

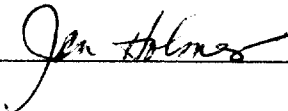
Social Work Practice with Alzheimer Caregivers

An Honors Thesis (ID 499)

By

Sheila A. Bracken

Jan Holmes, Thesis Director



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Introduction

A common myth in society is that people tend to become senile as they grow older. As more people live longer, we are forced to reexamine our assumptions concerning this myth of senility. Until rather recently, senility was considered intractable and a consequence of hardening of the arteries. However, senility is not a normal process of aging. The loss of memory and judgment once attributed to senility is now recognized as a form of dementia or senile dementia.

Physicians are slowly recognizing that a disease called Alzheimer's is a common disorder which produces a behavior once known as senility. Alzheimer's disease affects over 1.5 million Americans. It causes severe intellectual impairment in older adults and also in people under the age of 65. (U.S. Department of Health and Human Services at al., June 1981) Elias Manuelidis (1982) describes Alzheimer's disease as more devastating than cancer because the consequences of the disease mean the loss of "... the ability to communicate with their families and friends." (p.59)

Lawrence Altman, M.D. (1980) sees several misconceptions prevalent in relation to dementia. One misconception is that nothing can be done for the victim or the family taking care of the victim.

This misconception can be corrected by examining the many groups which have evolved to provide caregiving families with knowledge about the disease and support from others experiencing the devastating effects of the disease. The family coping with the deterioration of a family member has become the concern of professionals. Professionals working with the elderly population need to be aware of the effects of *the disease on the family. The disease*

unendingly consumes family, neighbor, community and professional resources and new support systems need to be explored to give assistance to the families in need. (Arie, 1981)

A review of current literature on the needs of Alzheimer caregivers produced few helpful articles. The disease has only recently come into the public eye. Attention is just beginning to be focused on the family or caregivers as well as the patient. To better understand the needs of the caregiver and examine ways professionals can serve caregivers more effectively, a survey was designed and administered to caregivers from the Alzheimer Support Group in Muncie, IN. The data from the survey provided information about caregivers' perceptions of their problems and needs when caring for victims of Alzheimer's disease.

This paper will give an overview of the disease, a review of the available literature on caregiver needs, findings from the survey, recommendations for social work practice, and recommendations for further research studies.

Explanation of Alzheimer's Disease

In 1906, Alois Alzheimer described a condition in a 51-year old female patient. This condition is now known as Alzheimer's disease. The woman was experiencing memory loss and frequent disorientation. She later became depressed and had hallucinations. After the patient died, Alzheimer discovered through an autopsy that her brain had shrunk (atrophy). There were deformed or distorted fibers in the nerve cells which Alzheimer named neurofibrillary tangles. These

tangles are now used as a major diagnostic test of the disease. (U.S. Department of Health and Human Services, et al., September 1981)

Another anatomical condition which distinguishes the disease from others is the presence of neuritic plaques. These plaques are composed of the waste material amyloid. The number of plaques and tangles is correlated to the severity of the intellectual impairment of the individual. Those victims with severe impairments have a large number of plaques and tangles in the memory areas of the brain, the cortex and hippocampus. (Aronson, 1982)

Alzheimer's disease is a progressive, degenerative condition of the brain. The disease was originally called presenile dementia. Dementia is a term used to describe the symptoms of declining intellectual ability interfering with daily functioning on the psychological, social and economic level. The losses which begin to appear during the course of the disease include a decline in mathematical ability, judgment, abstract thinking, memory, speech and coordination. An individual may experience personality changes with the continued deterioration of the brain. (Mace, 1981) Lawrence Altman (1980) describes more characteristics that may be present in an individual who has the disease. These characteristics are the disorientation of time and space, an impaired attention span and the lack of ability to acquire and retain newly learned information. The term presenile dementia was used to explain the degenerative condition when it affected people in the middle years, sometimes as young as 45 years old. Senile Dementia of the Alzheimer's Type (SDAT) is the name most commonly used today for the symptoms associated with the disease in both the younger and older generations. (Powell & Courtice, 1983)

The cause of Alzheimer's or SDAT is unknown although researchers are studying a number of possible factors which may cause the disease. The role of trace metal is being studied on many levels as a possible link to the cause. Aluminum found in Alzheimer patients has proven to be above the normal concentrations. The neurofibrillary tangles were identified as having aluminum within the nucleus of the cell, while the cells around the tangles did not have such a high concentration of aluminum. Research has yet to determine how such high concentrations of aluminum gains access to the brain. (U.S. Department of Health and Human Services, September 1981; Nolan, 1983)

The work of three different British medical teams, as reported by Harold Schmuck of the New York Times, confirmed a biochemical deficiency of the enzyme choline acetyltransferase as being connected with senile dementia. This biochemical deficiency was different from the changes which normally occur during the aging process of the brain. (Schmuck, 1979)

A slow virus or viruses producing the damage in the brain are other possibilities. Researchers are comparing the similarities found between Alzheimer's disease and other disorders such as Creutzfeldt-Jakob disease. (U.S. Department of Health and Human Services et al., September 1981) Genetic factors may also have some influence on the development of the disease. Down's syndrome and blood disorders among family members have been linked to the occurrence of SDAT in the family. When a close relative in the family has had SDAT, the probability of other members having the disease is four times as high as it is for individuals from non-affected families. (Nolan, 1983; Burnside, 1979; Melvin, 1981)

Memory loss is not a normal part of the aging process. On the average, 80 per cent of the elderly population do not experience problems remembering things. A person with SDAT will usually have a loss of memory in the early stages of the disease. Suspicious, reactions of paranoia and the lack of good judgment such as giving money away to the neighbors or putting the garbage in the bathtub, are examples of behavior associated with the disease. (Mace, 1981; Powell & Courtice, 1983) Confusion and disorientation during daily activities such as getting lost on the way to work are also seen. As the disease progresses over the years, the brain damage causes a loss of many different functions. Memory and motor functions such as walking, writing, balance, continence and speaking will all be affected in different ways and at different times. These changes may be accompanied by a change in personality. The losses develop slowly but progressively making every day a new challenge for the family involved. The disease usually ends in death from health complications or choking. In the later stages of the disease the victim forgets to swallow and involuntary muscles no longer function. The disease may progress rapidly and last as few as three to four years or as long as fifteen years. (Mace, 1981)

Review of Literature

The role of caregiving, taking care of a person with SDAT everyday, places many burdens on the person. Zarit et al. (1980) described some of the reasons the caregiver begins to feel burdened. These reasons include the caregiver's inability to find time for self interests, the excessive dependency people with Alzheimer's have on

the caregiver, and the constant fear and apprehension caregivers live with as they anticipate the appearance of more deterioration in a person's behavior. Watching the person deteriorate mentally was also cited by Safford (1980) as being a major problem. One way of coping with the anguish associated with Alzheimer's disease is to locate other people with the same problem to share experiences and support. Recognizing one's limitations in helping the person with SDAT also provides some relief from the stress. There is a strong sense of guilt and resentment found among those caregivers who do not acknowledge their own physical and mental limitations.

To help the caregiver manage the person with SDAT, Portnoi and Shriber (1980) suggest a familiar environment that does not bring about sudden changes. The familiar environment will help decrease the confusion the person with Alzheimer's is experiencing. (Mace, 1981) Adapting the family's lifestyle and sacrificing personal time for the confused and dependent person creates feelings of resentment and ensuing feelings of guilt by the caregiver. The family members involved are most likely middle to older age themselves, creating more stress in some situations. (Bumagin & Hirn, 1979; Silverstone & Bookin (1982)

The problems which these families face when caring for someone with SDAT begin with the emotional stress of the diagnostic process. Physicians hesitate to diagnose the disease without a battery of tests which take both time and money. Some physicians do not have enough knowledge about the disease to clearly explain to the family the behaviors and symptoms to expect and the problems which the family will face. Not knowing what to expect or being misinformed is

stressful. When caregivers expect the person with SDAT to continue to function at the same level of competency as before, anger and hostility toward the Alzheimer victim can result. At the same time, the caregiver may also feel guilty about being angry towards someone who cannot control what they do. (Mace, 1981) Some caregivers deny that the disease is present which causes unrealistic expectations about the person's capabilities. As the behavior of the person with SDAT becomes more impulsive or belligerent and requires constant monitoring, the physical strength of the caregiver becomes a concern. The person with SDAT will most likely be active and restless at night which further weakens the caregiver's strength and health. The caregiver is forced to accept new roles without adequate preparation. The 24-hour care required and the lack of resources in the community for family care providers are the major factors in the development of a deep sense of isolation frequent among caregivers. The amount of time required for care isolates the provider in the home. The lack of community resources forces the caregiver to deal with various feelings and crises alone. This often causes great stress. (Barnes et al., 1981)

Financial problems develop as the need for constant care grows. The chronic nature of the disease eliminates the individual from qualifying for Medicare. The mentally impaired only qualify if a nurse is necessary for daily injections or catheter changes under a physician's order. (Glennen, 1982; Powell & Courtice, 1983) The daily procedures of providing meals and assisting with toilet functioning fall on the shoulders of the primary caregiver. Nursing home residents do not benefit from Medicare, and Medicaid will only pay

after the "spend-down" is met.

Alzheimer's disease is a growing social problem because the expanding elderly population increases the number of individuals vulnerable to the possible development of the disorder. As the potential increase of Alzheimer's patients is occurring, there is a trend toward a decrease in the family support system. This means there are fewer people in the family to assume the burden of caregiving. (Silverstone and Bockin, 1982) Those assuming the caregiving role may experience higher levels of stress because of the excessive amounts of responsibility. Both of these factors influence the type and amount of care people with Alzheimer's receive.

To meet the needs of the caregivers, adult day care, other forms of respite care, and support groups have been formed in many communities. Centers providing day care to SDAI victims ideally have both medical/nursing facilities and rehabilitation opportunities. Socialization and recreational activities for the patient make up the major focus of the program while meeting the caregiver's need for time alone. Depending on the schedule of the program and the available funds, hot meals may also be served. Securing funds for these centers is the major problem and one that dictates what a program can offer. (Kodner, 1980) Respite care is an alternative coping mechanism. Nursing home or medical centers sometimes operate day care centers where Alzheimer patients may go for a few hours daily. The intention of respite care is to relieve the primary caregiver of the burden of providing 24 hour care. The home environment, which is familiar to the Alzheimer victim, may also be a place for respite care. Homemakers, a service usually found through a community agency, and

home health care services provide in-home types of respite care.

(Kodner, 1981) The opportunity for the caregiver to leave the house for a small amount of time can be supportive and refreshing for the individual.

The whole family is affected by the disease. (Powell & Courtice, 1983) Families dealing with an SDAT victim may be apprehensive about seeking help because of the stigma that the community places on mental impairment. There is a lack of knowledge of the disorder in the community and among physicians working in a community based practice . The support groups, which have recently been started in numerous communities, tend to alert people within those communities about the existence of the disease. (Silverstone & Bookin, 1982)

Self-help groups are places where people struggling with common problems can come to share and learn. (Toseland & Hacker, 1982)

Support groups provide information concerning symptoms, causes and expected behaviors related to the disease. Among group members, the sharing of feelings becomes a coping device against the devastating effects of the disease on caregivers. Relationships between family members and the support which can develop in that network are dealt with when family members agree to attend. (Zarit et al., 1982; Hartford & Parsons, 1982) In a pilot study conducted by Lazarus et al. (1981), members of the support group felt more in control of their feelings and the direction of their lives after they joined the support group. Some of the loneliness and isolation felt by caregivers were relieved by support group discussions and sharing.

Gwyther (1982) describes the roles professionals fulfill in the initial phase of self-help groups as being those of facilitator and

information giver. The professional group leader needs to clearly show how differently families react to the common experience of Alzheimer's. Finding suitable ways of coping and reinforcing the role of caregiver by showing its importance are essential tasks for the professional working with the families. The leader needs to be acutely aware of the varying levels of fatigue experienced by the different caregivers in a single support group. Gwyther (1982) suggests that the social worker's personal skills and previous group experience are very important. As the group becomes established, the professional should step out of the leadership role in the group and only provide consultation and support to the lay leaders.

Support groups are not the only resource in which social workers take an active role. Social workers should be present throughout the duration of the disease from diagnosis to death. (Kirschner & Rosengarten, 1982) An interdisciplinary team is essential in meeting the psychological, social and economic needs of families devastated by Alzheimer's disease. The social worker should complete a social history as well as an extensive assessment of the SDAI person's current functioning level including medications being taken, eating habits and social contacts. (Kirschner & Rosengarten, 1982; Aronson & Lipkowitz, 1981; Glassman, 1980) The social history will be more complete and helpful later if a description of any catastrophic reactions are included with the information. Catastrophic reactions are extreme reactions by a person with Alzheimer's. They are outrages or states of anxiety from something which normally would cause little or no reaction. (Rabins, 1981; Mace, 1981) The information collected should be shared with the professional network with the permission of

the family involved. Mobilizing community resources to advocate for better medical services during the diagnostic process, or even later, may be a social work role in certain communities. (Glassman, 1980)

From a community study, Aronson and Lipkowitz (1981) target three situations where social work intervention is necessary and suggest ways of dealing with the three. The single person with Alzheimer's disease who has little or no support from family or friends is the most vulnerable situation. All the fundamental tasks of living, such as cooking meals, managing money, etc. become a concern. The professional objective include making a realistic self-care assessment and setting up resources to insure the person's safety and personal well-being. The second arrangement involve a family which attempts to provide care but at the same time is overwhelmed with the responsibilities. Spouses who are elderly themselves and are the sole caregiver are typical examples of this arrangement. The professional must intervene to assure the safety of the Alzheimer patient and the spouse and at the same time give needed support and attention to the overwhelmed caregiver. Institutionalization may become necessary because of the spouse's inability to manage the SDAT person's condition. In situations where the person with Alzheimer's disease has an indifferent family but a friend who is willing to help, the social worker's responses will be based on legal concerns. The caring friend will not have legal rights over the finances of the person in order to secure necessary services. It is suggested that legal jurisdiction be sought as early as possible by the care providing friend in order to make adequate arrangements for the Alzheimer person. This is a delicate situation. Working with both the friend

and the family requires the social worker to take on the roles of mediator and advocate. Zarit et al. (1980) suggests that it may be more effective when working with overburdened caregivers to utilize the informal social systems available. Natural support networks, natural helpers and community resources are all suggested.

In the area of nursing home placement, the social workers and other professionals working in that setting should be available during the busy visiting hours in order to meet the needs of both family and patient. (Montgomery, 1982)

Perceptions and Needs of the Caregiver

One hour interviews were conducted with sixteen primary caregivers from the Alzheimer support group in Muncie, IN and with one social worker from a nursing home located in Muncie. The Muncie Support Group, during the time the interviews were conducted, had approximately 160 people on the mailing list. In the sample there were four males and twelve female caregivers ranging in age from early forties to middle seventies. In this group, 50 percent of the caregivers were in their forties. (see table 1) In contrast, the people with Alzheimer's Disease were all 60 years old or older. (see table 2) In the study, 46 percent of the caregivers were daughters and over half of the care providers were children of the person with ADAT. (see table 3)

There were four basic living arrangements existing between caregivers and Alzheimer patients in the study. Of the seven husband/wife relationships present (table 3), all of the spouses provided care in their own homes. Two of the caregivers, in addition,

had someone else living with them to help. These live-in people were hired by the caregivers and were strangers to the family before the disease became apparent. (see table 4) One caregiver commented on the difficulty of finding someone to take the position. After the person accepted the position, there were still problems because it was hard to keep the live-in assistant for any length of time. Three of the Alzheimer victims moved into family member's homes which required change for both victim and family. In terms of the caregiver living outside of the person's home, constant surveillance of the person's behavior and living environment were necessary. In one of the six cases, the family members took shifts in staying with the Alzheimer victim in her own home. This arrangement did not place the responsibilities all on one person, but allowed family members to share the burden.

Table 1 Caregivers

Age	Male	Female	Total
40-49	2	5	8
50-59	0	1	1
60-69	1	3	4
70-79	1	2	3
TOTAL	4	12	16

Table 2 Person with SDAT

Age	Male	Female	Total
50-59	2	1	3
70-79	6	5	11
80-89	0	2	2
TOTAL	8	8	16

Table 3 Caregiver's relationship to SDAT person

Daughter	1	3
Wife	1	4
Husband	1	3
Son	1	2

Table 4 Living arrangements

Caregiver not in home	1	6
Caregiving spouse in home	1	5
SDAT person moves in	1	3
Someone outside moves in	1	2

After the demographic information just described had been collected, the survey containing ten questions was administered. The questions were open-ended to provide insight into the perceptions and daily struggles of each individual caregiver. The following open-ended questions were used:

1. Could you list the five major problems you see that caregivers have?
2. Which would you say is the biggest problem?
3. What kind of help have you gotten in this area?
4. Do you know of any resources that could help you with this problem?
5. How did you find out about the support group?
6. What types of changes did you have to make in your everyday living?
7. As a caregiver, how have your responsibilities around the house changed?
8. Have the relationships within your family been effected by the disease? In what ways?
9. How do you cope with the stresses of caregiving?
10. Aside from the support group, what other kinds of help would you like to have now?

Each case of Alzheimer's is unique because of the varying effects on the person, the type of environment in which the person lives and the coping mechanisms of the family network. All sixteen cases were very different, but some of the major problems were reoccurring.

Each caregiver provided the interviewer with five of the major problems the disease had created for them. The most frequent major problem was the inability to get a complete night's sleep. (see table 5) Persons with Alzheimer's usually switch day and night activities or become restless at night. These nightly interruptions wear down the caregiver's strength. Seven of the caregivers listed the problem

of being tired and coping with restlessness of the Alzheimer patient as one of their major problems. One of the wives of a person with SDAT explained that while her husband was living at home she averaged about five hours of sleep a night. These precious five hours of sleep were not always consecutive. At various times during a single night, her husband would come into the room where she was sleeping and pat her on the head until she would tell him to go back to bed. This would happen three or four times a night.

Table 5 Question 1: Caregiver's major problems

restlessness at night	1	7	helplessness	1	7	financial	1	1
wandering/continual watching	1	5	violence	1	3	acceptance	1	2
confinement	1	4	physical/medical attention	1	7	lack of knowledge	1	2
dependence	1	4	incontinence	1	3	personality changes	1	2
isolation/loneliness	1	4	fear of falling	1	2	loss of someone	1	2
dealing with deterioration	1	3	knowing own limitations	1	2	guilt	1	1

The necessity of constantly watching the person with SDAT was the second most frequent problem list by the people interviewed.

Wandering and other behaviors requiring constant watching were described by thirty-one percent of the caregivers. One caregiver said her biggest problem was "watching him every minute". The spouse of one woman would continually take down the pictures off the walls of their home. Everything in her home had to be kept out of his reach. The social worker interviewed suggested the need for the family to create a safe environment in which the person could live. Car keys, poison and stairways become of particular concern when the Alzheimer victim continually explores and moves objects in the house. In many instances, the caregiver must use the same precautions that one would use in making the home safe for young children. Watching the person with SDAT is a necessary safeguard against accidents. One man had to

watch his wife carefully while on their weekly shopping trips because she had the habit of shoplifting. She could not remember that she had to buy the items she wanted.

Wandering away from the house is another part of the problem. Because the person with Alzheimer's Disease has trouble remembering things, they may be trying to go a specific place but are not sure where they are at a given time. Locking the doors became a tactic for one of the caregivers who listed wandering as a problem. The wandering of a person with the disease was described as dangerous by the daughter of a victim. Her mother may get lost, and because she does not speak, or recognize landmarks a stranger would not be able to direct her back home.

The complete dependency, the confinement placed on the caregiver, and the feelings of isolation and loneliness were all listed by other people interviewed. (see table 5) The dependency on the caregiver included following the person wherever he/she went, even to the bathroom. Some of the victims of SDAT would not allow anyone else except the person taking care of them to help them eat or do any other daily activity. It was hard for the caregivers to get out of the house because of the increasing deterioration of motor and mental capacities of the SDAT victim. Providing a wheelchair for his wife to use when going outside was one man's solution to coping with the confinement he continually felt. When constant care is required and the person with SDAT begins developing some strange behaviors, friends feel uncomfortable visiting and tend to visit less. Two of the caregivers described their situations as lonely because they did not have friends or family on which to depend. There was no one available

to talk with who would understand the loneliness and isolation that comes with an overdependent spouse.

The strong dependency Alzheimer patients have on their caregivers was chosen by twenty-four percent of the caregivers as being the biggest problem. (see table 6) This information was obtained from the second question on the survey. The caregivers felt that the amount of sacrifice in personal time and privacy was overwhelming. Watching the person with SDAT constantly, being followed by the person everywhere, and the refusal to be cared for by anyone other than the primary caregiver were all indicated in the survey as part of the dependency problem.

Table 6 Question 2: Biggest problem

dependency	!	4
dealing with deterioration	!	2
violence	!	2
feeling of helplessness	!	2
lack of knowledge	!	2
restlessness at night	!	1
financial	!	1
stays in bed	!	1
personality change	!	1
preparing meals	!	1

Table 7 Question 3: Help received with biggest problem

Nurse (in-home care)	!	6
support group	!	4
neighbors	!	3
physician	!	3
literature	!	2
lawyer	!	1
taking person out	!	1
psychiatric help	!	1
someone living in home	!	1
change physicians	!	1
Meals-on-Wheels	!	1
church support	!	1

It is from the demands of the dependent person and the deterioration of the disease that frustrations build-up and violence within the relationship by both the caregiver and the person with Alzheimer's disease can result. One of the daughters of an Alzheimer's victim confessed that her mother had trouble coping with the reality that her husband really had the disease. The frustration level was very high for her mother, and it was not uncommon for her mother to hit her father. There were no opportunities for her mother to "blow-off steam". Some of the behaviors which people with SDAT develop seem

purposefully planned to be stubborn, when in fact the deterioration is the cause. For those caregivers who are less informed or are under a high level of stress, these behaviors may be the catalytic factor in a violent episode. Violence was listed by two of the caregivers as being the most immediate problem. (see table 6)

Violent acts such as hitting or endangering a person in some way are also committed by people suffering from SDAT. An example of the violence possible would be the habit of one man who grabbed hold of his wife's hands or arms so tightly that it was very painful and dangerous. The person with SDAT was unaware of his strength and would not let go of his wife. One time she was not able to reach the phone to call her neighbor for help and was trapped in her house with the threat of being seriously injured. The caregivers are not always able to defend themselves. A person with Alzheimer's disease may not realize the strength that her or she possesses and the caregiver, in contrast, is tired from the 24-hour care responsibilities. This makes the caregiver very vulnerable to injury.

Two of the caregivers believed that dealing with the deterioration of the spouse was the biggest problem. Dealing with personality changes was difficult for one caregiver. It was emotionally difficult to accept that the person who once had provided intellectual stimulation must now be given directions on what to do if the phone rings. Two other caregivers did not see that the deterioration was as big a problem as just the overall feeling of helplessness that developed from all of the crises that occurred. The lack of knowledge about what to expect from someone with the disease presented a major problem for two other caregiver. The frustrations of not knowing

where to turn for help accentuate the feelings of helplessness.

Questions three and four of the survey sought information about resources used by caregivers. In both questions, the resource mentioned most often was the help provided by a nurse who administered home health care services. (see tables 7 and 8) In the Muncie area, the Health Care Center and the Visiting Nurse Association employ nurses who monitor the health of the homebound and also give bathing assistance. The second most commonly listed resource utilized by the caregivers was the support group. (see table 7) It is interesting to note that in question four, when caregivers were asked to describe sources of help for problems beyond the major ones, the caregivers listed none as the second most frequent answer.

As the caregivers deal with the problems created by the disease, changes in daily living patterns are necessary. The three changes most frequently described by the respondents were changes in financial arrangements, changes in life-style because of the necessary full-time care responsibilities and giving full-time care, and changes in the caregiver's mobility. (see table 9)

Table 8 Question 4: Known resources that could help

Nurses (in-home care)	1	4
none	1	3
physicians	1	2
neighbors	1	2
support group	1	2
National Association	1	2
family	1	1
Alpha Center	1	1
Silver Streak (transport.)	1	1
getting away	1	1
church	1	1
hospital	1	1

Table 9 Question 6: Types of everyday living changes

financial	1	5
full-time care/dependency	1	5
limited mobility	1	5
sleeping habits	1	2
whole schedule	1	2
teaching Mother to drive	1	1
visiting person less	1	1
stop working	1	1
sacrifice own needs	1	1
increase housekeeping	1	1
give up recreation	1	1
someone move in	1	1
visiting person	1	1

In the area of financial responsibilities, three of the five caregivers describing changes in daily living found it necessary to keep track of their personal finances for the first time. The other two people who made financial changes had to sacrifice some planned vacations and other expenditures in order to meet the financial needs of the person with SDAT. Paying for constant health care and obtaining power of attorney over the SDAT victim's finances were some of the changes explained in the interviews.

Providing full-time care was another change that five of the caregivers made because of the disease. The full-time care required made it necessary for some of the caregivers to give up planned vacations. Not only were vacations cancelled but, as one caregiver said, ". . . her [the person with SDAT] needs come first." Some of the other changes categorized in Table 9 were a result of full-time care requirements such as the necessity of one caregiver to stop working in order to watch her husband.

Providing full-time care was also a factor in the limited mobility the caregivers experienced in everyday living. The inability to leave the house on "the spur of the moment" was the most prominent change in daily living for one of the caregivers. One man who enjoyed many outdoor sports found it necessary to give up some of them because he needed to stay in the house more. Other caregivers found it easier to take their spouses with them on the shopping trips and outings to the golf course.

When looking at the changes made by the caregivers in terms of actual household responsibilities, taking control of the finances was again considered to be a major change for the caregivers. (see table

10) The increase or decrease in the amount of housekeeping duties were listed as changes by four of the people interviewed. Some of the caregivers mentioned that when a person has to be watched continuously the heavy housekeeping does not get done. For the male caregivers, the amount of their housekeeping responsibilities increased as their spouses with SDAT grew worse. Cooking the meals and shopping were new activities for some of the male caregivers. Two of the caregivers mentioned the need to keep all the furniture around the house in the same place. Catastrophic reactions, such as a person with SDAT refusing to sit in the living room because his/her favorite chair had been moved may result when changes are made in the house. Routine scheduling of meals, bedtime and medication also help to limit the number of catastrophic reactions.

Table 10 Question 7: Changes in household responsibilities

finances	1	5
routine schedule	1	4
housekeeping habits	1	4
shopping	1	2
watch person with SDAT	1	2
cooking meals	1	2
specific furniture placement	1	2
power of attorney	1	2
nurse for physical hygiene	1	1
no change	1	1

Table 11 Question 8: Relationships with family

supportive	1	5
drawn closer	1	3
guilt trip on caregiver	1	3
conflict	1	2
cannot cope	1	2
not accepting	1	1
do not talk about problem	1	1
not understanding	1	1
genetic worries	1	1
uncomfortable with SDAT	1	1
role reversal	1	1
lost contact	1	1
caregiver embarrassed	1	1

Question 8 dealt with effects Alzheimer's disease had on family relationships. Each caregiver gave a number of examples of how family relationships had changed. The change described most was that of a supportive family. (see table 11) Relatives outside the immediate family did not always completely understand the disease but were willing to do anything they could to help. The devastating effects of

the disease helped three of the families draw closer together.

Another situation which was described by three other caregivers concerned the attitude of the family toward the caregiver. One woman was placed in the nursing home by her family. The caregiver felt guilty about having to place her loved one in a nursing home even though she struggled to take care of the person in her own home. The family members were not always willing to accept that the caregiver could no longer handle or cope with the burden of providing constant care. Two of the three caregivers expressed feelings of frustration over the family's reaction because other family members were not at any time willing to try to take care of the person with Alzheimer's disease. One woman was placed in the position of having to go through a court battle with her stepsons in order to continue living in her home after her husband was placed in a nursing home. Not only did she feel guilty about placing him in the nursing home, but she was not given any support from the family members. Conflicts of that nature and also conflicts concerning who will provide care for the person with SDAT was cited by two caregivers as affecting the family. The daughter of a SDAT victim found that her caregiving activities took up a lot of time and began causing conflict within her own family. She said, "I began questioning how fair I was being to my children. I didn't always get things done at home. Where were my priorities?" One caregiver explained the struggle she was having with a necessary role change. She had to assume responsibilities that were once her mother's. The caregiver felt uncomfortable with the new relationship, but the way the disease affected her mother's behavior made the change necessary for her mother's safety. Some family members are

unsure of how to cope with the situations and behaviors of the SDA^T victim. The caregivers interviewed listed some family reactions as being uncomfortable, non-understanding and non-accepting of the disease. When the family does not talk about the problems associated with the disease or ignores the problem totally, as described by one caregiver, the caregiver is isolated from possible sources of help and forced to care for the SDA^T victim alone.

Finding the ways that caregivers cope with the different conflicts, responsibilities and behaviors was the purpose of question number 9 in the survey. (see table 12) The caregivers most often depended on hobbies, activities and sports as coping mechanisms. Six people in the study listed some type of activity as a way of coping with the constant care required. One couple enjoyed bowling and so did the husband's mother who had the disease. To help relieve some of the tension which would periodically build-up in the home situation, the family would regularly bowl and take the mother with them. They went on the same night every week which the mother incorporated into her routine and began expecting. This was a satisfactory arrangement for both parties. Other caregivers also found that taking the person with SDA^T along was enjoyable. Spouses were still able to enjoy some of the activities in which they participated before the deterioration of the disease became noticeable.

Table 12 Question 9: Ways to cope

hobby, activity, sport	!	6	church pastor	!	1	knowledge about disease	!	1
nursing home placement	!	3	senior citizens group	!	1	family	!	1
neighbors	!	2	professional help	!	1	tell person what he/she has	!	1
trusting God	!	2	support group	!	1	no way to cope	!	1
take person with SDA ^T out	!	2	supportive friends	!	1			
someone comes in	!	2	talk to people in nursing home	!	1			

Another way of coping with the stresses of caregiving suggested

by three of the people was nursing home placement. This action was very hard to accept for both the caregiver and the family involved. The caregiver was forced to accept that he/she was unable to adequately care for or meet the needs of the Alzheimer victim. The implications of this decision is not that the caregiver is inadequate as a care provider. Rather, the person with the disease has deteriorated to a point where the caregiver has sacrificed all of his/her needs to the care of the Alzheimer victim. For his/her own well-being the caregiver needs to be relieved of the primary caregiver role. Many of the ways people coped with the problems of Alzheimer's disease corresponded to the resources that were mentioned by the caregivers. (see tables 7 and 8)

The Alzheimer Support Group was considered both a resource and a way of coping for the caregivers. To find out where the caregivers received information about this resource question 5 was asked. Learning about the support group and where the meetings were held was primarily done by word of mouth. (see table 15) Six of the caregivers found out about the meeting by word of mouth from other families going through the same experience, church minister, or neighbors. The newspaper provided five caregivers with information about the support group. Two of the members had done a lot of personal research on the possibility of forming a support group and began the Muncie Support Group. The group has now been in existence for three years. In the survey, friends were also an important source of information about the support group. One of the friends who had provided information had had a similar situation with her own father. The Alzheimer's Disease and Related Disorders Association, Inc.

provides information on established support groups from the National Headquarters. However, only one caregiver used this resource.

Aside from the support group, the caregivers suggested a number of resources which they thought should be started or expanded in the Muncie Area. This information was in response to question ten of the survey. A day care center was the most common need mentioned. (see table 14) A day care facility in Muncie would bring considerable support to the caregivers. The facility would be a place where caregivers could drop off the person with SDAT and thus have a time of a respite for a few hours. Such a resource would need to have both a staff of professionals to provide adequate care and funding to finance the project. The staff would need to be flexible in providing care because of the diversity of people and the different levels of clientele functioning. The day care center would provide the person with SDAT an opportunity to socialize and would give the care provider free-time to relax, socialize and do other things. The caregivers are many times unable to accomplish necessary errands because of the constant monitoring needed of the Alzheimer victim.

Table 13 Question 5: Find out about support group

word of mouth	1	6
newspaper	1	5
friend	1	2
own information	1	2
National Headquarters	1	1
nursing home	1	1
professional contact	1	1
radio	1	1

Table 14 Question 10: Help needed now/ideas

Day Care Center	1	4
none	1	4
financial help	1	2
more support groups	1	2
in-depth explanation of SDAT	1	2
more friends	1	1
more work with family	1	1
Alpha Center participation	1	1
understanding doctors,nurses, nursing home staff	1	1

Two of the caregivers wanted to find out more about the disease. (see table 14) The hereditary implications, the causes of the disease

and the possibility of reversing the problems were all questions that caregivers had concerning the disease of their relative. The more information there is on the disease the easier it is for some people to cope with the effects of the disease. Information may be obtained through personal research or from consultations with physicians. One caregiver expressed a wish that physicians and social service agencies would work more closely with the whole family. More financial help was described by two caregivers as a needed resource. Families who have been successfully making ends meet find it difficult to have to ask for assistance as the cost of caring for the Alzheimer patient increases. Applying for a public assistance program can be a demeaning and undignified chore. The social worker interviewed found this reluctance to ask for financial help frequently in working with the families in nursing home. Guardianship and power of attorney are legal actions that can be taken to monitor the patient's financial status. Some caregivers were not informed of this possibility during the diagnostic process. One of the caregivers felt very strongly about the point that the doctors, nurses and nursing home staff should be more understanding toward the SDAT patient. The caregiver had trouble getting the nurses to understand that some of the actions by the person with Alzheimer's disease were not done on purpose or to irritate them. The understanding may develop as these professionals acquire more knowledge about the disease. Increased knowledge about the disease and a greater understanding by the professionals working with the cases were all suggested by the caregivers interviewed.

Limitations of the Study and Suggestions for Action.

This study of caregiver's perceptions of their needs has some limitations. The sample was not randomly selected from the total population of caregivers in Muncie. Only ten percent of the total membership of the support group was surveyed. Sampling members of the support group places further limits on the study. The survey only described the perceptions of those caregivers who were seeking help from the Alzheimer support group and who were willing to talk about the experiences through which they had lived. The survey was personal and the questions painful. The nature of the interview required caregivers to reflect on various moments during the progression of the disease which were painful to remember. Members of the support group were asked to participate in the study during one of the monthly meetings. People were also chosen with the help of Mr. David Duff, president of the support group. He provided names of caregivers who were willing to share their experiences. These caregivers were also asked if they knew anyone else from the support group who would be willing to be interviewed. The goal of the study was to survey caregivers and professionals having contact with caregivers. Two of the people were unable to be reached and one of the caregivers refused to be interviewed because the experience was too painful to be relived at the time of the interview. The coping levels of the caregivers and the ability to talk about the effects of the disease also restricted the size of the sample.

The reason for collecting the information was to expand on what the caregiver's perceptions and needs were during the progression of

the disease. It was not developed as a scientific study with statistically significant results as a goal. The study was meant to enhance the literature reviewed concerning caregiving and social work practice. Researcher bias tends to be the major drawback to the open-ended design used in the survey.

Some unanswered questions are raised from the type of sample used in the study. One concern is with those caregivers who are not attending the support group. There are no statistics on how many people in Muncie are taking care of a person with SDAI and do not attend or do not even know about the Alzheimer's support group. The support group affiliated with the Alzheimer's Disease & Related Disorders Association, Inc. in Muncie distributes a large quantity of information about Alzheimer's disease to the members, but those caregivers who do not attend the support group meetings may not be receiving this information. This information was cited by the caregivers as being one way of coping with Alzheimer's disease. (see table 12)

The figures in table 13 show that the most common way that caregivers found out about the support group was by word of mouth from friends and other non-professionals. Professionals provided this information to only one caregiver interviewed. This raises the question of how accessible information is about the disease and available assistance to physicians and other professionals. For example, because of the difficulties of diagnosing the disease, are physicians assuming that an Alzheimer patient's behavior is caused by age rather than a diseased process? The physicians may not be aware of the battery of tests required for a suspected diagnosis or

Alzheimer's Disease. Do the physicians and other service providers consider what affects this might have on the family involved and are they aware of what sources of help are available?

From the literature and the added information compiled from the survey, two general suggestions are made. The first suggestion would be to make information about Alzheimer's Disease and resources for coping more available to the caregivers. Information concerning symptoms of the disease, ways of coping with the progressive deterioration and lifestyle changes and added financial burdens should be provided. This would involve educating the physicians, social workers and other professionals in this field. Funding for in-services training and continuing education classes in geriatrics and gerontology need to be made available.

The social workers will be able to provide comprehensive assessments and realistic goals and objectives when working with the family if the knowledge about common caregiver struggles are applied in practice. Service providers need to be aware that families are involved with their elderly relatives. These relationships are an important component of their well-being. It is important for agencies to develop policies which broaden their clientele to include families. Another possibility for families would be more funding for the provision of incentives for taking care of the Alzheimer person longer. The incentives would make it possible for the family to continue meeting the needs of the SDAT victim.

Meeting the needs of caregivers must go beyond the direct service work of the practitioner. Community action is necessary in some instances. Legislative steps must be taken to secure funding for

proposed day care centers in Muncie and in other communities. Increased funding for already established programs that provide in-home respite care is also recommended for a more complete coverage of the diverse set of needs found among the families. Additional tax credits for those with dependent adults and available monies for the renovation of homes to provide safe, stimulating environments are also possibilities.

The support of further research on Alzheimer's Disease is a necessity for more insight into the causes and possible affects of the disorder. More research in the areas of physiological changes, possible causes of the disease and effects on the family will help increase resources for Alzheimer caregivers.

Conclusion

Alzheimer's disease is a deteriorating brain disease which not only effects the life and behaviors of the person having the disorder, but also places many stresses on the family which must provide constant care. There are a multitude of problems with which the caregiver of someone with SDAT must cope on a daily basis. In addition to helping the patient, the helping network needs to also direct its attention towards the caregiver who is generally overwhelmed, tired and many times alone in providing care.

Knowledge about the disease is in its infancy and more research should be done about the disease and the strain it places on the family and the primary caregiver. The survey conducted to supplement the available literature on the needs of caregivers showed the

diversity found among this group of people. The problems caregivers have concerning the total dependency and the lack of predictability of the Alzheimer victim can be lessened with the use of day care and respite services. The development of such resources points toward a need for lobbying and legislative action to secure adequate funds.

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