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Selected aspects of Alzheimer's disease

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Selected aspects of Alzheimer's disease

Abstract

Alzheimer's disease consists of a progressive atrophy of the brain without a known cause or cure (Gruetzner, 1988; Jarvik, 1987, in Karlicki, 1987; u. s. Congress, Office of Technology Assessment, 1987; Pajk, 1984). This disease affects 50% of the 2-6 million Americans suffering from dementing illnesses (Rabins & Folstein, 1983; Mace & Rabins, 1981). The number of Americans suffering from dementing illnesses could rise to 7.4 million by the year 2000 (U.S. Congress, Office of Technology Assessment, 1987).

SELECTED ASPECTS OF ALZHEIMER'S DISEASE

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Introduction

Alzheimer's disease consists of a progressive atrophy of the brain without a known cause or cure (Gruetzner, 1988; Jarvik, 1987, in Karlicki, 1987; U. S. Congress, Office of Technology Assessment, 1987; Pajk, 1984). This disease affects 50% of the 2-6 million Americans suffering from dementing illnesses (Rabins & Folstein, 1983; Mace & Rabins, 1981). The number of Americans suffering from dementing illnesses could rise to 7.4 million by the year 2000 (U.S. Congress, Office of Technology Assessment, 1987).

Alzheimer's disease is a devastating disease for both its victims and for the caregivers of those victims and is worthy of study due to the havoc it causes. This disease has a gradual onset, with problems with memory, comprehension and concentration being its first symptoms (Gruetzner, 1988). Gradually, the patient also begins to become disoriented, has lapses in judgment and is unpredictable in terms of affect (Gruetzner, 1988; Reisberg, 1984). As the patient's disease worsens, the caregiver must assume more and more responsibility for his/her care, with many patients expressing resentment rather than gratitude for the caregiver's efforts. In the end, the caregiver must assume total care for the patient.

Caregivers do need support. They are oftentimes overwhelmed and distressed by the level of care demanded by their demented relative. Support groups have recently become a way for caregivers to get some of the support that they need. Also, at times, professionals have become involved in the support groups. However, at this point in time, more research is needed to discover the current status of roles for professionals, such as social workers and counselors.

The purpose of this paper is to investigate selected aspects of Alzheimer's disease, the effects of this disease on the caregivers of Alzheimer's patients, and the support resources available for caregivers. The paper will also report on roles which professionals may fill on behalf of support groups.

A General Description of Alzheimer's Disease

Alzheimer's disease was named after Alois Alzheimer (Jorm, 1987; U.S. Congress, Office of Technology Assessment, 1987; Torack, 1981), a German Neurologist who described the condition in 1907 following the autopsy of a 55 year old woman who had previously displayed symptoms of short-term memory loss, paranoia and delusional behavior. Initially, this disease was thought to be a rare pre-senile disorder affecting adults of 45-60 years of age (Gruetzner, 1988; Torack, 1981; Galton, 1979). But in fact, Alzheimer's disease

is the major cause of dementia in older and middle-aged adults. Research of the past twenty-five years has indicated that Alzheimer's disease, rather than "hardening of the arteries," is the major cause of dementia in adults (Reiffler, 1987, in Karlicki, 1987; Cohen & Eisendorfer, 1986; Henig, 1979).

Although the cause of Alzheimer's disease is unknown, several theories have been proposed about the disease's origin. A first proposed cause is that of a slow-acting virus much like kuru or Cruetzfeldt-Jakob's disease (Gruetzner, 1988; Jorm, 1987; Kent, 1983). A second proposed cause is a genetic link suggested by the relationship between Alzheimer's disease and Down's syndrome (U. S. Congress, Office of Technology Assessment, 1987). A third proposal is that the disease may be caused by the loss of vital enzymes (Cohen & Eisendorfer, 1986) or by environmental factors. And finally, it has been proposed that Alzheimer's disease may be a form of advanced aging, indicated by the Alzheimer's-type lesions that have been found in most normal aging brains. However, it may also be true that there are two or more causes of this disease.

Since it has been acknowledged that brain deterioration is a major component of Alzheimer's disease, it is important to understand how the brain deteriorates during the course of the disease. The brain of the Alzheimer's victim becomes a disorganized organ due to the dysfunction of the

neurotransmitter, acetylcholine (Jorm, 1987; Cohen & Eisendorfer, 1986; Restak, 1984) which is directly responsible for the transmission of messages between neurons (Jorm, 1987; Restak, 1984). The result of such dysfunction is the destruction of neurons. Neurons become twisted, tangled and enlarged; large gaps in the brain result from such deformed neurons (Jorm, 1987; Cohen & Eisendorfer, 1986; Pajk, 1984; Tyler & Tyler, 1984; Kent, 1983). In addition, Jorm, Cohen and Eisendorfer, and Pajk reported that this deterioration centers around the hippocampus, the short-term memory center of the brain, and the cerebral cortex. In addition, the brain stem, the locus coeruleus and the hypothalamus, which regulates the pituitary gland, also show some deterioration (Cohen & Eisendorfer, 1986).

Since the cause and cure of Alzheimer's disease have remained a mystery, diagnosis of this disease has been difficult. Confirmation of this disease is made only through a post-mortem examination (Jarvik, 1987, in Karlicki, 1987; U.S. Congress, Office of Technology Assessment, 1987; Cohen & Eisendorfer, 1986) or by biopsy (Jorm, 1987). Diagnosis made during the course of the disease is made by the process of eliminating known causes of dementia and by the manner in which symptoms exhibit themselves over time (Gruetzner, 1988; Cohen & Eisendorfer, 1986; Pajk, 1986). The diagnostic process

is costly and time consuming, but these tests are important because they may indicate potentially reversible or treatable disorders, such as multi-infarct dementia, depression, malnutrition, reactions to medications or delirium, which can mimic Alzheimer's disease (Gruetzner, 1988; U.S. Congress, Office of Technology Assessment, 1987; Cohen & Eisendorfer, 1986; Brown, 1984; Pajk, 1984). The diagnosis process requires the services of several different types of professionals, both medical and helping professionals, since Alzheimer's disease affects all areas of a person's life.

For many families of the demented, the initial contact with doctors and other professionals can be a frustrating experience. According to many caregivers of demented patients, many doctors do not fully explain the diagnosis, the patient's limitations, plans that will need to be made for the future or changes that may occur in the nuclear or extended family (Mace & Rabins, 1981). In addition, Cohen and Eisendorfer (1986) cited cases in which the diagnosis was supplied inappropriately--such as, in clinic or hospital corridors or over the telephone. Such misinformation or inappropriately given information tends not to aid families as they try to cope with the diagnosis of Alzheimer's disease and the diagnostic procedure.

After all the probable causes have been ruled out and the patient has been given a probable diagnosis of Alzheimer's disease, the patient and his/her family must prepare themselves for a drastic change in the patient's personality. The patient and the family must also prepare themselves for return visits, so that professionals may record changes in functioning and perhaps reevaluate the diagnosis of Alzheimer's disease (Gruetzner, 1988; Cohen & Eisendorfer, 1986).

Progression of Alzheimer's Disease

Early Stages

Preparation for Alzheimer's disease is difficult for the victim and his/her family due to the varying symptoms and the duration of the disease. Alzheimer's disease has a gradual onset and its duration has varied from being as short as 3-4 years and as long as fifteen years (Cohen & Eisendorfer, 1986; Pajk, 1984; Rabins & Folstein, 1983). The first of many symptoms of this disease is short-term memory loss (Gruetzner, 1988; Roach, 1987, in Karlicki, 1987; Pajk, 1984).

The early stages of Alzheimer's disease have been marked by problems with memory, comprehension and concentration (Gruetzner, 1988; Mace, 1987, in U. S. Congress, Office of Technology Assessment, 1987; Reisberg, 1984). Due to these problems, many patients are unable to handle themselves in social or job-related situations (Gruetzner, 1988; Brown,

1984; Reisberg, 1984). Symptoms of the early stages of the disease also hamper the patient's ability to perform such routine tasks as balancing the checkbook or shopping for groceries (Gruetzner, 1988; Brown, 1984; Reisberg, 1984).

Orientation does not seem to be severely impaired during the early stages of Alzheimer's disease (Gruetzner, 1988; Reisberg, 1984). In addition, long-term memory does not seem to be affected in the early stages, and, in fact, for many patients long-term memory remains relatively intact throughout the course of the disease (Jorm, 1987).

Middle Stages

During the middle stages of Alzheimer's disease, denial continues to protect the victim, but it occasionally gives way to anger, suspicion and grief (Gruetzner, 1988; Reisberg, 1984). In addition to the changes in affect, the middle-stage Alzheimer's victim experiences episodes of disorientation to time and to place. During the middle stages of this disorder, the victim cannot be trusted to live alone or to drive without hazard due to lapses in orientation and judgment (Gruetzner, 1988; Cohen & Eisendorfer, 1986; Brown, 1984; Reisberg, 1984). In addition, the patient may wear clothes inappropriate to the season or to the time of day, may forget the date, may not remember a meal that he/she has just eaten, or may engage in activities that are inappropriate

for that time of day (Mace, 1987, in U. S. Congress, Office of Technology Assessment, 1987). During the middle stage the patient begins to experience difficulty in recognizing significant others (Gruetzner, 1988; Reisberg, 1984), and often may refer to his/her spouse as an "impostor." Due to these changes in the patient's orientation, the relationship between the patient and his/her spouse becomes strained. Part of the strain in the marital relationship takes on sexual overtones. For instance, many victims place inappropriate sexual demands upon their spouses (Gruetzner, 1988; Steur & Clark, 1982) or make attempts to seduce others (Cohen & Eisendorfer, 1986). At other times, some Alzheimer's victims become insensitive to the needs of their spouses in the sexual encounter (Gruetzner, 1988), while other patients accuse their spouses of being unfaithful (Kapust, 1982). In addition, some victims entirely lose interest in the act of sexual intercourse (Cohen & Eisendorfer, 1986).

Other symptoms relating to the patient's deteriorating orientation and judgment include day/night confusion and generalized anxiety (Gruetzner, 1988; Pajk, 1984). Patients often become restless and agitated during the night and tend to sleep during the day-time hours (Mace, 1987, in U. S. Congress, Office of Technology Assessment, 1987; Beam, 1984). Day/night confusion increases the patient's general confusion

(Beam, 1984) and has the potential to be dangerous if the patient has a tendency to wander (Gruetzner, 1988), which is another problematic behavior that begins in the middle stages of Alzheimer's disease. Wandering behavior is a significant and dangerous problem for patients and their families because an Alzheimer's victim may wander at any time. Because patients are often disoriented to time and place, they may decide to wander during the night or during cold winter months and this behavior puts victims at great risk of injury to themselves (Gruetzner, 1988; Beam, 1984).

In addition to the symptoms mentioned above, the Alzheimer's victim often develops symptoms that may be annoying and troublesome to family members. One such symptom is to change the patient's affect. Beginning in the middle stages of this illness, a patient's emotions quickly change from depression to anger to sadness to elation (Mace & Rabins, 1981). A symptom related to changes in the patient's affect referred to as "catastrophic reaction." A catastrophic reaction occurs when the patient becomes inappropriately upset, angry, paranoid or violent when asked to perform a given task (Gruetzner, 1988; Beam, 1984; Pajk, 1984; Rabins & Folstein, 1983; Mace & Rabins, 1981). Often, catastrophic reactions are linked with the response of the caregiver, for instance, when the caregiver becomes loud, tense or nervous,

the patient often displays similar emotions (Gruetzner, 1988; Pajk, 1984; Rabins, 1981).

Other symptoms which may be troublesome to families of demented during the middle stage include preservation and hyperorality (Beam, 1984). Preservation is the repetition of a word or gesture, while hyperorality entails putting everything into one's mouth. In addition to being annoying, such symptoms can be hazardous to the patient's health. Some, but not all, Alzheimer's victims develop the symptoms of hallucinations and delusions, particularly at night (Gruetzner, 1988; Mace, 1987, in U. S. Congress, Office of Technology Assessment, 1987). These symptoms are also quite troublesome to family members, but frequently hallucinations and delusions can be controlled with appropriate treatment (Mace, 1987; in U. S. Congress, Office of Technology Assessment, 1987).

Alzheimer's disease also brings about a variety of behaviors that are inappropriate and embarrassing to family members. One such behavior--accidental shoplifting--occurs due to the patient's tendency to hoard and to his/her lack of judgment (Beam, 1984). Episodes of exhibitionism are another example of embarrassing behavior due to a patient's lapse in judgment. Beam believed that many of these indecent exposures were caused by the patient's inability to judge a

proper place to urinate. This act of urinating or defecating in inappropriate places is an additional troublesome behavior exhibited by Alzheimer's victims that is embarrassing to their caregivers.

In addition to the above mentioned symptoms related to the patient's deteriorating judgment, many victims seem to lose interest in their appearance and hygiene. This lack of interest on the part of the patient seems to be due not only to the Alzheimer's victim's deteriorating judgment, but also because of the depression that many patients experience (Pajk, 1984). This depression occurs because many victims are very much aware that something terrible is happening to them (Pajk, 1984; LaBarge, 1981). When depression is present in Alzheimer's victims, it needs to be treated because the patient's functioning and overall mental/emotional state can improve markedly once the depression is treated (Gruetzner, 1988).

As the victim reaches the final part of the middle stages of Alzheimer's disease, he/she develops a fear of bathing and experiences incontinent episodes (Gruetzner, 1988; Reisberg, 1984). At this point, the patient needs help with most activities of daily living and often reacts towards the caregiver with agitation rather than with gratitude (Gruetzner, 1988; Reisberg, 1984).

Final Stages

The symptoms of the middle stages worsen as the patient enters the final stages of Alzheimer's disease. He/she will need help with all activities of daily living: bathing, eating, turning in bed and elimination (Gruetzner, 1988; Reisberg, 1984). Also in the final stages of Alzheimer's disease, communication is often limited to grunts and screams.

However, many patients do not reach the final stages of this illness. The Alzheimer's victim is more susceptible to illness than is the average person. Powell and Curtis (1983) reported that this illness reduces the remainder of a person's life by one-third. For patients who do survive the complications of Alzheimer's disease, they will reach a comatose state with death following shortly thereafter (Gruetzner, 1988; Reisberg, 1984).

Effects of Alzheimer's Disease on Families

Demographic and Social Considerations

Many families have in the past and will continue in the future to care for their elderly, demented relatives. At the present time, only 5% of the elderly living in the United States are institutionalized at any given time (Esposito, 1987, in Karlicki, 1987; Brody, 1981; Shanas, 1979). Often, the responsibility for the care of the demented patient falls upon one family member, usually the spouse or

the middle-aged daughter of the patient (Miller, 1981; Robinson & Thurnher, 1979). Such caregivers frequently experience a lack of support for a variety of reasons.

Ill health, geographical mobility, family conflicts and the stereotype that it is the daughter's responsibility to care for the sick and the elderly are the demographic and social reasons that have been cited as the reasons for the caregiver's lack of support among family and friends as they attempt to care for their demented relative (Mace & Rabins, 1981). In addition, the fact that women are now producing fewer children and are becoming employed in record numbers will continue to restrict the number of available caregivers for demented patients (Monk, 1979).

There are many other social changes that occur in any particular family when a member becomes demented. There are many changes in family responsibility that may cause anger, resentment and misunderstanding to occur (Jorm, 1987; Mace & Rabins, 1981). For example, some family members do not want to accept the severity of their impaired relative's illness and, therefore, back away from offering assistance (Cohen & Eisendorfer, 1986). At other times, one family member may accept total responsibility for the care of the demented patient (Cohen & Eisendorfer, 1986) and may neglect to inform other family members of the severity of the patient's condition

(Gruetzner, 1988; Mace & Rabins, 1981). In short, individual family members react to their impaired relative's illness in a variety of ways. The caregiver often bears the brunt of the burden as he/she tries to respond to the patient's needs.

Caregiver Burden

Responding to an Alzheimer's patient's needs is often a tiresome and endless task. Because the victim cannot be trusted to live alone past the early to middle stages of this disorder (Reisberg, 1984), the caregiver must monitor the patient's every move. The patient's behavior has produced what is referred to in the literature as burden (Morycz, 1980). Burden, for the purposes of this paper, includes caregiver resentment, work overload, conflicts with other family members and lack of support from formal and informal resources, such as the helping community, family and friends. The caregiver often feels resentful because he/she is bound to the caregiving situation. Caregivers who have had especially poor relations with their demented relatives experience especially high levels of resentment (Mace & Rabins, 1981).

Many caregivers have responsibilities such as child care, employment and home maintenance in addition to patient care and therefore experience work overload (Gruetzner, 1988; U. S. Congress, Office of Technology Assessment, 1987; Mace

& Rabins, 1981). In addition to patient care and the caregiver's other responsibilities, Alzheimer's disease often causes problems between the caregiver and his/her spouse and children. Other family members are often resentful of the Alzheimer's patient because he/she demands so much of the caregiver's time (Mace & Rabins, 1981), resulting in a lack of time the caregiver has to spend with family members other than the patient (Gretzner, 1988).

In addition to causing conflict between family members, Alzheimer's disease affects the caregiver's socialization needs. Many caregivers, either due to exhaustion or embarrassment over the victim's inappropriate behavior, become isolated from friends, adding to their burden (Cohen & Eisendorfer, 1986; Beam, 1984). In such cases, the caregiver becomes isolated at his/her own choosing because the behavior of the patient becomes too embarrassing. Many caregivers would rather stay at home than alone with the patient than to risk the disapproval of others (Kapust, 1982). In addition, many caregivers fear the disapproval of others due to their own bizarre thought patterns, such as feeling so frustrated, angry and resentful of the patient that they have wished for his/her death (Barnes et al., 1981). Many caregivers do not wish to expose themselves to friends and relatives who do not understand the problems of dementia (Barnes et al., 1981).

In other cases, however, friends and relatives isolate themselves from the caregiver and the patient and gradually lose contact because they are uncomfortable with the patient's change in behavior (Morycz, 1980). In addition, some friends and relatives are critical of the caregiver's efforts (Gruetzner, 1988; Cohen & Eisendorfer, 1986; Peck, 1983; Morycz, 1980). Potential sources of aid, such as friends and the professional community, have been reluctant to support the patient and his/her family since the Alzheimer's victim retains physical vigor and appearance, and does not look ill, until late in the middle stages of the disorder (Barnes et al., 1981). Often, caregivers have been particularly angry with doctors who have delivered a diagnosis and then seemed not to offer any support as how to deal with the problem of Alzheimer's disease (Cohen & Eisendorfer, 1986; Mace & Rabins, 1981; Barnes et al., 1981). Many caregivers have no one--friends, relatives or professionals--on whom they can depend for support, friendship or guidance and are extremely isolated.

In addition to isolation, relatives who are caregivers of Alzheimer's patients also face problems with role reversal, which occurs because the patient is unable to assume traditional responsibilities. Although role reversal is difficult for all caregivers, it is particularly problematic

when the caregiver is the spouse. Because older adults grew up when household responsibilities were clearly divided along gender lines, it is often difficult for them to accept new, often foreign, responsibilities. When a spouse becomes demented a husband often has to learn the mechanics of meal preparation and home maintenance, while the wife of a demented husband will have to assume the responsibilities of financial security and auto repair. These changes occur when the spouse/caregiver is most vulnerable and prone to stress (Barnes et al., 1981; Mace & Rabins, 1981).

Adult children look up to their parents and other older relatives for qualities of leadership and often feel guilty when they must "take over" their older relative's responsibilities for care and for security (Mace & Rabins, 1981). Not infrequently, adult children are saddened, embarrassed and grieved by the changes in their older relative's personality brought about by Alzheimer's disease (Esposito, 1987, in Karlicke, 1987). In addition, many caregivers are embarrassed by the physical care aspects they must assume for their older relative (Mace & Rabins, 1981). Other emotions, in addition to the sadness, embarrassment and grief, are felt by adult children when they accept caregiving responsibilities for a demented relative. For example, an adult child may feel trapped and manipulated by

the caregiving relationship if the prior relationship had been a poor one (Mace & Rabins, 1981). Obviously, the better the quality of the past relationship, the less burden and resentment the caregiver will have whether he/she is a spouse or an adult child of the demented patient (Zarit, 1987, in Karlicki, 1987).

Another change in the patient's behavior that is likely to add to the caregiver's feelings of resentment and burden is the change in the patient's sexual behavior brought about by Alzheimer's disease. Demented persons still have sexual needs and desires, but due to the chemical imbalance brought about by this disorder, these needs and desires are expressed in bizarre or inappropriate ways. This especially sensitive problem area is made more difficult by the fact that spouses are generally uncomfortable in expressing sexual problems with others (Kapust, 1982).

The above mentioned changes in the patient's behavior contribute to an increase in the caregiver's burden. Caregivers often react to their increased burden by experiencing emotional discomfort. Emotions such as frustration, depression, guilt, denial and anger become the caregiver's constant companions (Powell & Courtice, 1983). The discovery that a relative has Alzheimer's frequently sends caregivers on an emotional roller coaster, with many

caregivers suffering extreme emotional discomfort, and going through anticipatory grieving (Gruetzner, 1988; Powell & Courtice, 1983).

Anticipatory Grieving

Anticipatory grieving follows a series of steps for the caregiver, including denial, overinvolvement, anger, guilt/depression and, finally, acceptance (Gruetzner, 1988; Powell & Courtice, 1983). In the first step, the caregiver denies that a problem exists. Gruetzner (1988), and Powell and Courtice (1983), reported denial to be dangerous because it does not allow the caregiver to plan for the future--such as selecting a conservator or changing the will--until it is too late. Following denial, overinvolvement occurs. Caregivers seek to meet the patient's every need and may refuse assistance, often at great risk to themselves (Gruetzner, 1988).

Anger is the next step of anticipatory grieving. The angry caregiver may ask him/herself, "how could this happen to me?," followed by "how could he (or she) do this to me?" (Powell & Courtice, 1983). Anger is often aggressively expressed at the patient, but it is also displayed passively (Gruetzner, 1988). Powell and Courtice (1983) suggested that caregivers express passive anger when they withhold medication or ignore the patient's needs. At other times,

caregivers direct anger back at themselves, causing guilt and depression (Gruetzner, 1988; Powell & Courtice, 1983).

Many caregivers become depressed because they are unable to handle the stresses of living with a relative with dementia. Powell and Courtice (1983) cited several physical and emotional symptoms that many caregivers experience, including insomnia, exhaustion and the contemplation of suicide. Depression, if not treated, will build on itself since many caregivers believe the patient would improve if only he/she could "do more" (Barnes et al., 1981).

The stages of anticipatory grieving eventually allow the caregiver to accept and to prepare for the loss of the Alzheimer's victim and to plan for the future (Gruetzner, 1988; Powell & Courtice, 1983). However, anticipatory grieving may not allow the caregiver to come to terms with other emotional problems, such as loneliness and isolation. The spouse of a demented person has at times, felt like a "prisoner of love" or a "walking widow" because he/she has lost the companionship of a loved one but is not at liberty to begin a new relationship (Barnes et al., 1981). Spouses of demented patients feel anger at the patient for putting them in this "limbo" position and then experience guilt for feeling anger towards the patient (Powell & Courtice, 1983).

Caregivers, whether they are spouses or adult children of demented patients, are often able to come to terms with the ravages of Alzheimer's disease by utilizing community resources and by gaining information about the disease itself (Gruetzner, 1988). Gruetzner reported that new situations will often cause a caregiver to return to an earlier stage in the anticipatory grieving process. Clearly, coping with Alzheimer's disease is an ongoing process. The use of various types of formal and informal support networks, such as support groups, can be of tremendous benefit to caregivers and their families as they attempt to come to terms with the ravages of this disease.

Community Resources

Support Groups

Attendance at Alzheimer's support groups is one method that can be used to manage caregiver burden. A support group meeting is one of the first places caregivers go to receive additional support. Caregivers do need support and are not likely to find it in many communities because formal resources are often hidden and are geared toward frail, but non-demented, elderly persons (U. S. Congress, Office of Technology Assessment, 1987). Families often must search painstakingly before they are able to find relief through the formal support network. In addition, many families do not search for help

until they are well on their way to major burnout or depression (Mace, 1987, in U. S. Congress, Office of Technology Assessment, 1987).

Support groups help to fill in the gaps left by the formal support network. At an Alzheimer's support group, a caregiver can meet and gain support from others who are "in the same boat" (Pearson, 1983), and gain information about coping strategies, community resources and the disease itself (Gruetzner, 1988; Cohen & Eisendorfer, 1986). One such organization is the Alzheimer's Disease and Related Disorders Association Incorporated (ADRDA), whose goals include family support, education, advocacy and encouraging research. The ADRDA was formed to help family members of Alzheimer's victims (Mace & Rabins, 1981). The ADRDA was founded in 1979 when seven support groups from various parts of the country banded together (Cohen & Eisendorfer, 1986; Mace & Rabins, 1981). One of the seven founding groups--Alzheimer's Support, Information and Service Team (ASIST)--was founded in 1978 in Seattle due to the relationships and friendships that developed among families that participated in Alzheimer's disease research (Cohen & Eisendorfer, 1986). As of 1985, there were 149 ADRDA chapters and more than 1,000 family support groups nationwide (Hochman, 1985).

Participants in the ADRDA often joined this organization believing that it would be a good way to help the impaired family member (American Journal of Nursing, 1984). Later, however, these participants gained the opportunity to express their own emotions of frustration, anger and loneliness and found that to be helpful for themselves. The growth of this organization indicates the vast need and lack of resources for persons caring for Alzheimer's patients.

While Alzheimer's support groups may not postpone institutionalization of demented patients (Mace, 1987, in U. S. Congress, Office of Technology Assessment, 1987), they do offer caregivers much needed support, information and education about dementia (Gruetzner, 1988; O'Connor et al., 1987; Cohen & Eisendorfer, 1986).

The continued availability of support groups is needed for those caregivers who are willing to accept their need for help (Mace, 1987, in U. S. Congress, Office of Technology Assessment, 1987). The release of pent-up emotions allows the caregiver to realize that he/she is not alone and may lessen the risk of physical and/or mental difficulties. However, support groups are by no means a replacement for psychotherapy or other needed medical and support services (Aronson & Yatzkan, 1984). Many caregivers do need medical attention and by becoming involved in a support group, this

need is more likely to be recognized than it would if the caregiver isolated him/herself at home.

Other Community Resources

Community resources that have recently been developed for the Alzheimer's patient and his/her family include adult day care and respite care (Sands & Suzuki, 1983). Adult day care centers provide dependent adults with daily activities and allows families to have freedom for personal and professional reasons. Adult day care seems to be most appropriate for early and middle stage Alzheimer's victims; the structured environment and emphasis on activity may help reduce disorientation and confusion. In addition to adult day care, temporary respite units at hospitals and at nursing homes offer caregivers an opportunity to take a break from Alzheimer's disease. Such units have been beneficial to caregivers who have needed longer periods of respite than have been available through adult day care centers. However, such services may not be appropriate or wanted by every caregiver. Mace (1987) reported that many families want to provide total care for their demented family members and may refuse help when it is clearly needed (in U. S. Congress, Office of Technology Assessment, 1987).

In the past, doctors often suggested institutionalization as the only option for families with a demented relative

(Cohen & Eisendorfer, 1986). Now, however, it is recognized that the home environment might be a better option since it is familiar to the patient and the patient is more likely to receive better care if he/she remains in the home (Cohen & Eisendorfer, 1986). However, home care can only be seen as an ideal option if the caregiver and the patient are receiving adequate support from formal and informal resources, such as support groups, family members and friends. If the caregiver is overburdened or stressed-out, the patient is likely to not receive adequate care and is also quite likely to become abused (Gruetzner, 1988).

Needs of Patients and Coping Strategies for Caregivers

Managing the patient's environment may help to improve the patient's functioning and, thereby, reduce the caregiver's stress level. Alzheimer's patients also have basic human needs that a caregiver needs to consider, one of the most important of which is the need for plenty of activity. Activity promotes the patient's self-esteem and the highest level of mental functioning (Sheridan, 1987; Beam, 1984). Activity is also important because it promotes the patient's physical health (Rabins & Folstein, 1983). Sheridan (1987) cited many examples of activities that would be appropriate for victims of Alzheimer's disease, such as music, exercise, crafts, games and reminiscence. Sheridan further suggested

that these activities be "failure-free"--that is, adapted to fit the needs and capacities of the person with Alzheimer's disease.

Another need of the Alzheimer patient is to have a simple and safe environment. By making the environment simple and safe, the victim's confusion may be lessened, and he/she will be less likely to injure him/herself (Gruetzner, 1988; Cohen & Eisendorfer, 1986; Beam, 1984). Simplifying and safeguarding the environment includes reorientation devices, lighted hallways and fiddle-proof locks (Beam, 1984).

Alzheimer's patients also need to have a caregiver who is relatively calm and non-confrontative. Alzheimer's patients behaviors are often annoying and troublesome and by distracting the patient, rather than confronting him/her, the caregiver is often able to diffuse the issue (Gruetzner, 1988; Cohen & Eisendorfer, 1986). Beam (1984) strongly discouraged caregivers from confronting the patient about aspects of his/her behavior. Confrontation tends to confuse or frustrate the patient while distraction and affection tend to put him/her more at ease (Beam, 1984).

Many, but not all, Alzheimer's patients may also need medication to control certain troublesome aspects of their behavior. Agitation, depression, hallucinations and delusions may be controlled by medication prescribed by a physician

(Gruetzner, 1988; Cohen & Eisendorfer, 1986). However, medications should never be used as any kind of a restraint (Gruetzner, 1988; Beam, 1984) or in lieu of physical exercise (Cohen & Eisendorfer, 1986). Close monitoring of all medications is essential because of a risk of interactions between drugs and each medication's side effects (Gruetzner, 1988). Alzheimer's disease also brings about a metabolic change in the brain, which can reduce the effectiveness of any medication taken by the patient. Due to the above mentioned reasons, these authors recommended that the patients be started out on low dosages of medications, gradually increasing them over time and that caregivers carefully monitor what effects these drugs have on the patient.

The above mentioned needs of Alzheimer's victims can also be seen as coping skills for caregivers. Such coping strategies may ease the burden of the disease for caregivers and also may make life a little easier for patients. These and other coping skills may be learned when a caregiver attends an Alzheimer's support group meeting (Gruetzner, 1988; Cohen & Eisendorfer, 1986). To ensure that these groups continue to serve the caregivers of Alzheimer's patients, professionals may involve themselves in such groups.

Roles of Professionals in Support Groups

Many professionals have become involved in initiating and/or facilitating the type of support group that is offered by the ADRDA, which is long-term in nature and promotes discussion, information and support (Aronson & Yatzkan, 1984). Such professionals include social workers, the clergy, nurses, physicians, teachers and psychologists (Toseland & Hacker, 1982). In the initial, planning stages of forming a support group, professionals will want to gain information about the need for a support group in their community. Professionals and non-professionals will need to be consulted as the professional gains information about the "target population" because both can be seen as "experts" (Chutis, 1983). Professionals are considered to be experts because they have knowledge in counseling skills, group process, decision making/problem solving and in developing coping strategies. Non-professionals can be seen as experts because they have experience in living with a difficult situation (Chutis, 1983).

Other researchers have suggested reasons why non-professional, prospective members should be included in the organizing process of a support group. Toseland and Hacker (1982) pointed out that support group members often fear professional dominance over the support group. Harris (1981) suggested that commitment to the support group is

more certain if professionals involve prospective support group members in the initial, planning stages of the group process.

In addition, professionals have assumed other roles in Alzheimer's support groups. One such role has been to provide a linkage between the support group and the community (O'Conner et al., 1987; Toseland & Hacker, 1982). This involves the professional assisting with linking individuals and services to a common concern, and could also include referrals (Toseland & Hacker, 1982). The professional/facilitator can, in this way, perform a vital service both to the community and to the individual support group member. Another role that has been assumed by professionals involved in support groups has been that of advocate. Caregivers often know which services they require to improve their functioning and professionals, by acting as advocates, can help caregivers to obtain these services (O'Connor et al., 1987). An additional role that professionals have assumed in support groups has been to supply material support, such as finding a place to hold meetings and obtaining supplies for such meetings (Toseland & Hacker, 1982).

Often, support groups started by non-professionals will ask a professional to provide them with back-up to help the group more firmly establish itself (O'Connor et al.,

1987). At other times support groups may need help in identifying experts to speak at meetings. Above all, professionals are encouraged to be flexible when dealing with support groups in order to help meet the needs of the participants.

Conclusion

Alzheimer's disease is a devastating illness, both for the victim and for the family and friends of the demented person. Alzheimer's disease slowly destroys the victim's personality and it also destroys the world of the demented person's significant others. Since most demented persons are cared for in the home, and informal means of offering guidance, education and information would seem to be an appropriate means of supporting the caregiver(s), who desperately need help in coping with this disease.

Professionals can assist in the development and facilitation of Alzheimer's support groups. Professionals involved in support groups need to learn to be flexible and to allow the group to process on its own. The roles of advocate and advisor are also available to professionals interested in assisting these overburdened caregivers.

Support groups are only a beginning and should not be used in lieu of psychotherapy or other needed medical treatment, but they do get an otherwise overburdened and

perhaps isolated caregiver involved in the community where he/she is likely to receive assistance. Professionals can do much to support this informal resource.

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