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Families of Alzheimer victims: A counseling overview

Abstract

Alzheimer's Disease is a disorder of the brain causing memory loss or serious mental deterioration that is progressive in nature. Eventually the individual is incapable of functioning independently in society. It is an impairment of orientation, memory, intellectual functioning, judgement and concentration. The disease affects an estimated 1.5 million Americans, with the number expected to increase as the elderly population grows (National Institute on Aging (NIA) 1985) .

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FAMILIES OF ALZHEIMER VICTIMS
A COUNSELING OVERVIEW

A Research Paper
Presented to
The Department of Educational Administration
and Counseling
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In Partial Fulfillment
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Master of Arts

by
Marcia Ann Oltrogge
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Alzheimer's Disease is a disorder of the brain causing memory loss or serious mental deterioration that is progressive in nature. Eventually the individual is incapable of functioning independently in society. It is an impairment of orientation, memory, intellectual functioning, judgement and concentration. The disease affects an estimated 1.5 million Americans, with the number expected to increase as the elderly population grows (National Institute on Aging (NIA) 1985).

The cause of Alzheimer's Disease, or senile dementia of the Alzheimer's type (SDAT), is unknown, though the changes most commonly linked to it occur in the outer layer of the brain. This layer, the cortex, has groups of nerve endings which appear to degenerate and disrupt the passage of electrochemical signals between the cells. These disrupted areas have a similar characteristic appearance and are called "plaques". Changes also occur in the nerve cells of the cortex. These abnormal fibers accumulate and become neurofibrillary tangles. The greater the number of placques and tangles, the greater the disturbance of intellectual function and memory (Burnside, 19879; Glosser & Wexter, 1985).

The process of diagnosing SDAT is one of elimination. Conclusive evidence is found only through autopsy. There are many disorders with similar symptoms that must be eliminated as a possible cause before a diagnosis of SDAT can be made by the physician or neurologist. These include: pernicious anemia (a severe form of blood disease marked by a progressive decrease in red blood corpuscles), a drug reaction, hormonal imbalance, depression, strokes, alcohol or other drug misuse, brain tumor, chronic meningitis or other infection, head trauma, multi-infarct dementia (caused by decreased blood supply to the brain), Pick's disease (atrophy of the cerebral cortex), Parkinson's disease with dementia, metabolic problems, endocrine diseases, hearing loss, anemia, or even fecal impaction (Reisberg, 1983; Younkers Gerontology Project (Y.G.P.), 1983). Diagnostic techniques such as computer tomography (CT scan), electroencephalograph (EEG), studies of the spinal fluid system and comprehensive blood work must be completed. After other diseases or possible causes are excluded (many of which are treatable) a diagnosis of Alzheimer's Disease can be made.

There are four stages through which the SDAT victim progresses. They may overlap and progress at different rates, depending upon the individual case. Usually the disease is slow and steady deterioration, but this can fluctuate; it is always degenerative.

In Stage 1, the symptoms are vague and nonspecific. The person has less energy, is more irritable and intolerant, and slower to learn or react. Stage 2 has the individual requiring more assistance with specialized activities, is incapable of calculations, concentration, planning ahead or coping with disappointment. As Stage 3 is reached, the person is obviously disabled and increasingly lethargic. He is disoriented to time or place, uncertain how to act, has poor short-term recall, and greater behavior changes. The final stage finds the individual requiring assistance with simple basic tasks.

Perceptions are distorted and previously known people are unrecognized (Burnside, 1979; V.P.G., (Y.G.P.) 1983; Reisberg, 1983).

In this paper I will describe the dramatic impact that SDAT has on the family unit, the counselor's role, and future implications for training and reasearch. Alzheimer's disease not only threatens the existence and survival of the patient, but severely threatens the family unit also.

Impact on the Family

As the symptoms of Alzheimer' disease vary among individuals, so does its affect on their families. All are under increasing stress precipitated by the disease and its ramifications. As the victim progresses through the four stages, the quantity of care and strain increases for the family.

The intense stress on the family is affected by different variables. These include age of onset, marital status, sex, race, family size and composition, severity of symptoms (wandering, incontinence, aggression,restlessness, and forgetfulness) and functional incapacities in daily living skills. The degree of physical assistance, vigilance and disruptiveness also affects the tension the family is under (Morycz, 1985).

Caregiver

The caregiver is the primary person providing basic day-to-day assistance with daily living skills. This person may be a spouse, sibling, child, grandchild, relative, friend, or on rare occasions, a parent. The victim can be residing with this person or in close enough proximity that this relative is the one responsible for overseeing the SDAT victim's well-being (Powell & Courtice, 1983).

The rewards of the caregiver role may at times be overshadowed by the enormous amounts of energy involved and the futility one feels as they realize there will be no progress, only decline. Occasionally, increasing temper outbursts result in violence, accusations and suspicions. Or, the SDAT patient may rarely exhibit this temperament, appearing cheerful with only rare mood swings. The unpredictability can sap energy from the caregiver and create hard feelings and distrust (Powell et al., 1983).

Structure

Alzheimer victims do not adjust easily to change. They learn a set routine and any disruptions can affect their temperament and orientation. A family may try to follow a schedule to simplify the daily living routine but as scheduling problems naturally appear, the SDAT person may exhibit disorientation, confusion, and temper outbursts. The stress on a family trying to live within a self-imposed structure or suffer the consequences is restrictive to normal family activities and growth. The caregivers may feel guilty for having to disrupt routines for their own or the family's need and hence ignore themselves or resent the SDAT relative (Powell et al., 1983; NIA, 1985).

Mood Swings

Mood swings are quite apparent in most SDAT patients. There may be underlying causes (a new situation, a crowd, confusion, etc.) or the person may be just overreacting to simple, basic needs as hunger, sleep, or toileting. At times, a victim may be living in the past and projecting a distant unpleasant memory on a current situation. A caregiver trying to understand the variety of forces impacting on the mood of the impaired may feel frustrated, anxious, and helpless (Morycz, 1985; Marszalek & McDowell, 1985).

Safety

Alzheimer's victims often are not able to adequately protect themselves from safety hazards. A house must be made a potentially accident-free as possible, much as a house is "child-proofed". This can be traumatic to an adult-child caregiver or a parent of an SDAT person. The loss of the normal person and the replacement with one who needs basic protection is stressful. Living in a home where a family has to always be cognizant of where they put things disrupts routine living (Powell et al., 1983).

Finances

Finances are a source of potential conflict. Often victims are unable to manage their own money. They are confused by it, often losing vast sums or accusing their caregivers of theft. The caretaker can be burdened with enormous debts while trying to provide the best care possible. A family member may be unable to work because of the necessity of caring for the SDAT impaired. There may be increased medical and housing expenses, in-home health aides, and special equipment. The house itself may need reorganization and structural changes to adequately allow a person with Alzheimer's to function. All these expenses may not be covered by the SDAT relative's income and savings and the caregiver will assume the debts.

The legalities of handling another person's money can be complicated and confusing. The lawyers, various agencies and other family members' inquirings and concerns can create tension for the caregiver (Glosser & Wexler, 1985; Powell et al., 1983).

Respite

The emotional burden will often increase as the illness progresses. The caregiver is tied down to the home because the patient is unable to stay alone. This isolation can lead to resentment, depression, anger, and frustration. The family member, unless given respite (i.e. a break away from the patient) is in danger of becoming physically and emotionally ill themselves. The caretaker may not realize they need recreation, socialization and a chance for their own time. Or, if they do, they feel guilty and selfish. The stress and tension can be overwhelming, especially if the caregivers' health is being neglected (Keller, Cairl, & Kosberg, 1985; Fisk & Pannill, 1985).

Living Situations

At some point in time, before the disease progresses to far, the caregiver will have to examine the living situation. This is influenced by background characteristics, patient symptoms, and the functional capacities of the victim. The caregiver may have physical limitations, a negative attitude toward the aged, especially in a situation where there may be little or no reciprocity.

Caregivers and SDAT patients living in a separate household can cause individual and interpersonal stress. The anxiety for the SDAT victim's health and safety, the daily trips to check on them, the added household chores of running two separate homes all take their toll on the caregiver. They may feel guilty and torn between their own family and the impaired relative.

The decision to explore nursing home placement can be difficult. There may be ambivalent feelings and guilt. The judgement that they are lacking in love and patience by requiring placement can cause the caregiver to resist this as a necessary step. Negative connotations about nursing homes are common. Caregivers often view placement as totally negative instead of as a naturally progressive step associated with aging and Alzheimer's (Powell et al., 1983).

Death

A chronic disease, as Alzheimer's is, means ultimately dealing with death. Many of the plans people make as they grow older to deal with their death (i.e. wills, cemetary plots, burial contracts, funerals) the caregiver is required to make because the SDAT impaired individual is unable to make them. This can be confusing both personally and legally.

Alzheimer's, with its inevitable end in death, allows the family to mourn over a period of time, in advance of the actual death. They may not understand or be prepared for the grief process and the strain it puts on the caregiver and family. Denial of the eventual outcome may be the preferred method of dealing with this area by some families (Powell et al., 1983; Pagel, Becker & Coppel, 1985).

The Counselor's Role

The counseling role in working with the families will be multifaceted. Counselors will be called upon to educate, help explore, mediate, support, or consult. They will need to be familiar with the variety of services available, as well as the physiological changes the SDAT person undergoes. This does not imply that counselors must be expert in all areas but know how to locate information and refer families, as required, to various services (Powell, et al., 1983; Morycz, 1985; Alvarez & Cohen, 1985).

Practical Concerns - Counselor Responses

Mood Swings

The unpredictable and sometimes violent emotional outbursts associated with SDAT can be traumatic for a family. The counselors can teach families coping techniques while helping them realize that they are not necessarily the direct cause of the problem. If caregivers are threatened by violence, counselors need to confront this issue and explore ways to safeguard caregivers. Generally, this is not the case and counselors can work on techniques to assist caregivers adjust to the stress caused by mood swings. These techniques include relaxation, understanding the impaired person's present reality (often they are mentally dwelling in an earlier time of their lives) or learning not to argue can improve the quality of life and relieve stress (Phelps, Beard, Scott, & Maves, 1982).

Safety

Acceptance of the decreased independence of an SDAT victim and the increased need for vigilance on the caregiver's part can cause strong emotional feelings. The response may be resentment towards the SDAT person, grief over the loss of the family member or chronic anxiety brought on by worrying over potential accidents (Morycz, 1985; Powell et al., 1983). The counselor can assist the processing of these thoughts and help develop interventions that may alleviate the symptoms. Insuring that the environment is secure from physical hazards can give emotional comfort and stress release to the caregivers (Powell et al., 1983).

Respite

Dealing with an impaired relative can leave the caregiver little time of their own. Each individual needs their own time to relax, socialize with peers, pursue a hobby and to have the burden of caring for an SDAT relative lifted. Counselors who are aware of these needs can encourage caretakers to utilize resources available without guilt. By helping them recognize that they can potentially deal more positively with the impaired person if they also take care of themselves, counselors assist in improving their quality of life (YGP, 1983).

Stress

Counselors can recommend and teach relaxation techniques to help caregivers deal with crisis as they occur. By encouraging physical fitness and basic health maintenance, counselors will promote a more positive outlook both physically and emotionally.

Caregivers are often reluctant or lack the skills necessary to use all the social supports available to them. Neighbors, friends, and family members represent a potential network for physical and emotional assistance they could help alleviate tension and stress (Tsemberis, 1985).

Nursing Homes

Exploring nursing home placement can be confusing and stressful. Counselors can help reframe the situation as a necessary act of love instead of selfishness and unkindness. They may also help families in deciding what criteria are important in choosing a good nursing home. These may include licensure and accreditation of the nursing home to insure basic, adequate treatment. Medical and other services, care costs, an explanation of Medicare and Medicaid, financial arrangements, relocation of the relative and the adjustment period both the SDAT patient and family member must go through are also areas to touch upon. Counselors can help families evaluate their stress level and what benefits can be derived from placement. Realizing the amount of stress in caring for someone at home and how restrictive it actually is can ease the guilt about nursing home placement (Morycz, 1985; Marszak et al., 1985; Townsend, 1985; Jansen & White, 1985). The physical burden may ease after placement but caregivers are still likely to feel guilt, depression, and estrangement. Counseling during the placement period can help the family realize that these are natural feelings.

Death

Counselors can help in the anticipation of bereavement by allowing families to share thoughts and feelings, plan life without the family member, and begin the grieving process. This may allow the grief process to progress quicker and less painfully (Powell, 1983). Families that can begin to accept the impending loss are enabled to restructure their lives more rapidly to begin the rebuilding process.

Counseling Approaches

Individual

Individual therapy can focus on worries and fears that may be preventing caregivers from being able to work, relax effectively or have positive interpersonal relationships. By uncovering conflict and working through anxiety, hostility, sexual and dependency feelings, the counselor can help families deal with stress. Exploring options, potential solutions and feelings can foster a more productive life (Powell et al., 1983; Janson et al., 1985).

Individual therapy is not used to a great extent with caregivers. When it is utilized, it is usually short-term, and addresses practical concerns. It can be effective and long-term in isolated cases, but there are other methods that studies show to be preferred and probably more effective (Powell et al., 1983; Glosser et al., 1985).

Family

Family therapy can help families learn to mutually support each other and decrease the burden on a single member. Research suggests that this is especially important when the initial diagnosis and prognosis are made and discussed (Powell, 1983). Developing guidelines and making joint decisions can alleviate later difficulties concerning finances, housing, and respite. Emotional support and cooperation generally result in less friction, shared responsibility, and a common bond. Many times without counseling, a family can be torn apart by jealousy, misunderstandings, financial troubles, and strain. Counselors can help families analyze the situation, use techniques to reduce problems, and lay the groundwork for a supportive environment. An open discussion of the future can help dispell fears and anxieties and let family members share the burden. Working out potential problems, developing a care structure, agreeing on finances, and respite for principle caregivers can avert future problems (Powell et al., 1983; Jansen et al., 1985).

The dynamics of who becomes the primary caregiver and the roles played by other members can be very complicated. A person can assume the role out of guilt, default, being an only child, placement in sibling order, parental preference, age, sex, marital status, to gain recognition, martyrdom and rivalry. All of these can create family tension. Counselors can help families deal with their issues and resolve them in a satisfactory manner. Or, at least, give the members a chance to discuss, air feelings and worries, and share their viewpoints (Jansen, et al., 1985).

Groups

An increasingly popular and effective tool counselors can utilize is the support group. Made up of persons who have family members with SDAT, a support group can provide accurate information about the disease, as well as teach skills for managing the behavioral, legal, financial, social, and interpersonal problems associated with the disease. Support groups offer an opportunity to share and receive support for feelings they have concerning caring for a SDAT victim. Studies/sources show that family members rate support groups extremely high on helping learn how to deal with problems (Glosser et al., 1985). It appears that meeting others with similar concerns and sharing information and practical solutions eases caregivers' stress at a higher rate than would be expected from the actual information shared. These groups help alleviate participant's feelings of isolation and loneliness (Glosser et al., 1985). Counselors can coordinate, develop, and facilitate discussion (especially at initial meetings), but ideally the group should eventually be member-led with the counselor assuming an advisory, consultant role.

Implications for Counselors

Alzheimer's disease will be a growing area of counselor concern as the American population ages. Statistics show that five to six percent of individuals over the age of 65 years have this illness. With the rising elderly population, this will amount to a virtual epidemic in the coming years. Counselors need to be aware of what the disease is, its affect on the family system and what techniques and structural changes can help families cope when a member has Alzheimer's.

Counselors need to be familiar with the current trends and innovative programs available to SDAT victims. These include adult day care (where the impaired person can spend the day with peers in a structured environment outside the home), in-home health care (where someone comes into the home to help with basic health and hygiene), and respite care (which enables the caregiver to spend some time to themselves). Caregivers' knowledge about these programs and encouragement to utilize them can be invaluable, especially if the caregiver initially feels guilty about wanting and needing some time for themselves, a job or their own family (Keller et al., 1985; Fisk et al., 1985).

I believe that education appears to be the key to effective counseling. By educating families about the disease, myths and anxieties can be dispelled and understanding fostered. By increasing awareness of the disease, a valuable support network of friends, neighbors, and co-workers can be formed. Counselors can be leaders in lobbying for funding to develop groups, dispense information and serve on boards designed to promote understanding of the disease.

Training counselors in the stages and characteristics of SDAT can optimize their effectiveness in all forms of therapy, be it group, individual or family. Awareness of concerns families may have, including hygiene, constipation, dressing, exercise, mealtime and leisure activities and possible emotional concerns, such as depression, sexuality, agitation, and nervousness can help families cope more successfully (Lincoln, 1980). Practical information, self-help guides, and resource packets can provide valuable assistance to families trying to care for an impaired relative.

Self-help groups, facilitated by a counselor, should be available throughout the country to help families adjust and support each other. They can be a set number of sessions or on-going (preferably both are available) but they should be functioning (Glosser, et al., 1985).

One day, Alzheimer's Disease may be better understood. But until that time, counselors must help families adjust and care for impaired relatives in as stress-free and stable environment as possible.

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