to suggest that AD is an immunologic disorder, it is possible that some AD victims are affected by an autoimmune response system directed at cholinergic (and noncholinergic) functions.

Acetylcholine deficiency. It was noted earlier that acetylcholine deficiency is common in AD cases. There is typically more than a 50% reduction in the amount of acetylcholine present in the brains of deceased AD victims (Bartus et al., 1982). Although a "cholinergic hypothesis" has evolved in recent years, its purpose is generally regarded as descriptive rather than indicative of etiological factors. It appears that the decrease in choline acetyltransferase activity results in significant impairments only if it is superimposed upon an already dysfunctional system (Hardy et al., 1986). Much of the research in this area continues to focus on the replacement of acetylcholine through pharmacological treatment.

Head trauma. It appears that a history of significant head injury is more common among AD victims than others. Mortimer (1985) and Heyman et al. (1984) found that head injury with loss of consciousness was about five times more prevalent among AD patients than among controls. Though case reports such as Rudelli et al.'s (1982) indicate that single head injuries may directly result in the onset of AD, such reports cannot be confirmed with certainty. More intriguing is the possibility that multiple head injuries significantly increase the risk of obtaining AD. Uhl et al. (1982) have documented the cases of several ex-boxers who suffered from dementia pugilistica, a syndrome that mirrors AD to a significant extent. Thus, repeated head trauma may be associated with the onset of AD, although there is a need for more controlled research to verify this possibility.

Viruses. There is no evidence that AD can be transmitted from person to person (Cohen et al., 1986; Bruce, 1984). Some researchers have attempted to compare the onset of AD with the onset of infectious diseases such as scrapie (in sheep and goats) and Creutzfeldt-Jakob's disease. For example, Wisniewski (1983) has noted that the amyloid plaques evident in scrapie and in some Creutzfeldt-Jakob's cases closely resemble the neuritic plaques found in AD cases. Since there appears to be a relationship between amyloid formation and infectivity, it has been suggested that infection of a genetically susceptible individual may

result in AD (Wisniewski & Merz, 1985). Though viral hypotheses cannot yet be dismissed, they have not been supported by research.

Aluminum intake. The role of aluminum in the development of AD continues to be debated. Recent studies have focused on the possibility that olfactory intake of aluminum may lead to the formation of plaques and tangles in the olfactory cortex and nearby areas of the brain. Roberts (1986) has hypothesized that some cases of AD may essentially begin in the nose through the process of olfaction. Most researchers have reacted with skepticism toward this hypothesis, though the studies in this area continue. A more common perspective is that the presence of aluminum and silicon deposits in the brain may accelerate the formation of tangles and plaques (Esiri et al., 1986). Since aluminum levels in the neurons of AD victims do seem to be elevated (Crapper et al., 1980), it is possible that aluminum may play such a supporting role. However, this possibility needs to be tempered by findings that the structure of tangles experimentally induced by aluminum differs from the structure of tangles observed in AD cases (Mortimer et al., 1985). In sum, it appears that aluminum may contribute to the development of AD, but is doubtful that aluminum intake is a primary etiological factor.

Nutrition. Although there is little evidence that poor nutrition is a factor in the onset of AD (French et al.,

1985), malnutrition can lead to metabolic changes which affect cognitive functioning (Cohen et al., 1986). For instance, it is believed that vitamin B12 deficiency is among the precursors to the onset of subacute combined degeneration (SACD), a disorder that mimics AD to a degree (Vatassery et al., 1983). Vitamin deficiency is a fairly common problem among older persons; thus, the nutritional aspect is considered important in the assessment and treatment of AD and related diseases.

Stress. Evidence appears to be inconclusive as to whether stress facilitates the development of AD. Sapolsky et al. (1986) have presented some neuroendocrinological evidence in support of their hypothesis that chronic stress increases the risk of AD. Also, a high rate of dementia has been noted to affect torture victims (Jensen et al., 1982). However, French et al. (1985) have found no significant differences between AD victims and controls in terms of previous stressful events (e.g. death of spouse or divorce). More research is needed to determine the role of stress in AD onset.

Medical Treatment of AD

Current treatment of AD is primarily pharmacological. Many types of medications are utilized in attempts to counter the numerous symptoms of the disease. Unfortunately, as of now these medications offer only limited relief for persons with AD.

Effective drug treatment is limited by several drawbacks. The most prominent of these drawbacks are the unknown etiology of AD and the apparent absence of animal models to approximate experimental effects. However, recent progress in the search for disease causes has resulted in some gains in treatment efficacy. This is particularly true in regard to the treatment of memory loss.

Since memory loss is the foremost symptom of AD, the discussion of treatment effects can be divided along the lines of memory-related symptoms and other behavioral symptoms. In turn, a discussion of memory-related treatment can be delineated in terms of the efficacy and non-effectiveness of particular medications.

Treatment of memory loss. Certain medications have been found generally ineffective in the treatment of memory deficits. The use of lecithin and choline began after the discovery that acetylcholine levels were deficient in AD victims. It was thought that these drugs would restore acetylcholine levels which in turn would stimulate cognitive functioning. However, they have been dismissed as largely ineffective (Dysken, 1987; Brinkman et al., 1982). The drugs naloxone and naltrexone are opioid antagonists that once were believed to increase responsivity to stimuli. These drugs have not produced the desired effects (Steiger et al., 1985; Hyman et al., 1985). Similarly, the neuropeptides ACTH and vasopressin have not proven helpful

in improving memory functioning (Crook, 1987; Soininen et al., 1985).

Other memory enhancing drugs have shown more signs of effectiveness. Hydergine is a drug that first came into use in the 1950s and remains the only FDA approved medication for the treatment of intellectual decline (Dysken, 1987). Many studies have shown that Hydergine produces slight to moderate improvement in short-term memory and mental alertness (VanLoveren-Huyben, 1984; McDonald, 1979). However, there is also evidence that the positive effects of Hydergine are limited to a subgroup of AD patients (Bagne et al., 1986; Cutler et al., 1985). Another drug, tetrahydroaminoacridine (THA), has shown signs of producing moderate memory improvement among a greater proportion of AD patients tested (Summers et al., 1986). Currently, researchers are determining the effects of THA, a cholinergic agonist, in order to decide whether it should be marketed (Hager, 1988). Perhaps the most promising results have been obtained when drug combinations such as THA and lecithin have been administered to AD victims (Jorm, 1986).

Treatment of secondary symptoms. As noted earlier, AD can include an array of symptoms. The secondary symptoms of AD are often treated by medications such as neuroleptics and antidepressants. Drugs such as antianxiety and sleep medications are sometimes prescribed, also.

Neuroleptic medications are indicated when AD victims experience severe agitation or hallucinations. Although often effective, these medications do produce side effects which occur more readily among older patients. As a consequence, certain drugs are used more often than others. For example, Steele et al. (1986) found that while Haldol and Mellaril were both effective in reducing severe agitation in AD cases, Mellaril seemed preferable due to inducement of fewer side effects. Because of their potency, neuroleptics are contraindicated if other problems (e.g. heart or liver) are present (Cohen et al., 1986).

Antidepressant medications are also prescribed in some AD cases. Symptoms apparently due to the dementia may in fact be due to depression. Antidepressant medications often used among older patients include: Aventyl, Elavil, Sinequan, and Desyrel. These medications can produce side effects as well, although the newer medications (such as Desyrel) appear to be less harmful. Lithium, the treatment of choice for bipolar disorder, appears to be more harmful than helpful for many AD victims (Randels et al., 1984). However, most antidepressant drugs are capable of alleviating depression for some persons with AD.

Antianxiety medications and sedative-hypnotics can aid in treating the secondary symptoms of AD as well. These medications can serve to decrease motor restlessness, tension, and insomnia, for example. Administration of

antianxiety drugs to patients with dementia is usually confined to the class of drugs called the benzodiazepines. Ativan, Serax, and Xanax are common antianxiety medications prescribed for those with AD. Although these drugs can be helpful (particularly Serax), they can produce side effects such as ataxia, confusion, and sedation (Risse et al., 1987). Not surprisingly, some of these medications are used to treat sleep disturbances because of their typical sedating effects. Some common sedative-hypnotics include Dalmane and Halcion. These sleep medications are used only for short-term management of sleep dysfunction (Cohen et al., 1986).

The medications noted above comprise only a part of the treatment of Alzheimer's disease. A comprehensive treatment plan often includes: exercise, physical therapy, occupational therapy, speech therapy, or nutrition management (Mace et al., 1981). Persons with AD can benefit from these interventions well into the late stages of the disease. Rehabilitation plans need to be tailored to each patient and her or his abilities and capabilities. Family members can aid in developing these treatment plans and in implementing them as successfully as possible.

Alzheimer's Disease and Family Interaction

It has been noted that Alzheimer's disease presents enormous challenges for families. As the disease progresses, an increasing amount of caregiving behavior is necessary in order to deal with emergent symptoms. Family members - especially primary caregivers - may come to experience caregiving as their major function in the family. Even relatives such as grandchildren, nieces, and nephews can be impacted by the disease. Due to the impact of the disease on families, it seems relevant to look at some of the apparent ways in which AD changes aspects of family interaction.

It is important to consider how the roles of family members change with the onset of AD. A role can be defined as "... a prescribed pattern of behavior expected of a person in a given situation by virtue of his or her position (designated status) in the transaction" (Shibutani, 1961, p. 47). A role can also be described as "... a pattern of reciprocal claims and obligations" (Greene, 1986, p. 90). Undoubtedly, the role of an AD victim's spouse can be profoundly influenced by the disease. The roles of AD victims' children can also be influenced - especially if primary caregiving is necessary. Young children and other family members may become "secondary caregivers." For primary and secondary caregivers, role changes can engender

a high degree of burden. Family systems can experience significant stress as well.

AD needs to be viewed in a family context. Models of family interaction can aid in the description and assessment of families with AD victims. Analysis of roles and interaction can provide implications for treatment of those families on the verge of severe dysfunction. It should be noted, however, that the majority of families with AD victims appear to deal with role adjustments, caregiving burden, and systemic changes in healthy and resilient ways.

The Role of the Spouse

AD can affect the relationship of the victim and her or his spouse in a number of ways. In the early stages of the disease, the denial of behavioral symptoms can be an issue. The person with AD may deny experiencing any significant problems if confronted by the spouse. Sometimes the spouse may deny the symptoms as well and may actively engage in "covering up" certain behaviors - particularly when other people are present (Cohen et al., 1986). Loyalty issues can arise once the spouse recognizes the severity of the symptoms, since the victims are sometimes incapable of recognizing them (or may continue to deny even if somewhat aware). Another problem that may occur early in the course of AD is misinterpretation of the symptomatic behavior as being volitional in nature. For example, the spouse may interpret the victim's repetitive questions as a means to

irritate. Misinterpretation of symptomatic behavior is especially likely before the disease has been diagnosed and if there have been significant marital difficulties (Zarit et al., 1985). Even so, communication problems are quite common among couples struggling with the onset of AD.

Because the behavioral changes associated with AD usually occur subtly and gradually, frustration and anger may come to characterize relationships influenced by AD. Persons with AD may have good days in which their symptoms are not even noticeable. This may make the "bad days" harder to deal with. It has been noted that the unpredictability of symptomatic behavior is a hallmark of AD (Pagel et al., 1985). Victims and their spouses can become confused and distraught by the variability of behavior. Frustration can arise when the victim can no longer perform certain tasks or has difficulty communicating his or her needs. Spouses may not deal with these problems as patiently or tolerantly as is desired. An escalation of conflict may ensue while the management of anger becomes more difficult. These problems can be compounded if the person with AD exhibits irrational thoughts or paranoid ideation. This may lead to mutual withdrawal.

As the disease progresses, the spouse of the victim eventually comes to realize that she or he is involved in a changed relationship. The spouse with AD may become aware of this as well. A relationship once based on egalitarian

principles may become similar to a parent-child relationship. The person with AD may be physically present, but in some ways she or he is psychologically absent. The spouse of the AD victim may grow uncertain as to what role she or he is truly playing, and there may be "boundary ambiguity" as to the role of the member with AD in the family (Cohen et al., 1986; Boss et al., 1984). This can produce much discomfort for some spouses and for other family members.

There appear to be differences in the ways that spouses confront the changes noted above. Most spouses of AD victims are put in the position of being highly directive with their spouses. There is some evidence that husbands (male caregivers) are more comfortable with this adjustment than are female caregivers. Miller (1987) has found that wives of AD victims often find it uncomfortable to assume traditionally "masculine" tasks such as car maintenance and financial management. Also, wives seem to involve their spouses more in mutual activities, whereas male spouses tend to separate personal activities from those of their wives. Thus, it appears that female spouses may be more attuned to the relationship aspects of AD, according to Miller. However, other researchers (e.g. Fitting et al., 1986) have found indications that husband caregivers are more invested in marital relationships than are wife caregivers.

Other studies have compared the burden levels of caregiving husbands and wives. According to George et al.

(1986), caregiver burden can be defined as the physical, psychosocial, and financial difficulties experienced by family members providing care for impaired older adults. Thus, Pratt et al. (1985) found that wives and husbands did not differ significantly in terms of caregiver burden. However, Fitting et al. (1986) found that wives of AD victims reported greater marital deterioration and more depression than did husbands of AD victims. In a longitudinal study, Zarit et al. (1986) showed that wives appeared to initially experience greater burden than husbands; this difference in burden was no longer apparent in a follow-up two years later. It was suggested that the wives' burden decreased when they adopted the husbands' more task-oriented approach to caregiving.

Spouses of AD victims seem to face a variety of difficulties related to their caregiving functions. An important and consistent finding has been that the level of caregiver burden is negatively related to the degree of family support and unrelated to the severity of AD symptoms (Scott et al., 1986; George et al., 1986; Zarit et al., 1980). Among the key variables associated with family support are: frequent visits by other family members, agreement about the AD victim's level of mental and physical functioning, and agreement about care provision (Scott et al., 1986). Conflict with adult children about AD victims' care requirements increases burden levels (Chenoweth et al.,

1986). These conflicts are more likely to occur in early stages of the disease when those not living with the AD victim deny or are aware of the symptoms' extent. Another tendency frequently reported by caregiving spouses is the loss or distancing of friends and extended family. Dealing with the disease is confining and time consuming; caregivers often note that they withdraw from others perhaps as much as other withdraw from them (Haley et al., 1987; Chenoweth et al., 1986).

It appears that caregiving spouses attempt to handle and cope with the disease on their own as much as possible. Some of the coping strategies they use that seem to be effective in lessening burden are: confidence in problem-solving, reframing problems, and seeking spiritual support (Pratt et al., 1985). Some spouses who retain their physical and mental health are able to cope with all the responsibilities of caring for persons with AD and do so with little outside assistance. However, many caregivers experience health problems of their own and some develop psychological problems in coping with AD. Haley et al. (1987) compared caregivers of AD victims with controls (i.e. noncaregivers) and found that caregivers reported more physical and mental health problems than controls did. Among caregivers, over 40% experienced clinically significant depression. The poor physical and/or mental health of the primary caregiver seems to be the most

important factor in families' decisions to institutionalize AD victims (George et al., 1986). About 25% of victims are eventually institutionalized (Morycz, 1985).

The late stages of AD can have varying effects on spouses of persons with AD. Some spouses experience a sense of relief if the victim is institutionalized in a facility that meets her or his needs. More likely, the predominant feelings of spouses relate to anticipatory grief as well as guilt (Cohen et al., 1986). Among other reasons, the guilt may be due to the necessity for institutionalizing, the sense of wonder as to why the disease struck their spouses and not themselves, or the realization of the pain and sacrifice of other family members and friends.

The Roles of Adult Children

The adult children of AD victims are often important figures in the caregiving process. Nearly 40% of informal caregivers are adult children (Stone et al., 1986). Many of these individuals are faced with the tremendous responsibilities of caring for their parent while raising children of their own. Since most adult children involved in caregiving are women (Quayhagen et al., 1988; Zarit et al., 1985), substantial conflicts may arise in caring for both the parent and children. As some have noted, the process of caring for one's parent can create substantial anxiety and ambivalence (Brody et al., 1985; Cicirelli,

1983). Thus, it is important to consider the roles of adult children in the care of persons with AD.

It was noted earlier that in the early stages of AD, adult children may be slower to recognize the behavioral changes exhibited by their affected parent. It is assumed that the main reason for this is adult children usually do not live with their parents and, therefore, cannot observe the daily behavior of the parent with AD. They may deny the symptomatic behavior by ascribing it to "normal" aging processes or, if the diagnosis is not yet made, by blaming the spouse of the victim for being intolerant. More often, there is a problem in communicating information about the progress of the disease. Parents may be hesitant to involve their children in the caregiving process. Certain family secrets may be kept among parents, among children, and among parent-child combinations (Cohen et al., 1986; Hooyma et al., 1986). If or when the disease is diagnosed, adult children may become fearful about the ramifications - both in terms of their own risk of developing the disease as well as the imminent effects of the disease on the victim and the family. A family denial process may occur even after the disease is diagnosed.

Regardless of the degree to which they initially accept the reality of AD, some adult children eventually enter into the caregiving process. Although most adult children who are primary caregivers are women, adult sons are likely to

be the primary caregivers if they are "only children" or if the daughter has a poor relationship with the parents (Powell et al., 1983). Otherwise, adult sons are usually secondary caregivers. Frequently the filial responsibilities are shared - particularly if there are only two or three adult offspring (Matthews, 1987). Powell et al. have presented some interesting ideas on how unconscious motivations and family dynamics may induce certain adult children to become more active in the caregiving process (these aspects won't be discussed here).

Cultural influences also seem to play a part in the caregiving behavior of American families. Just as women are expected to be the primary caregivers of children, so it seems they are expected to become the primary caregivers of parents who are chronically ill. Similarly, the caregiving behaviors of adult children tend to be divided along traditional lines; the adult sons often play an "instrumental" role. Palo Stoller (1983) interviewed over 500 adult children caregivers and found that although marital status diminished about equally the amount of the time adult daughters and sons spent on caregiving for chronically ill parents, paid employment significantly decreased the amount of time the sons spent caregiving but did not decrease the amount of time the daughters spent caregiving for their parents. Thus, the "women in the middle" of two families often experience much stress (Brody, 1981; Horowitz, 1985).

It was mentioned above that women tend to be the primary caregivers both of children and of their chronically ill parents; this was not meant to imply that these two roles are necessarily similar. Recently, there has been much discussion about "role reversal" in parent-child relationships. Many adult children report anxiety and awkwardness in caring for their parents. However, it has been noted that adult children cannot truly become parents to their parents, since a debilitating disease such as AD still cannot return a person to earlier levels of physical and mental development (Shaw, 1987; Brody, 1974). Perhaps it is more accurate to think of adult caregiving as an additional role or to consider it part of a role conflict. Whatever the case, it certainly cannot be denied that caring for a parent with AD can be a difficult experience.

Caregiving can lead to significant burden for many adult children. Robinson (1983) and Zarit et al. (1980) have found that the caregiver burden for adult children is similar in degree to the caregiver burden of AD victims' spouses. George et al. (1986) have found that adult children experience significant burden but not as much as caregiving spouses. Factors such as physical health and support systems may mitigate some of the burden for adult children in comparison to spouses of those with AD (Cantor, 1983). Nevertheless, the burden is often substantial and sometimes leads to depression and marital difficulties for

adult children. Grandchildren also may develop problem behaviors (Cohen et al., 1986). In addition, many adult children not directly involved in caregiving due to geographical distance (or other reasons) tend to experience guilt and strain - particularly if they are in conflict with siblings involved in caregiving (Schoonover et al., 1988).

When adult offspring are involved in AD cases, the importance of these family members should not be underestimated. Serving as a bridge between generations, their ability to cope with the ramifications of the disease impacts on the current and future generations of their families. The role of adult children will be discussed again when intervention issues are considered.

The Roles of Other Family Members

Thought it is true that spouses and adult children of AD victims are most likely to be involved in caregiving functions, other relatives frequently play direct or indirect roles in caregiving. Siblings and grandchildren of those with AD sometimes contribute to the caregiving process. Also, in-laws are involved quite often.

The most likely in-law to be involved in caregiving is the daughter-in-law. In Palo Stoller's study of 1983, daughters-in-law were reported to be active in caregiving in about 5% of the cases and sons-in-law in about 3% of the cases. Although there is little research on the impact AD and caregiving have on in-laws, it has been suggested that

the involvement of in-laws tends to introduce additional factors to be considered in families' interaction. For example, there may be value differences between the daughter-in-law and her spouse with respect to caregiving. The daughter-in-law may believe that her career goals and immediate family should be given priority, or she may believe that her husband is underinvolved in caregiving (Hooyman et al., 1986). Other potential sources of conflict include divergent perceptions about the AD victim's level of functioning and lack of affection between parents and their children-in-law. On the other hand, in-laws can provide valuable caregiving and support. They may set aside more time for their children so that their spouses can perform caregiving functions for parents.

Siblings of AD victims can be of value in caregiving as well. On occasion, they are the primary caregivers; this is likely when or if the victim's spouse passes away and there are no adult children. Although caregiving siblings are often included in caregiving studies (e.g. Pratt et al., 1985; George et al., 1986), few studies have focused specifically on their experiences. Indications are that though they may not face as significant a burden as the spouses of AD victims, siblings are not immune from caregiver burden (George et al., 1986). Besides dealing with the decline in functioning of those they've known nearly all their lives, siblings and their spouses are

typically aging as well. Occasionally, longstanding problems in the sibling subsystem can surface and negatively influence relationships and caregiving (Kirschner, 1985). These difficulties may not be easily resolved.

The relationships of AD victims and their grandchildren certainly span fewer years than the typical bond between older siblings. But the AD victim's relationships with her or his grandchildren can be important as well. These relationships can be just as positive as those of most grandparents and grandchildren (Cohen et al., 1986). Although grandparents do tend to expect assistance from their grandchildren when the former are in need, grandparents derive the greatest satisfaction from simply interacting with their grandchildren (Kivett, 1985). Younger children can show much sensitivity while being with grandparents who have AD. With regard to teenagers, some adolescents do tend to withdraw from their grandparent, but many exhibit concern and assist with certain caregiving activities (Mace et al., 1981). Grandchildren who are not yet adult age do need guidance from their parents about the disease, since children can also be negatively affected by AD (Hooyman et al., 1986).

It is clear that AD can have a substantial impact on nuclear families as well as extended families. One can envision its onset as having a sort of ripple effect on the entire family - with those closest experiencing the brunt of

its immediacy. However, it is also important to recognize that each family will respond in its own unique manner, and each family's responses will depend on its particular structure and coping mechanisms.

The Family System

When considering the roles of various family members, it needs to be kept in mind that the ways in which roles develop and change is partly a function of the interaction of family members. Role adjustments usually occur when one or more family members lose or gain the capacity to perform certain functions. The role of each family member cannot be viewed in a vacuum. With regard to AD, the role of the person with the disease certainly cannot be viewed in a vacuum. In particular, the behavioral symptoms of persons with AD should be examined in the context of their families.

Although many authors and researchers have aptly considered AD a family problem, few have noted the possibility that certain family interaction patterns may exacerbate the behavioral symptoms of AD. For example, the degree to which a person with AD evidence paranoid ideation may be partly due to certain features of family communication, such as overly rigid boundaries. Also, it may be that in some cases family members' shared perception of the symptoms is flawed and misguided. Memory loss and repetitive behavior may be misconstrued as volitional for too long a time - especially in more dysfunctional families.

This can promote unnecessary hostility and conflict (Zarit et al., 1985). Just as it may benefit to consider the past "habits" of the victim (Shomaker, 1987), it may be helpful to consider past and present family interaction problems.

There has been little research concerning the possibility that interpersonal problems in the family increase the risk of AD. Nee (1985) has described a Canadian study indicating that 75% of AD patients had been in either a severely dysfunctional family of origin or a previously dysfunctional marriage. However, the sample size of this study was small, and apparently, larger studies have not been conducted. Although it may be possible that family dysfunction increases the risk of AD for an older, more "vulnerable" person, the main suggestion here is that previously dysfunctional families have a more difficult time coping with Alzheimer's disease than healthy families.

It may be unlikely that families with one or more AD victims have more longstanding communication problems than families in the general population. In fact, the bulk of evidence from caregiving studies seems to suggest that families of those with AD show a good deal of strength and resilience. On the other hand, there is evidence that some of these families experience significant dysfunction in terms of troubled relationships and symptomatic behavior among one or more persons other than the AD victims themselves. Although there is a need for research in this

area of family functioning and AD, the assumption here is that a small proportion of families with AD victims have longstanding dysfunction, and a nearly equivalent proportion of families in the general population have longstanding dysfunction.

Given that most of the families affected by AD are basically healthy and some are dysfunctional, it does not necessarily follow that families will react to the disease in accordance with their level of functioning. For example, a supposedly dysfunctional family which tends toward disengagement may pull together surprisingly well in response to the onset of AD. Conversely, a healthy family accustomed to few significant problems may essentially collapse when confronting the disease. Though these scenarios are probably the exceptions rather than the norm, they point to another major factor that may need to be considered. This factor is the manner in which a particular family deals with a crisis situation.

Although systems conceptualizations of families with AD victims have not been numerous, a few authors have utilized systems perspectives in describing the crises these families encounter. For example, Bonder (1986) has noted that onset of the disease disrupts the organization of a family. New roles and responsibilities can be unfamiliar and uncomfortable for family members; wholeness is affected since the AD victim eventually loses the capacity to

function adequately. The usual feedback mechanisms that involve certain interactional patterns are altered. The fact that the symptoms of the disease can be highly unpredictable creates a lack of homeostasis and diminished control. This lack of homeostasis and control can affect family relationships as well as induce anxiety in each family member. If the family does not act to change this process, more severe difficulties may develop.

A more comprehensive family systems and crisis model has been presented by Famighetti (1986). Utilizing aspects of family developmental theory, Famighetti has applied the Double ABCX crisis model (McCubbin et al., 1983), to processes typically encountered by families with Alzheimer's victims. The developmental stage of the family needs to be kept in mind when considering variables such as support networks and family restructuring. Other variables that also need to be taken into account are: the family's prior experience with stressful situations, the family members' caregiving availability, and the duration of the disease. It is posited that families with AD victims proceed through several stages in coping with the impact of the disease.

In the first of the five stages experienced by these families, members deal with the initial symptoms of the disease. There tends to be a collective family resistance as the family tries to make adjustments without major changes in the family's interaction patterns. The family's

prior strains affect its ability to adjust. As the second stage develops, family resistance continues - mainly in the form of denial. However, at least one family member engages in seeking information and resources. The family starts to define the crisis and makes some decisions about managing problems. The third stage is characterized as the "exhaustion stage." The family experiences internal exhaustion while realizing that its coping system is not adequate enough to meet the family's need for cohesion. Thus, the family begins to restructure and to readjust its roles. This appears to be a critical stage in the family's adjustment to the disease. In the next stage, the family moves toward homeostasis if it has restructured in a functional manner. However, this family consolidation process is challenged by the imminent need to institutionalize the member with AD because of her or his declining health. Among the factors involved in the consideration of institutional placement are adequate resources, shared definition, and the primary caregiver's health. The final stage of this model is termed "family adjustment." The family's resolution of the crisis depends on its adjustment to the institutionalization of the member with AD.

Although Famighetti's model includes a useful analysis of the multiple crises typically confronted by families affected by AD, it does appear to have a few weaknesses.

For example, there is a tendency toward overgeneralization in assuming that each family follows the same trajectory. It may be that in some families institutionalization takes place at an earlier point; it may not occur at all in other families. Another weakness of the model is that it has little description of what occurs when families do not adjust well to a stage. Also, there seems to be an assumption that all members of the family repeatedly respond in the same way; there needs to be more recognition of individual differences. On the other hand, Famighetti's model is noteworthy in that it features two major family theories effectively applied to a problem area which only recently has been considered a family matter. This model will be addressed again here when intervention issues are discussed.

In research on Alzheimer's disease and family interaction, Scott et al. (1985) also have applied McCubbin and Patterson's Double ABCX Model. Scott et al. have noted that the A factor in the model, pile-up of stressors, may be especially salient in situations involving AD. These stressors can include the reemergence of unresolved prior conflicts, normative transitions of family members, and disagreement about care of the member with AD. The B factor, family resources, is relevant when viewing the family's ability to cope with the disease. The C factor, which includes the family's definition of the crises,

involves elements such as family members' shared perspective of the crisis situation. In interviews with caregivers and other family members, Scott et al. have found that common stressor - provoking conflicts are: frequency of visiting the member with AD, treatment of the member with AD by other family members, certain family members doubting the illness, and certain family members feeling overburdened. These conflicts are frequently covert. Some families avoid conflict, while others handle conflict by communicating directly. When family members are congruent in their perception of family problems, there is more coping effectiveness and less burden.

In a related study, Scott et al. (1986) have found that primary caregivers report more burden when there is inadequate family support. Based on an analysis of family interaction patterns, these researchers have described five family support styles. A cohesive family style is the most common; this style is characterized by adequate instrumental support and positive affect. (In this study, instrumental support is defined as forms of help such as physical care and financial assistance. Social-emotional support is defined as the degree of positive affect and negative affect expressed by family members). According to Scott et al., the second most common support style is the divided style. This family coping style evidences a moderate degree of positive affect and a moderate degree of negative affect.

In other words, caregivers in these families receive some positive support but also experience problems with support from other family members. Another support style is termed detached style. This style is characterized by low positive affect, low negative affect, and adequate instrumental support. Caregivers in these families receive little emotional support, but this is not viewed as problematic in the eyes of caregivers or other family members. An intense style is characterized by high levels of both positive and negative affect. These families have highly supportive family members as well as members whom caregivers do not view as supportive. Finally, the conflicted style of family support is evidence by low positive affect and high negative affect. Scott et al. do not elaborate on this support style. Their study seems to show that about 70% of the families had a cohesive support style. In the other families, it may be that certain styles of communication are as ineffective in coping with AD as they are in confronting more normative transitions.

The coping styles described by Scott et al. in the 1986 study noted above seem to approximate family clinicians' analysis of the structural characteristics of some families (e.g. Minuchin, 1974). For example, Scott et al.'s description of the intense support style might be found in family systems described as enmeshed. Also, the detached coping style could be found in disengaged family systems.

The assessment of families' subsystems and boundaries can be helpful in determining how families might respond to crises. However, it should be kept in mind that the development of AD is a distinctly non-normative stressor which can and usually does change the manner in which family members interact. For example, it has been noted that a disengagement process often occurs between those with AD and their spouses (Cohen et al., 1986). The spouses (as well as some AD victims) realize that verbal communication is more difficult than it once was and will become even more difficult in the future. In addition, the boundaries between spouses and between the couple and their adult children sometimes can become ambiguous as the disease progresses. Therefore, assessment of these families should take into account families' responses to the disease progression as well as families' prior history of functioning.

Assessment of families with an AD victim might also include an analysis of caregiver burden. It is typical for the primary caregiver to be somewhat overburdened. However, if this burden reaches extremely high levels for an extended period of time, the burden may be a symptom of a dysfunctional family system. For example, a wife may take over virtually all caregiving tasks because conflict about care is bringing about deteriorating relationships with her adult children. She comes to believe that her children have

abandoned her, while the children believe that their mother has assumed the role of "martyr." This can create an unusual situation in which the primary caregiver becomes the "identified patient" despite the presence of the member with AD. Clearly, the family system is not functioning as well as it could be. Thus, the primary caregiver's level of burden may be an important indicator for use in family assessment and intervention.

The studies of family interaction and caregiver burden seem to provide some implications for helping professionals. One apparent implication is that some families with AD victims have more difficulty in dealing with the multiple crises of the disease than do other families. It is quite likely that the more troubled families need professional assistance of some kind. Although there needs to be more definitive data on the matter, it also may be that families with a history of dysfunction tend to have more difficulty coping with the disease than previously functional families.

It is clear that whether or not families have prior dysfunction, the onset of AD activates the potential for numerous problems in families. Some families remain resilient and need little outside assistance. Other families turn to various forms of outside help which will be discussed now.

Helping Options for Families of AD Victims

Families impacted by AD usually experience repeated crises. These families differ in the ways they respond to the crises. Usually at least one family member eventually seeks outside support.

There are a number of helping options available to family members. The focus here will be on four common sources of intervention and support: individual counseling, support groups, family meetings, and family therapy. Although there are other types of support available (e.g. religious), the four sources noted above appear to be the most frequently utilized and described. The amount of information and research on each of these sources varies as well. For instance, there is quite a substantial amount of research on AD support groups but very little research on family therapy and individual counseling specific to AD problems. With this noted, the following is a description of these particular methods of intervention and support.

Individual Counseling

Most accounts of individual counseling regarding AD matters center on the primary caregiver. Because AD can have such a profound impact on the life of the primary caregiver, she or he frequently experiences a wide range of intense feelings and thoughts. Anger, guilt, and frustration are among the feelings expressed frequently by

primary caregivers. There may be thoughts of physical abuse, suicide, or even homicide. Often, caregivers who seek counseling believe they have lost control of their situations. They may have difficulty dealing with hostile or seemingly irrational outbursts by those with AD, for example. Caregivers may feel overwhelmed in struggling to provide care as well as handling their other daily functions.

It has been suggested that while individual counseling of caregivers should involve empathic listening, counseling should focus on enhancing problem solving (Zarit et al., 1985). Both support and education can help the caregiver to improve problem solving skills. Also, helping the caregiver to view the AD victim's behavior from a different perspective (i.e. reframing) may increase the caregiver's tolerance and understanding. It is important that caregivers recognize their own needs as well as respect the individuality of those with AD.

Individual counseling also may be effective for the AD victims themselves. With the onset of the disease, these persons can often experience intense shame, anger, and frustration. They may become depressed and express suicidal intentions. They may have difficulty adjusting to increased dependency. Those in the early stages of the disease may respond well to a counseling approach that offers support and encouragement (Cohen et al., 1986). As the disease

progresses, verbal and attentional skills do deteriorate; this tends to limit the effectiveness of counseling efforts.

Individual counseling may not prove helpful if there are significant communication problems in the family. Conflict about caregiving or more longstanding relationship problems might be resolved more readily through family meetings or family therapy. Family members also have the option of joining an AD support group.

Support Groups

In the last decade there has been a proliferation of Alzheimer's support groups for relatives of those with AD. Through local chapters of the Alzheimer's Disease and Related Disorders Association (ADRDA), a national organization, family members can obtain information about the logistics of support group meetings in their community or nearby cities. Accompanying the growth in number of these support groups has been the realization and recognition of the disease's impact on families and support networks.

The AD support group has become the most common modality in aiding families of AD victims (Wright et al., 1987; Wasow, 1986). Not surprisingly, information and research in this area is far more prevalent than among the other AD intervention and support options. The following is a description of the variability in logistics, process, and outcomes of these particular support groups.

Although each support group has its own rules regarding the location, duration, and frequently of meetings, the logistical aspects of these groups tend to be similar. Most groups take place in a hospital or nursing home setting. Other settings include community agencies and universities. The length of individual meetings typically ranges from one to two hours (Glosser et al., 1985; Barnes et al., 1981). The frequency of meetings ranges from weekly to monthly (Wright et al., 1987; Steuer, 1984). Some groups are ongoing and open-ended, while other groups meet for a certain period of time (e.g. eight weeks). Ongoing groups are more likely to meet biweekly or monthly, while time-limited groups usually meet weekly or every other week (Glosser et al., 1985; Steuer & Clark, 1982).

A more important aspect of the "basics" of group meetings is the composition of the group itself. The typical and perhaps ideal size of a group is seven to ten members. However, the size of a group at any one time can range from two to twenty or more (Steuer, 1984). Also, there is some evidence that groups are more effective when the members have similar relationships to AD victims. For instance, a group composed of AD victims' spouses appears to work better than a group composed of spouses, adult children, and siblings of those with AD (Wasow, 1986; Steuer et al., 1982).

With regard to the structure of group process, there also appear to be some indicators for increased group effectiveness, though there is more debate about these issues. Highly structured groups tend to be didactic in scope; the emphasis is on imparting information about AD and its effects. Groups that tend to be unstructured focus on expression of feelings and mutual support. Many group facilitators utilize these two approaches sequentially or attempt to combine them. Often, a consideration of the effectiveness of these approaches is supplemented by factors such as the duration of the group and the timing of group membership. For example, Steuer et al. (1982) found that unstructured, time-limited, and closed groups promoted more cohesiveness and mutual support than didactic, structured, and open-ended groups did. Meanwhile, Shibal-Champagne et al. (1986) utilized several approaches and found that a structured and time-limited approach was most effective in creating mutual support and increasing members' coping skills. On the other hand, Schmidt and Keyes (1985) found that an unstructured and time-limited approach was especially effective in promoting group cohesiveness. Thus, one common finding appears to be that time-limited meetings are more effective than ongoing meetings.

The group process approach used by Schmidt and Keyes revealed another important issue. When these facilitators employed an active psychotherapy approach instead of a

supportive but nontherapeutic approach, group cohesion and mutual support were a good deal greater. Typically, AD support groups are not geared toward a focus on expression of painful emotions; Schmidt and Keyes suggested that it is common for there to be a group defense against such expression of feelings. Support group leaders rarely confront this group defense. For example, Barnes et al. (1981) stated that a focus on the expression of negative feelings would make many group members even more depressed. Lazarus et al. (1981) came to a similar conclusion. This was disputed by Schmidt et al., who claimed that empathy and individual growth were maximized when group members were encouraged to express the intense feelings they were experiencing.

Others have addressed the appropriateness of providing group therapy to caregivers. In conducting a study involving caregivers' perceptions of their support group experiences, Wright et al. (1987) have found that while caregivers valued group factors such as universality and group cohesiveness, they tended to not value the group factor of expressing feelings. Even so, nearly 80% of the caregivers reported that their groups had been helpful or very helpful in providing emotional support. In reviewing studies on coping and caregiver support groups, Wasow (1986) has suggested that group leaders and group members need to consider the effects of ventilation of feelings. Some group

members may come to value shared expression of feelings, while others may find this depressing or aversive. Group facilitators should make it clear whether the group meetings will focus on expression of feelings, and perhaps the development of more therapy-oriented groups for caregivers can give these individuals an additional option to select.

Most studies of support group outcomes also have focused on the reports of caregivers and other relatives who have participated in groups. As noted above, support group participants often report that certain aspects of group meetings are more positive than others. Glosser et al. (1985) found that the information provided about the medical aspects and management of the AD symptoms was rated as very helpful by participants. Of seventeen factors, the factor effect rated as least helpful to the participants' situations was the resolution of family conflict. Therefore, support group participation apparently did not help to reduce conflict in the participants' families. Kahan et al. (1985) conducted a controlled study and found that group participants did report reduced levels of burden and depression when compared to a group receiving no treatment. However, a controlled study by Haley et al. (1987) indicated that although support group participants found the education and mutual support to be helpful, there were no significant differences between group members and waiting list controls with regard to level of life

satisfaction, degree of social support, or level of depression.

Although there is a need for more controlled studies and systematic evaluation in terms of support group outcomes, certain themes appear to have emerged from previous studies. One theme is that certain factors are important in promoting the effectiveness of support groups. It appears that groups composed of persons similarly related to AD victims (e.g. spouses) and groups that are time-limited tend to be especially effective in creating mutual support. Another consistent theme is that while most persons who participate in AD support groups have positive experiences, the support groups have little or no effect on certain aspects of these persons' life situations. In particular, family communication problems may not be resolved through participation in AD support groups. It is frequently noted that some support group participants might also benefit from family meetings or family therapy.

While support groups remain the primary modality in helping relatives of AD victims, it is obvious that other helping options also need to be considered. Family meetings and family therapy are examples of alternative sources of support and intervention.

Family Meetings

The use of family meetings is a support option for families of those with AD. Although family meetings have

not been emphasized a great deal in the literature on AD and families, it has been noted that meetings can be valuable in some situations. Guidelines have been suggested in relation to various aspects of family meetings.

For the most part, the focus of family meetings is on the identification and resolution of problems related to AD and caregiving. Family meetings can help to foster the recognition that family members need to "pull together" in order to cope with the numerous crises they are likely to confront. Although meetings often include the provision of emotional support for and among family members, emphasis is usually on the facilitation of an objective appraisal by family members as to the delineation of tasks and functions they need to perform (Hooyman et al., 1986; Mace et al., 1981). In addition to improving problem solving skills, family members can attempt to anticipate and prevent some problems that are common in families with AD victims. The leader of family meetings does not give advice to families but does collaborate with family members to assess and resolve specific problems.

Though there may be some overlap between the role of family meeting leaders and that of family therapists, there are some notable differences. Family meeting leaders may find it helpful to assess the structural characteristics of the families they see, but they do not seek to change the structures of these families. Unless there is evidence of

severe family dysfunction, leaders work with the existing family structure and attempt to "go with the flow." There is an assumption that families have been functional and do have the capability to cope with crises that arise. If this is not the case, the family can be referred to a family therapist. Some conflict among family members is to be expected and can be dealt with, but the purpose of the meetings is not to enhance conflict management skills. However, leaders of family meetings may tend to educate more initially than do family therapists; examples of this might include providing information about recent advances in AD research or acquainting families with various community resources.

As to the question of who should lead family meetings, it may be that a geriatric social worker has better qualifications than most. This individual typically is aware of the various components of AD and is knowledgeable about community resources. However, other professionals can be effective leaders as well. A physician who is sensitive to family matters can be of value - especially in the early stages of the disease. A nurse could be helpful as well. Psychologists, family therapists, and educators with substantive knowledge about AD can be effective leaders of family meetings. Knowledge of family interaction or group process issues is clearly advantageous.

Related to the question of who should lead family meetings is the question of where the meetings should be

held. Zarit et al. (1985) have noted that family meetings seem to be more constructive when they are held in the home of a family member. This is usually more comfortable for family members and reinforces the notion that the family is not in need of therapy. However, caution should be taken when the leader and family choose a location. Splits and alliances among family members may lead to the exclusion of certain relatives (Hooyman et al., 1986).

It is important to consider which family members should attend family meetings. Mace et al. (1981) have suggested that all members of the family should be invited. Hooyman et al. (1986) have stated that it may be helpful to invite members with peripheral roles in order to activate their interest and to obtain more information about the family's dynamics. However, Zarit et al. (1985) have suggested that the primary caregiver decide which family members should be invited to attend. Regarding attendance by the member with AD, both Hooyman et al. and Zarit et al. have noted that this would depend on the agenda of family members. For instance, if family members are concerned with the demanding behavior of the member with AD, it may be advantageous for her or him to attend so that all members can attempt to recognize each other's limits.

Suggestions regarding the process of family meetings have been presented. Mace et al. believe it is important to focus on practical aspects such as financial concerns and

inheritance as well as caregiving tasks. Potential changes such as institutionalization should be discussed in the early stages of the disease. Zarit et al. (1985) stress that meeting leaders should assess the family's interaction and problem solving patterns, facilitate identification of obvious and "hidden" problems related to the disease effects, and support or augment the family's problem solving process through reaffirmation or encouragement of alternative suggestions. It is important that the family use its available resources; for example, there should be a reasonably equitable distribution of caregiving tasks. Hooyman et al. outline three phases of the meetings they lead. In the first phase, family members focus on concrete problems by writing wish lists. After all members discuss their wish lists, the stage of negotiation and compromise takes place. This leads to the final phase involving the development of a written family plan. This plan includes caregiving tasks as well as other family duties. Finally, Fabisewski et al. (1986) have presented a model for meetings of families that have an institutionalized member with AD. These meetings focus on medical information and emotional support for family members. They differ from the meetings described by the other authors above in that Fabisewski et al. provide ongoing, periodic meetings. Family meetings usually have been considered as "one time" occurrences with suggestions for follow-up.

Since family meetings are not usually documented as ongoing, there appear to be no outcome studies of their effectiveness. Since clinical evidence has indicated that family meetings can be of benefit, perhaps these meetings should be ongoing in some situations. This suggestion will be expanded upon in the final section of this report. However, it needs to be noted that not all families benefit from such meetings (Hooyman et al., 1986). In particular, meetings with severely conflicted families can be troublesome. Family therapy may be necessary for some families of persons with AD.

Family Therapy

Although family therapy is occasionally used with families affected by AD, this type of intervention appears to be used less frequently than individual counseling or self-help support groups. The low usage of family therapy may be due to therapists' assumptions that there is little hope for positive change because of the disease process, or it may be due to little awareness of the impact a disease such as AD has on families (Lansky, 1984). The victim's irreversible pathology does not suggest irreversible problems in functioning of her or his family.

It has been suggested that family therapy can aid in reducing the severity of dementia symptoms (Pasnau et al., 1981). In some cases, the family's interaction may accelerate or exacerbate problems related to AD. For

example, dysfunctional interaction may increase the probability of agitation or depression; this may lead to premature institutionalization. Common problems in dysfunctional families affected by dementia include: ignorance and denial of the disease, irrational role assignments, failure of integration, retardation of maturation, intensification of pre-existing family issues, and misestimation of the AD victims' level of passivity (Lansky, 1984). The emergence of one or more of these problems may warrant family intervention.

Some intervention techniques have been suggested in order to deal with these family problems. Pasnau et al. have proposed the following sequence of therapy functions: empathic sharing, family history, reassessment of problems, and negotiation. These authors also stress the importance of medication in the management of symptoms. Other techniques have been drawn from intergenerational therapy. These include the rebalancing of priorities in dealing with loyalty conflicts and the restructuring of parent - adult child relationships (Shaw, 1987). There is little data on the effectiveness of these techniques when they are applied to AD cases.

Family therapy is one of the important sources of intervention and support for families affected by AD. Unfortunately, it appears as though family therapy is among the resources that have been underemphasized and

underutilized in helping these families. In addition, there has been a profound lack in coordination of services provided for families with AD victims. These problem areas will now be addressed, and possible solutions will be presented.

Models of Service Provision

It seems as though the treatment of "older families" is the last frontier of family intervention. Despite the growth of the family therapy movement and the emerging awareness of the impact that various age-related diseases have on families, there has been only a minimal increase in provision of services to these families. The lack of intervention for older families perhaps can be attributed to the "myth of family alienation" (Greene, 1986). This is the belief that older persons live on their own and have little or no connection with other family members. This myth has been perpetuated by some helping professionals whose clients have tended to be somewhat isolated from their families (Shanas, 1979). These observations have obscured the fact that about 80% of older people have living children, and many of the others have living spouses or siblings. For impaired older persons, the major source of social support continues to be other family members (Brody, 1981). If this support is deficient despite the presence of other family members, some type of family intervention might be indicated. Similarly, if caregivers are not receiving sufficient family support, professional support or intervention might be helpful.

Curiously, even though family support appears to be the most salient factor in predicting caregiver burden, the predominant modality of intervention with families of AD

victims continues to be the community support group. Although these support groups seem to have some redeeming value, they do not appear to aid in promoting family support. In fact, if only one family member (e.g. primary caregiver) attends support group meetings, it may be that family conflict increases because of the potential for disparity in knowledge about AD. It seems important, then, that family intervention be used in conjunction with (or in lieu of) support groups.

Zarit et al. (1985) have presented a comprehensive model of intervention combining individual counseling, community support groups, and family meetings for those families affected by AD. The main source of intervention in this model is individual counseling for the primary caregivers; the first stage of the intervention process primarily involves this modality. After several sessions of individual counseling, a family meeting is usually conducted. According to Zarit et al., the family meeting is often needed when individual counseling of the primary caregiver ceases to be productive. After the family meeting is held, the primary caregiver joins a support group while usually continuing to attend individual counseling sessions. It is noted that although there are occasional variations in this process, the typical pattern of intervention is the one described above. Although Zarit et al. provide no outcome

data, they suggest that this intervention process is usually effective in helping caregivers.

Since Zarit et al.'s model is unique in its multiple intervention approach to helping families with AD victims, their proposal warrants some careful consideration. Zarit et al. do appear to recognize that family interaction variables need to be taken into account in the assessment and intervention of these families. Their use of the family meeting is an acknowledgment of family environment factors. However, when one views the scope of their model, the timing and the limited use of the family meeting can be called into question. Since the family meeting is typically not held until several sessions of individual counseling of the primary caregiver are completed, it is possible that family communication difficulties may be unnecessarily promoted before the family meeting is held. Indeed, Zarit et al. imply that family system factors often act to sabotage or hinder the effectiveness of the individual counseling process. It may be that the coping support and information gained by the primary caregiver through individual counseling is positive feedback which creates a disparity between the cognitive resources of the primary caregiver and those of other family members. This may promote more family conflict. If there is an increase in family conflict, it is unlikely that one family meeting can sufficiently deal with emerging problems. After the family

meeting is held, referral of the primary caregiver to a support group or continued individual counseling seems to skirt the resolution of family problems.

In a broader context, Zarit et al. essentially take a psychodynamic approach to the resolution of what many consider a family dilemma. With the emphasis on individual counseling, the primary caregiver is basically the "identified patient" of the family. An apparent assumption is that once the primary caregiver is "fixed," then family functioning will improve. While it is important to recognize that the primary caregiver role is very significant in families affected by AD, the reciprocity of roles must be considered as well. Changes in the resources and behavior of a family member are likely to have an impact on the interaction of all family members; seemingly positive changes can have a negative impact. Consequently, it is important to emphasize family interaction factors and to implement some sort of ongoing family assessment and support process.

Model of Family Support

When there are family problems related to AD, the preferred focus of support or intervention should be on the family unit. Even though individual counseling and community support groups sometimes need to be considered when helping families impacted by AD, it does seem that family meetings and, if applicable, family therapy are the

most appropriate sources of support and intervention. The following is a model that differs quite substantially from Zarit et al.'s proposal in terms of emphasis on particular sources.

In the model presented here, the primary source of support is the family meeting. It is apparent that many families affected by AD can benefit from periodic meetings. Early in the course of the disease, it is especially important that family members become informed about the various aspects of the disease. Family meetings can serve to educate family members and to promote a shared consensus among member as to the condition of the AD victim. Family meetings held early in the course of the disease can be extremely helpful to the meeting leader as well. Assessment of family interaction can give the meeting leader some indication about current and future coping patterns. Families that obviously will not benefit from future meetings can be directed toward alternative resources.

As the disease progresses, families that continue to attend meetings can collaborate with the meeting leader in attempts to solve the more practical problems related to AD. The majority of these problems are likely to revolve around the allocation of time and effort to caregiving tasks. If certain families are adept at problem solving, it is unnecessary to focus much on emotional support aspects. However, if certain families are having difficulty in

developing effective solutions to practical problems, it may be advantageous to emphasize emotional support or to consider referring specific members to support groups or individual therapy.

Although it may not be necessary to focus on emotional support in the early stages of the disease course, attention to the expression of feelings may be helpful in the late stages of AD. Family members may be dealing with such AD symptoms as aphasia and agnosia; members can experience painful feelings when the AD victim can no longer speak to or recognize them. In addition, there are feelings of grief and sometimes there are intense feelings of guilt. Family members must begin to consider whether institutional placement is necessary - a consideration that can be emotionally loaded as well. While it is important to have family members express painful feelings, families need to be encouraged to avoid making decisions based on feelings. Problem solving should continue to be practical and focused on concrete items. The appropriate expression of feelings is unlikely to hinder this problem solving process.

Although it is assumed here that the family meeting is the most propitious option to use in resolving family problems, sometimes other sources of intervention and support are necessary. For example, referral to support groups or individual counseling should be made when it is obvious that family meetings are more harmful than helpful.

Also, it is important to consider the timing of referral. In the early stages of the disease, the use of individual counseling or support groups should be minimized in order to emphasize family cohesion; family therapy may be a more viable option during this period. In later stages, all options should be taken into account if family meetings are not effective.

With regard to the timing or frequency of family meetings, the particular family situation needs to be considered. A reasonably functional family with adequate problem solving abilities probably does not need to meet with the leader more often than bimonthly or even quarterly. A less adaptive family may have to meet monthly. More frequent meetings may induce termination or create an overly therapeutic environment. If meetings are held too infrequently, the support process may seem superficial.

Another logistical matter to be considered is the setting of the meetings. Multiple family meetings may allow the facilitator(s) to be more strategic in planning meeting locations than is possible when only one meeting is held. For example, family members who are marginally involved in the caregiving process could be given opportunities to host family meetings. If the facilitator believes that a neutral site would be advantageous for one or two meetings, the facilitator's office could be utilized. Of course, decisions about meeting sites need to be made in

collaboration with family members. Perhaps a certain cautious flexibility should be employed in choosing meeting sites in order to avoid exacerbating any splits in the family.

As to the question of which family members should be invited to the meetings, it may be helpful to initially contact as many members as possible. Although members should be informed that the meetings may be held on an ongoing basis, it could be communicated that the first meeting is especially important. The AD victim should be invited if family members are comfortable with her or his presence at meetings. If family members are agreeable to having a caregiving friend or neighbor attend, this person should also be invited. Members who do not attend but seem to be important in the family support process should be intermittently encouraged to attend. Clearly, family system factors need to be noted when inviting persons to the meetings.

Family process factors will now be emphasized as the proposed model is explicated. This model follows a stage approach which expands on Famighetti's conceptualization of the coping processes common to families affected by AD. Unlike Famighetti's model, this model will focus on support and intervention themes.

As noted earlier, Famighetti (1986) has proposed a model describing the coping process of families influenced

by AD. The crux of his model consists of the pre-crisis phase and the four stages involving crises: diagnosis and early progress of the disease (characterized by family resistance), exhaustion stage, family consolidation, and family adjustment. Although Famighetti has noted that this model could be applied to family intervention issues, he has offered few suggestions as to how this could be done. The model proposed here includes some incorporation of Famighetti's theoretical postulates into a process of family support and intervention.

In Famighetti's model, the period before diagnosis is termed the pre-crisis phase. During this period the symptoms of AD gradually become evident. Families may deal with the onset of these symptoms in different ways. Some families may engage in an active denial process; they may attribute the behavioral changes of the member with AD to aging or to her or his personality traits. Even when these families become aware that something is significantly wrong, they may minimize or "cover up" the AD symptoms. This can be viewed as a resistance to change that does not necessarily signal a dysfunctional system but may indicate how the family copes with future crises. Meanwhile, other families may respond to the ambiguous symptoms of AD in a calm but concerned manner. They become well aware of the AD victims' behavioral changes and take appropriate measures to identify the reasons for these changes. These families may

deal with future crises in a similar manner. The two family response styles noted above may reflect how families have dealt with non-normative stressors in the past; families with a history of non-normative stressors may follow previous coping patterns. It may be harder to predict the coping styles of families with no prior non-normative transitions.

Although families tend to have certain coping styles, individual family members may differ in their responses to the onset of AD. Variations in family members' responses may create a good deal of conflict even in supposedly nonconflicted families. For example, certain family members may downplay the AD symptoms and oppose evaluations by specialists, whereas other family members may respond by advocating immediate evaluations. This conflict may continue for an extended period of time. The potential for conflict may be higher in the pre-crisis phase than in any other stage of the disease process. Prior difficulties in the family could be renewed and exacerbated by the onset of AD.

Because of the insidiousness and ambiguity of the AD symptoms prior to a definitive diagnosis, certain aspects of support and intervention are not likely to be profitable in the pre-crisis phase. Since the professional may be no more certain about the causes of the AD symptoms than family members are, family sessions may become a forum for

arguments and circular reasoning. Both the identification and solution of problems would be tentative. Family therapy may be counterproductive if splits in the family are mainly due to differing "theories" about the behavioral symptoms. Family members may have little inclination to attend AD support groups if they are not sure a member has AD. Resistance to counseling of any kind may be substantial - especially in families with members who doubt that AD or any other disease is affecting a member of their family.

On the other hand, certain types of support may be helpful for families in the pre-crisis phase. For example, it is important that family members receive accurate information about AD and related diseases. Physicians and nurses may be especially helpful in providing information and in giving family members some indication of potential diagnoses. Even though the diagnostic process can be long and arduous for everyone involved, families need to be encouraged to begin the process as soon as they are aware of significant behavioral changes exhibited by the potential AD victim. If there is conflict about the severity of symptoms, meetings with physicians should be attended by more than just one concerned family member. Otherwise, a family meeting led by a helping professional may be effective in giving members information about potential caregiving issues. It is better for family members to be informed about potentially irrelevant issues than to be uninformed about highly relevant issues.

According to Famighetti's model, the first genuine crisis most of these families encounter comes after the diagnosis of AD. Family members become aware of the major demand they will face in future months and years. In the stage termed diagnosis and early progress of the disease, the typical response of families continues to be one of resistance. This resistance can be manifested in the continued denial of the disease and its impact. Family members' shared definition of what is occurring may be inaccurate or inappropriate. It is often believed that adjustments can be made without significant changes in families' established patterns of interaction. However, at the same time, families search for information about the disease and begin to consider various resources to be used in management of the disease and its effects. Decisions about medical care and day care need to be made. Financial resources become important and obviously vary among families.

The coping styles of families also vary once the disease is diagnosed. Among the factors that may influence family coping styles are families' access to resources, families' preexisting level of functioning, and families' access to accurate information about AD. The practical aspects of managing the disease are affected by the availability of adequate resources. For instance, some families in rural areas may encounter substantial hardships

in receiving health care or day care services. Also, families' prior strains and typical patterns of interaction cannot be ignored when assessing their coping styles. Previously dysfunctional families may be more likely to exhibit excessively conflicted or detached support styles. Meanwhile, families' access to and interpretation of information about AD are important as well. As Famighetti has noted, family members' shared definition of their situation is largely determined by the accuracy of information obtained about the disease.

In working with families that have members recently diagnosed with AD, helping professionals should emphasize the factors noted above. Family meetings can include the provision of valuable information that increases the probability of consensus among family members as to the condition and the care of the AD victim. The educative aspect minimizes the likelihood that families will make inaccurate appraisals or unwise decisions about evident and potential problems. Family members can learn to anticipate and understand the progressions of symptoms; this may help to increase objectivity and mutual tolerance. With regard to prior level of family functioning, it would be advantageous for helping professionals to obtain an adequate family history. The family history need not be extremely detailed but should include critical events and transitions. This can help the facilitator to assess the family's

flexibility and resilience. Of course, assessment should include observations of the family's current interactional patterns as well. The overall assessment of the family is important in any decision involving referral to alternative resources. For example, families with very diffuse or rigid boundaries and a history of dysfunction can be referred to a family therapist. Finally, it is critical that families are aware of the resources available in the areas where they live. Family meetings can aid in promoting knowledge about existing resources and in developing plans to utilize these resources. Availability of families' resources can be clarified so that community resources are not overused or underused.

As noted earlier, it is important that problem solving focuses on concrete tasks and objective items. This focus is especially important in the initial family meetings so that families learn to avoid making impulsive or irrational decisions. Hooyman et al.'s suggestion that family members formulate a written plan or contract outlining the tasks each member can perform seems to be one way to promote objective problem solving. Although families do need some emotional support in the early stages of AD, a task-oriented approach seems to engender better family functioning early in the course of the caregiving process (Zarit et al., 1986; Hooyman et al., 1986).

An objective approach to problem resolution early on may also minimize family resistance to formal support

options. It has been noted that many relatives of AD victims have a distinct aversion toward therapy of any kind (Winogron, 1987; Wasow, 1986). An emphasis on family relationships or emotional aspects may backfire and increase resistance in some families. In later stages, family resistance to change may decrease as the impact of the disease magnifies.

The severity of AD's effects eventually leads many families to redefine coping patterns and members' roles. Families begin to manifest accommodation rather than the assimilation response that is often exhibited before and just after diagnosis. For the minority of families that is never truly furnished with a definitive diagnosis, the accommodation process may take shape more gradually and subtly. The acknowledgment of severe strain and the subsequent move toward family restructuring characterize the exhaustion stage of the coping process. According to Famighetti, a common signal of this "exhaustion" is a depression which permeates the entire family system. Shared feelings of anticipatory grief gradually engender the acceptance of the disease and its terminal outcome. This acceptance helps to facilitate modifications in coping patterns and role allocation.

If a family has not yet made an active search for external support, it is likely to do so in the exhaustion stage. An increase in family cohesiveness and an

improvement in morale are typical family goals in this stage. Since families are usually in flux during the exhaustion stage, there is a potential for substantial problems. For example, the primary caregiver or another family member may evidence significant depression or behavior problems. Also, with the symptoms of AD typically worsening, behavioral management may become difficult. Once the restructuring process is begun, previously stable families may become increasingly chaotic or rigid. It is likely that families more open toward use of external resources will evidence adaptive restructuring. Again, it seems that family meetings and family therapy may be the preferable helping options for families in this stage.

Assuming that the facilitator has been working with a family in previous stages, support and intervention should not be radically different during the exhaustion stage. However, there may need to be more emphasis on the expression of feelings. At some level, the family must come to terms with the inevitable decline and death of the AD victim. If feelings such as grief and guilt are not acknowledged and expressed, the family may have difficulty in restructuring and in confronting future crises. Mutual expression of feelings may not be as painful at this point because the AD victim is still usually quite healthy in the middle stages of the disease course. With respect to families' attempts at restructuring, it is important that

family members share a consensus about changes in caregiving. This consensus should be based on observable behavior and facts. For example, the spouse of an AD victim may appear to be overloaded in terms of the amount of caregiving tasks she is handling. Despite her denial that she is severely stressed, she appears to be very tired and family members report that recently she has been ill for an extended period of time. It is obvious that some type of task reallocation is necessary, but it cannot be implemented unless the primary caregiver agrees to give up some tasks. It would appear, then, that negotiation and compromise are especially important in this stage of the family coping process.

Although most families are able to restructure through problem solving and compromise, some families may have difficulty doing so for a variety of reasons. Certain families may face an inordinate pile-up of stressors, while others may be going through a troublesome developmental transition. In simple terms, some families may essentially collapse from exhaustion. Family therapy may be necessary to help these families in need of restructuring.

If a family is being seen for the first time and appears to be in the exhaustion stage, it is probable that the family is having problems redefining and restructuring roles and interactional patterns. The facilitator should try to explore how the family has dealt with the disease-

related crises it has encountered. Again, certain families may have adequate problem solving skills but may simply be overloaded with stressors. Other families may need to learn new ways of addressing problems. A coping style that was functional in the early stages of the disease process may become inadequate. Family meetings can help to promote cohesion and morale which may be lowered due to pile-up of stressors or inadequate coping responses. Referral to other sources (e.g. family therapy or support groups) should be considered if family meetings are counterproductive.

Families that achieve cohesiveness through restructuring eventually stabilize to a certain degree. Slight or occasionally significant modifications in family interaction are then measured in light of previously established patterns; family members attempt to share an awareness of the "goodness of fit" between these two components (Hansen & Johnson, 1979). One element of this process is the family's shared awareness about the role of the AD victim. This usually involves the realization that the member with AD can no longer function without the care of others. Relative stability in the family and a shared awareness of members' roles characterize the family consolidation stage. With the awareness of changes in family members' roles and functions, emerging problems are identified in consideration of family stability and congruence factors. New crises often do not seem as severe

due to confrontation of previous crises and the reestablished stability of the family.

A major decision typically made by families in the consolidation stage concerns the institutionalization of AD victims. Influencing the decision to institutionalize are such factors as the availability of resources and the health of primary caregivers. Many families delay institutional placement as long as possible. Sometimes this is done at the cost of the primary caregiver's or family's healthy functioning. If the family has had difficulty reorganizing or dealing with anticipatory grief and guilt, placement can be extremely stressful for family members. Also, if family members are not in congruence about the health and care of the member with AD, conflict may destabilize the family system.

Support and intervention for families in the consolidation stage should focus on maximizing consensus through assessment of resources and, secondarily, encouraging feeling expression about matters related to AD. Families need to determine whether present family and community resources are sufficient to continue home care of the member with AD. The facilitator can help families by clarifying what resource options are available - particularly in regard to community resources. In terms of family resources, the role of the primary caregiver is very important in the assessment process. It is posited here

that in all stages of the coping process - and especially in the consolidation stage - the primary caregiver's mental health is a strong indicator of family functioning. If the family system does not adjust well to the crises it encounters, it is likely that the primary caregiver will experience overburden, depression, or other psychological and physical problems. Poor family adjustment also may increase the probability that other family members (e.g. "secondary caregivers" or young children) will evidence concomitant, if less intense, problems in functioning.

When families are in the process of deciding about institutionalizing AD victims, facilitators should give families a straightforward assessment of the family systems' functioning levels. Families need not agree with this assessment but can take it into account when considering their own situations. If family members disagree with each other about their capability to continue home care of the member with AD, all viewpoints should be respected, and a negotiation process between family members should be initiated.

When families in the consolidation stage are negotiating about caregiving issues, objectivity is not enhanced when personal feelings are ignored or minimized. Because of the increasingly ambiguous role of the family member with AD, families in this stage often seek to "close out" that member's role by acknowledging her or his

psychological absence. This recognition can provoke intense feelings of grief, anger, or guilt. Awareness and expression of these feelings can aid in the anticipatory grief process and can also help to humanize significant conflicts. In addition, feeling expression may help family members to begin maintaining some emotional distance between themselves and the member with AD.

In the consolidation stage, individual counseling or support groups may be of benefit to members in families that are generally stable but are deficient in some sense. For example, a primary caregiver whose family has a shared awareness about most caregiving issues but has a somewhat detached style of interaction may be having feelings of overwhelming grief or guilt. This individual may need additional counseling or group support. It is unlikely that in this stage individual counseling will counteract the process of family meetings. If family meetings are terminated once the member with AD is institutionalized, individual counseling or support groups should meet the needs of specific family members.

In Famighetti's model, the resolution of the crisis involving institutionalization of the AD victim signifies the final stage in the coping process. The family's ability to cope with its decision about placement is a marker of the family adjustment stage. If the family member with AD is institutionalized, the family still faces the potential of

crises. There may be severe financial strain due to the cost of nursing home or hospital care. The family may be dissatisfied with the quality of care in the institution. Certain medical facilities may be unwilling or unequipped to confront the behavioral and physical symptoms of the disease. Although these crises usually do not engender significant family restructuring, they can be highly stressful for family members. Even if a family has few problems related to the institutional placement, it still must confront the decline and death of the AD victim.

Famighetti does not mention that some AD victims are cared for at home up until their deaths. Some individuals may pass away before entering the final stage of the disease. Others may be cared for at home with the assistance of family members and a nursing attendant. It is likely that families of these victims experience numerous problems as well. Perhaps the foremost difficulty is the strain involved when observing the physical and psychological deterioration of a loved one. Also, caregiving tasks can be time-consuming, strenuous, and awkward. Although it is likely that these families' stability and congruence levels are quite high, there is always the potential for conflict about care (e.g. institutional placement). Support from friends, neighbors, and some family members may decrease. Adult children and grandchildren, in particular, may find home care aversive.

Recognition that each family member will have unique coping and grieving responses may be a facilitative approach to support of families in the adjustment stage. Though family members may have a shared meaning or awareness of the AD victim's health and the family's caregiving strategy, each family member will apply her or his meaning to the grieving process based on cognitive and affective responses to personal relationships with the AD victim and other family members. It is important that each family member clarifies and expresses these thoughts and feelings. However, since there is a potential for substantial disparity in the tone and depth of family members' responses, facilitators should be aware of interaction in which certain family members attempt to shame others or change the feelings of others. The probability of such interaction could be minimized if a part of each meeting is set aside for problem resolution.

Since families in the adjustment stage are likely to have years of experience related to health care matters, most of their problems may focus on external support issues. They may be disillusioned or perhaps "burnt out" after struggles with an inadequate health care system. They may be correct in assuming that they know more about AD than most doctors, nurses, and helping professionals. These family viewpoints should be respected and acknowledged. However, the facilitator should avoid being "triangled" into

potentially divisive battles between families and other professionals. Meetings should continue to focus on the objective appraisal and resolution of specific problems. Conflict between family members will continue to arise and take precedence over more abstract problems. Eventually, matters concerning the death of the AD victim will be of prime importance.

The death of the family member with AD may signal the end of most families' need for professional support or intervention. Families that have dealt with anticipatory grief in a forthright and expressive manner may find it unnecessary to attend further family meetings or therapy sessions. Families that do need continued support should be encouraged to continue attending meetings. These families may have difficulty in readjusting roles or in expressing grief appropriately. Perhaps it is more likely that specific family members will seek assistance through counseling or support groups. Whatever the case, the facilitator(s) should keep in touch with these families through meetings or follow-up phone contact.

The continuum of family support and intervention outlined above is designed to coincide with the process of family coping proposed by Famighetti. This model is not a stage-discreet or stage-transitional model. Stage-discreet models do not address how families proceed from one stage of development to the next, while stage-transitional models

ignore possible differences in families before and after transitions. According to Famighetti, a stage-transitional branching model is preferable in describing the coping process of families affected by AD. His model combines elements of typical stage-discreet and stage-transitional models and is intended to address continual changes at various levels of family functioning. Although the stage-transitional branching model is not easily tested empirically, it appears to offer a comprehensive applicability to developmental and clinical processes. The model described here combines Famighetti's concepts with elements of McCubbin and Patterson's Double ABCX Model - a model that focuses on problem solving. It is one approach to the amelioration of the multiple and long-term difficulties often experienced by families with AD victims.

Some comments are necessary about the applicability of the model described above. It is not suggested that this model will meet the needs of all families impacted by AD. It was noted earlier that families with preexisting dysfunction may benefit only from ongoing family therapy. Conversely, very healthy and resilient families may need no formal support or may only utilize the option of AD support groups. Perhaps about half of the families with AD victims meet these two conditions (i.e. dysfunctional or very healthy). The remaining 50% or so of families confronting AD may be relatively functional but have significant

problems in handling the multiple crises typical of AD. These are the families that may benefit the most from periodic family meetings with supplementary use of other helping options.

It should also be noted that though an ideal scenario is that family meetings take place throughout the course of the disease, sometimes the disease course is well over ten years. Numerous factors may diminish the likelihood of such a continuum of support. Even so, a limited number of family meetings may prove beneficial for families that become overloaded while in a particular stage or get "stuck" in a troublesome interaction pattern. Positive effects are likely to occur when these families truly assimilate the process of meetings.

For families choosing to terminate the formal meeting process after only a few sessions, it is hoped that a valuable model is provided for any subsequent family meetings. Functional families should be able to successfully implement their new or modified problem solving techniques if they continue to meet informally; these families should be encouraged to do so. If formal family meetings are not successful, other helping options need to be explored.

An effort has been made here to integrate certain support and intervention options in a manner that takes into account interactional and developmental processes of

families impacted by AD. The efficacy of this particular integration of helping options is partly contingent upon the presence of a coordinated and accessible service delivery system in states and communities.

Coordination of Services

It may be an understatement to say that the delivery of services to families with AD victims has been inadequate. In many respects, this is not surprising since only in the 1980s has AD gained prominence. More people have become informed about the disease, and there has been a concomitant increase in assistance to those affected by AD. However, AD victims and their relatives continue to find numerous roadblocks in their quest for adequate treatment and support. Many states and communities have a glaring lack of services for these families, whereas other areas have delivery systems that are fragmented and ineffective. The state of Kansas is not immune from these problems, according to the Kansas Alzheimer's and Related Diseases Task Force (1986). The following is a comment made just three years ago by a Wichita man whose father had dementia:

"It's the families who need the help. We talked to seventeen attorneys to find one who would accept (our) case. There is no one place or phone number that can answer specific questions. I have been told I am asking questions that no one has ever asked before. If

we do not find a place for Dad, we are going to lose Mom, too. I do not want my kids to have to go through what we have gone through to get help." (Kansas Alzheimer's and Related Diseases Task Force, 1986, p. 26).

With increasing calls for assistance and greater public awareness of AD, some states and communities have begun mobilizing efforts to provide coordinated systems of support for families impacted by AD. Since many of these initiatives have taken form in the last few years, there is little information about their effectiveness. Unfortunately, there seem to be some significant factors working against the probability of short-term (and perhaps long-term) success of these program initiatives. These factors include older persons' underutilization of community services, financial constraints, and prior history of problems in the coordination of services for certain populations.

It does appear that there is an underutilization of community services by the older population. A government study has indicated that only about 3% of eligible older persons use community services (Soldo, 1987). It has been found that the elderly comprise only about 4% of community mental health center clients (Atchley, 1980; Dobelstein, 1985). Reasons for this lack of utilization have been suggested. Krout (1985) has noted that a lack of awareness about programs is a common problem among older persons.

Chappell et al. (1986) have suggested that access to programs is a factor to consider; for example, transportation can be a problem for many older citizens. Wasow (1986) has proposed that a cohort effect may account for AD caregivers' aversion toward formal social support. Services such as support groups and therapy were not particularly evident or popular until the last twenty years or so. It is also possible that older persons have been accustomed to viewing problems in terms of the medical model - a model that dominates perspectives of care delivery. For instance, many caregivers may view formal support needs as evidence of their illnesses.

Another factor that appears to be problematic in the implementation of new services for families impacted by AD is the financial dimension. These families can suffer severe financial strain due to the cost of health care related to AD. Although many of these families may benefit from additional services such as respite care and family therapy, they may not have the resources to pay for such services. From a societal perspective, new programs cost money, and it appears that federal and state budgetary constraints will be substantial in the next few years. This may limit the growth and flexibility of formal support services for families with AD victims.

A third factor that needs to be considered in adding and expanding services is that recent history offers prime

examples of failed attempts to coordinate services among formal care providers and between formal and informal care providers. For instance, in most states deinstitutionalization of the "mentally ill" has been a disastrous process. There has been a lack of coordination between formal service providers and even a greater lack of coordination between these providers and informal support providers. As Chappell et al. (1986) note, there appear to be similar problems in the delivery of services to "disabled" older persons. The lack of coordination (along with other factors) has created a system that overemphasizes formal services in health care matters and underutilizes formal services in social service matters. With regard to families with AD victims, even the delivery of health care services has been hampered by disorganization and incompetence (Bonder, 1986). As noted earlier, there also seem to be problems in the availability and coordination of formal support services for these families.

Despite the troublesome factors noted above, it is likely that more new programs will be implemented in order to serve families impacted by AD. Recent growth in services such as home health care, respite care, and support groups seems to indicate a trend toward greater availability of formal support programs. An increase in the number of services indicates that coordination of services will become more important in future years. A broad proposal concerning

the coordination of formal and informal health care programs and social services is beyond the scope of this report. However, a few comments are in order regarding formal and informal support services.

Although there is general agreement that community support should serve to supplement the informal support of families, friends, and neighbors, it seems that ideas and behavior patterns vary as to the degree of formal support that is necessary to assist those in need. Some believe that formal support should be as minimal as possible (Dobelstein, 1987). Available data suggest that in the U.S., most people - and especially older people - use formal support services as little as possible (Sauer et al., 1985; Chappell et al., 1986). An alternative proposal supported by some is that community support should be appropriate for the population served (Chappell et al.; Silverman, 1981). This view holds that for certain populations, complementarity between formal and informal support systems is vital. It is suggested here that many families impacted by AD need more than the minimum dosage of community support. Unfortunately, it appears as though these families do not use formal support systems as much as may be appropriate. This may change with more education and increased availability of accessible services.

This is not to suggest that the provision of information is a unidirectional process. Professionals have

much to learn from families as well as the converse. The literature on AD is filled with anecdotes describing significant tension between families and formal care providers. An expedient coordination of formal and informal support services cannot occur without collaborative efforts between helping professionals and families impacted by AD. Traditional and authoritarian methods of care provision simply cannot suffice when the multiple crises of AD are confronted.

Long held societal attitudes may need to be modified as well. Hopefully, the somewhat cavalier attitudes of current older generations toward formal support services will not be as prevalent when today's younger generations mature. Similarly, the apparently fashionable viewpoint that equates community services with "welfare" needs to be modified. Perhaps most importantly, it is hoped that the myths and biases directed toward older persons will abate as the older population increases. Education and experience are the keys to changing these nonconstructive attitudes.

It is imperative that federal, state, and municipal policy makers take the initiative in fostering new attitudes toward older persons and in formulating new approaches to the development of cohesive systems of care provision for the older population. It appears that progress in these areas is just beginning. Even so, the plight of families with Alzheimer's disease victims points to the urgency of

solving the many problems faced by the aged and their relatives. These are challenges not only for policy makers but for us all.

Discussion

The presence of Alzheimer's disease can have a substantial impact on families with AD victims. These families typically confront multiple crises which portend numerous challenges to their cohesion and endurance. Phrases such as "the 36-hour day" and "the never-ending funeral" have been used to describe the difficulties these families often encounter in the coping process (Mace & Rabins, 1981). Many families seem to show remarkable resilience and courage in dealing with AD while proceeding with the other aspects of their development. Other families are not as fortunate and experience substantial problems in functioning. Factors such as the shared awareness of problems and role adjustment capability may influence families' coping efficacy. Family members' coping responses also differ and are affected by members' roles and relationships to those with AD and other family members.

Although this report has focused on the interaction of family members, there has been some acknowledgment of specific members' roles. Certainly, the role of the member with AD cannot be minimized. Along with the fact that there are variations in the manifestation of AD symptoms, AD victims evidence differing responses to the disease. Some eventually come to accept the presence of the disease and its consequences, while others express denial or strong negative feelings during much of the disease course.

Behavior related to these feelings is more difficult to deal with among some AD victims than among others. Whatever the case, family members and professionals need to treat these persons with dignity and respect. AD victims' feelings should not be ignored, and their capabilities should not be underestimated. Their hopes and dreams are not unlike those of all persons.

It is likely that one of the foremost hopes of those affected by AD is that a cure for the disease is found. It appears that in this respect, some gains have been made in the last decade. Researchers have a better understanding of AD development, and diagnostic methods have become a bit more efficient. It is still not clear what the causes of the disease are; this means that a cure for the disease is not likely to be formulated in the near future. However, it does appear that treatment of the disease will become more effective in the next decade. Recent studies involving the use of drug combinations have produced encouraging treatment outcomes. Soon, treatment may serve to decrease the magnitude of AD's impact on its victims and their families.

With regard to future research on AD and family interaction, there is also much to be learned. There is a need for more controlled studies based on actual observation of family members' interaction. Past studies have been largely anecdotal or based on the reports of one or two family members. Also, there has been an apparent

overemphasis on the role of primary caregivers. It seems rather trite to convey findings indicating that primary caregivers experience burden. A more systemic orientation may be necessary in order to identify and describe problems related to coping.

It is not yet clear which communication factors are most important to the healthy functioning of families impacted by AD. Conversely, few studies have described the coping patterns of previously dysfunctional families or the characteristics of families that first manifest problems such as physical abuse after AD onset. Knowledge of these families' dynamics may lead to better intervention for families influenced by AD.

Very few outcome studies have been conducted on the utilization of AD-related support and intervention methods other than AD support groups. The model proposed in this report provides a framework to assess the value of ongoing family meetings; this support option may be appropriate for some families with AD victims. A framework is also provided for more family therapy outcome studies. Although most of these families do not need therapy, it is hard to believe that none can benefit from this modality. Also, there is little data on the efficacy of individual counseling, though it appears that counseling of primary caregivers may be counterproductive in certain stages of the family coping process. Finally, more information is needed about the

provision of support to AD victims. It has been noted that in some communities there are support groups for AD victims (Ory et al., 1985), but it is not known if these support groups are of much benefit. Perhaps as awareness of AD's impact grows, more outcome studies will focus on issues related to this disease.

In closing, it is important to reiterate that most older persons do not suffer from AD or other forms of dementia. Although AD will be a growing problem in future years due to the projected increase in number of older adults, there is little need for the kind of hysteria that is accompanying the emergence of other major diseases. Alzheimer's disease and similar disorders should not be equated with typical aging processes. On the other hand, there is room for many more objective studies and realistic appraisals of these severe disorders. AD and other forms of dementia do have an impact that cannot be ignored.

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FAMILY SUPPORT CONSIDERATIONS
IN ALZHEIMER'S DISEASE TREATMENT

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Abstract

Alzheimer's disease is a neurological disorder characterized by an irreversible decrement of intellectual abilities. Symptoms of this disease include severe memory impairment and perceptual judgment impairment. Problems such as confusion and paranoia are common. Alzheimer's disease strikes adults of all ages, but most often it affects older adults. The disease is terminal. Due to its severity, Alzheimer's disease has a significant impact on victims and their relatives.

Families with Alzheimer's disease victims constitute the focus of this report. These families typically confront many crises related to the disease. For example, crises can occur after diagnosis of the disease or just before institutionalization of the family member with the disease. Families vary in their abilities to cope with these crises. Some families that experience difficulties in the coping process need formal support or intervention.

This report includes suggestions for a continuum of support to aid families in confronting Alzheimer's disease. It is posited that ongoing family meetings may be especially helpful for some of these families. Family therapy, support groups, and individual counseling are other helping options to be considered. The need for integration and coordination of these and other services is discussed as well.