Addressing the Needs of the Cognitively Impaired Elderly From a Family Policy Perspective

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Management of the cognitively impaired elderly person in the community is presumed to be cost-efficient and the American way. Although this is what should be done, most would agree that paying for the services that make it possible to do so is not currently within the means of the median income of the family ($25,986) or of the female head of household ($15,350) in this country. This paper reviews the changes in the family, current family policies, and practices of our businesses and government and proposes the services that could be used to support both the impaired person and the family in the management of this evolving societal issue. Strategies for development of payment mechanisms for the proposed services are presented.

Since the 1960s, a new phenomenon has developed: Middle-aged people have increasingly experienced the presence of an older adult in their kinship network. By 1963, approximately 25% of persons over the age of 45 years had a surviving parent. By the early 1970s, 25% of persons in their late 50s had a surviving parent, as did 20% of those in their early 60s, 10% of those in their late 60s, and 3% of those in their 70s. At the time of this writing, 10% of all elderly persons have a child over the age of 65 years (Select Committee on Aging, 1987). By 1987, there were 29.8 million persons over the age of 65 years. This number will grow steadily but more slowly in the 1990s, to 34.9 million in the year 2000. This slowing is due to the relatively few number of babies that were born during the Great Depression era. The most rapid increase in persons over 65 years of age will occur between 2010 and 2030, when the baby boom generation reaches the age of 65 years. At that time, the number of elderly will jump from 39.4 to 65.6 million persons (Staff, 1988). Along with the increase in older adults, we are facing an alarming increase in the number of older adults with senile dementia of the Alzheimer type (SDAT).

Most dementias occurring in the general population occur in persons aged 65 years and older; the frequency of the dementias is in the range of 3% to 5% of the elderly residing in the community. An additional 2.5% of persons with dementia in long-term care facilities must be added, yielding a total of 5.5% to 7.5% of the total population aged 65 years and older with SDAT (approximately 2 million persons). The prevalence of SDAT is relatively low before age 75 years but increases to 20% or more in persons aged 80 years and older (Gurland, 1985; Select Committee on Aging, 1987).

The implications of these projections are staggering, because persons with SDAT experience a progressive loss of functional capacity that necessitates the supportive presence of a caregiver from the earliest stage of the disease process. Adding to this problem, the declining fertility rate has caused a smaller population to care for the needs of these persons. Daughters constitute 29% of the population of caregivers; wives, 23%; husbands, 13%; and sons, 9%. The remainder of caregivers is composed of daughters- and sons-in-law, grandchildren, siblings, other relatives, friends, and other unpaid helpers (Select Committee on Aging, 1987).

The median family income in 1988 in the United States was $25,986 (Cashell, 1989), with women making a significant contribution to that amount, whereas the median income of households headed by women was $15,350. When a family member forfeits employment to care for an impaired person, it threatens the family’s income as well as the ability to purchase goods and services that support the economy. Employment represents a potentially conflicting demand for caregivers. A major insurance company recently conducted a survey and found that approximately 20% of their workers aged 30...
years and over were providing some form of care to an older adult, and in 10% of the cases, they reported spending more than 35 hr a week at this task in addition to their full-time job. National estimates indicate that 11% of caregivers actually quit their jobs to assume the caregiver role (Select Committee on Aging, 1987).

By 1986, approximately 52 million women were in the work force, 200% more than at the end of World War II. During this same period, the number of men in the work force increased by only 50%. The trend of women working shows no sign of abating. The need for child care services has moved from being a family concern to being a political issue (Bloom, 1986). Now a new issue is on the agenda—the need for elder care. Currently, the average woman will spend 17 years of her life caring for a dependent child and 18 years caring for dependent parents (Select Committee on Aging, 1987). Tight labor markets will cause employers to build incentives to support working caregivers, and because 75% of new jobs will be in service and product industries, which are jobs that traditionally have been held by women, these jobs will need to allow for flexibility (Bloom, 1986). Rising wages and innovative personnel practices will relieve financial and complex logistic burdens on children who are acting as caregivers to their elderly parents. Because men also participate in the caregiving process, they too will need flexibility to balance the new demands on their day.

The Effect of the Cognitively Impaired Elderly on Families

The importance of adult children in the lives of the elderly has been investigated in several major studies in the 1970s and 1980s. Most older persons wish to be independent of their families. However, when in need of assistance and in times of crisis, they turn to their children (Bengtson & Treas, 1980; Brody, 1977; Shanas, 1979). Our nation is confronted today with an aging population, and although older Americans enjoy improved health and economic status, the composition of the older population now includes the very old (i.e., those over age 85 years). Their survival depends on others’ resources. Not only has the number of older Americans increased, but their proportion relative to other age groups has grown dramatically. The care of aging parents is threatened by the declining birth rate and by social change. Kin resources become easily overextended because there are fewer adult children to share the responsibility, and most studies show that geographic proximity also creates a problem. Children provide aging parents with companionship, financial aid, gifts, advice, and counsel. These family exchanges usually reveal a sexual division of labor. The daughter usually fosters close emotional ties through services and visits, and the daughter is usually responsible for the care of the elder family member. Most women now work because they need the money (Brody, Kleben, John-

sen, Hoffman, & Schoonover, 1987), thus the number of women who will quit work to furnish daily care to ill elderly family members is uncertain (Treas, 1977).

Most of the research on aging and the family presumes marriage and parenthood. The nuclear family model tends to establish filial support as the measure of family relations in later life (Shanas, 1962). This approach has overlooked the age-peer relationships with extended kin and friends who conceivably also function as part of the informal support system (Johnson & Catalano, 1983). Cicirelli (1983) suggested that older people will substitute close relationships with more remote kin when children are not available, or they will consider help from unrelated support persons. Lopata (1979) suggested that the potential for aid from relatives other than children has been grossly exaggerated. Johnson and Catalano (1981) studied 28 older adults that had been released from an acute care hospital in San Francisco to determine the social support system for childless adults. The childless married group had fewer resources from which to draw than even the childless unmarried group. The childless unmarried group were socially active with friends, neighbors, and church activities. The childless married group, however, were not socially active and had fewer kinship resources. Friends provided an important source of sociability but were not a source of instrumental assistance for this group. For the childless married group, distant kin (nieces and nephews) became intermediaries and served as managers to get formal support.

Currently, only 5% of our nation’s impaired elderly are institutionalized. The proportion rises from 2.1% of those under 75 years of age, to 7.1% of those from age 75 to 84 years, to 19.3% of those aged 85 years and over (Brody, 1985). Among elderly persons with impaired skills in daily living, only 1 of 5 are living in nursing homes; the remainder live in the community, primarily because of the assistance of family, friends, and neighbors. Furthermore, about three fourths of noninstitutionalized disabled elderly rely solely on voluntary, informal care. Only 5% receive all of their care from paid sources (Liu, Martan, & Liu, 1986).

Currently, there are over 5 million childless older Americans, or about 20% of the population over age 65 years. Without children, the elderly are at a disadvantage regarding access to informal help. This trend is expected to increase in the next century (Treas, 1979). Another possible limitation in providing help for the elderly patient is the increase in marital disruption. Shanas and Sussman (1977) estimated that 42% of all family types in the United States in 1976 were composed of remarried adults; widowed, separated, or divorced adults; and single adults. Adult children in this category frequently face financial difficulties (Troll, Miller, & Atchley, 1979), practical problems with duties of everyday living (Stevens-Long, 1979), and problems in interpersonal relationships with parents (Spanier & Hanson, 1982). These problems and
others, such as adjusting to new family situations (e.g., adjusting to a new spouse or to work responsibilities) may limit the ability or the willingness of adult children to provide assistance to their elderly parents.

In a study conducted by Montgomery, Gonyea, and Hooyman (1985), the majority of caregivers had provided unpaid care for 1 to 4 years; however, one fifth provided care for a cognitively impaired person for more than 5 years. Eighty percent of caregivers provide assistance 7 days a week. Seventy-five percent of daughters and others, such as adjusting to new family situations (e.g., adjusting to a new spouse or to work responsibilities) may limit the ability or the willingness of adult children to provide assistance to their elderly parents.

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Caregiving averaged 36.7 hr per week for the care of a person with cognitive loss and 24.8 hr per week for the care of a frail elderly person; the time difference is due to the fact that the person with cognitive impairment must be supervised. Four out of 5 persons provide housekeeping chores, financial management, and transportation, and two thirds attend to personal care needs, including activities such as bathing, dressing, and meal preparation. Fifty percent of caregivers must help the impaired elderly person with such basic tasks as getting out of bed or moving around inside the house (Select Committee on Aging, 1987).

Cicirelli (1983) conducted a study to explore the amount of help provided by adult children who have experienced marital disruption and compared it with the help provided by children with intact marriages. The children's help to their parents was assessed for 16 types of services, which were classified into three groups: daily maintenance of independent living, social and community activities, and psychological support. Adult children with marital disruption attempted to meet their parents' need for help, but this help was found to be significantly less than that given by children with intact marriages. Job responsibilities were cited as a main reason for limited help. Psychological help was an area where those with marital disruption found that they could be helpful. Perhaps their own losses make them sensitive to their parents' needs in facing the losses encountered in old age. The most significant level of help among all children was in the social and community area, whereas help with the maintenance of daily life was at the lowest level among all children. Twenty-nine percent of the adult children with intact marriages and 16% of those with marital disruption believed that they could continue to help their elderly parents under any circumstances. The number of elderly who need help will increase, and marital disruption will become the norm. This finding again suggests the importance of formal social support for aging parents to provide direct care for the impaired elderly.

Some families, when faced with an elderly parent in need of assistance, provide assistance by bringing the parent into the home. Mindel and Wright (1982) conducted a study to understand the importance of family life satisfaction. They based their model on the hypothesis that kinship ties that provide mutual aid and help with household tasks and child care would produce satisfaction, and that the extent to which the arrangement might cause inconvenience and lack of privacy would be seen as negative. Fourteen household and extra-household activities were categorized into five family roles: housework, child care, cooking, home maintenance, and outside employment. The results showed that the more dependent the elderly person, as measured by age, impairment, activity, and role behavior, the lower the family satisfaction. When the elderly person could assist with the family activities that contributed to the functioning of the household, the arrangement was satisfying. It was found that without specific directions and supervision, the cognitively impaired person could not assist the family and thus might cause disruption in a family that is already managing a complex series of events and activities.

Shanas and Sussman (1977) suggested that the United States has organized a structure that provides education for the family and care for the sick and frail and that the family's major role is to provide emotional support and crisis intervention and to link the elderly person to the bureaucratic system. The situation that has evolved over the past two decades, however, would challenge Shanas and Sussman's position. The data support the presence of a voluntary system of caregivers who provide care that ranges from emotional support to assistance with even the most basic activities of daily living. If we are going to control the costs of managing the impaired elderly, we must design and implement methods of maintaining them in the community. Such an approach relies on family members, which makes for a social problem: How will we as a nation balance the demand for productive workers with the demand for care for our nation's elderly?

Problems Faced by Families Caring for the Cognitively Impaired Elderly

Because SDAT affects many people, we must proceed cautiously, but we must also recognize the urgency of the problem. The management of a person with SDAT is expensive. We must consider the cost of both social services and lost income. The Alzheimer's Disease and Related Disorders Association estimates the annual costs for nursing home and community care, omitting the hospital and physician services under Medicare and private insurance, to be $23 billion for the nation (Kane, 1986). Hay and Ernst (1987) projected the annual expected direct costs for families providing care to be approximately $9,000. They also suggested that the expected indirect costs contributed each year by the family approach $9,000, thus totaling $18,000.

The literature describes disruptive behaviors and deficits in the person with SDAT that are troublesome to the caregiver. Such descriptions include aggressiveness, outbursts, assaultiveness, wandering, disturbed sleep,
and incontinence (Swearer, Drachman, O'Donnell, & Mitchell, 1988) as well as agitation, insecurity, lessened responsiveness, lessened cheerfulness, irritability, selfishness, crudity, and suspiciousness (Rabins, Mace, & Lucas, 1982). These characteristics indicate the difficulties that caregivers face in managing a cognitively impaired person. They do not indicate that disruptive behaviors are not present in all stages of the disease or in every person with SDAT.

SDAT is slow and progressive and occurs in stages. The life expectancy of an afflicted person can be 10 years or longer. Provided below is a description of the capabilities of individuals with SDAT throughout the disease process. I have summarized the mean scores of persons with SDAT by disease stage, as measured on the Functional Behavior Profile (Baum, Edwards, & Morrow-Howell, 1991). This description provides an overview of the problems that both the impaired person and the caregiver face in dealing with SDAT. Whereas most descriptions of SDAT report the person's troublesome and disruptive behaviors (Swearer et al., 1988; Teri, Borson, Kiyak, & Yamagishi, 1989), I have described the person's capabilities. Such an approach will help clinicians design educational strategies that can help the caregiver learn to support productive behaviors that can lead to successful management strategies.

Stage 1. Persons at the initial stage of SDAT usually show appropriate behavior in activities and can do what they are asked to do if the instructions are simple. These persons can safely be left at home alone. They usually perform activities without frustration and in a reasonable time frame, but they may need encouragement to begin a task. They cannot learn a new, complex activity, but they can perform complex tasks that have been used so frequently that they become automatic. The caregiver begins to face problems at this stage, particularly with the impaired person driving. Additionally, the relationship between the caregiver and the impaired elderly person is changing, and all involved notice that something is seriously wrong.

Stage 2. At this stage, which is still relatively mild, persons continue to perform activities appropriately and are independent in grooming and hygiene. They can perform a simple task independently, but often need encouragement to begin the activity. They need cognitive support to perform a more complex task (i.e., a task with multiple steps). They can often perform a task that they have overlearned independently. They can socialize when another person has initiated the conversation, especially if the topic is simple and direct. If they are successful with what they want to do, they are not frustrated, but this requires the caregiver to simplify the task and assist the person verbally in the stages of the task. It is no longer a good idea to leave such persons alone if they cannot independently make a local phone call. They could push a Medicaid button if the cue were evident, but that would be risky. It now takes more time for them to do something, because they rely on someone else to give directions for completing the task. Problems at this level include the need for supervision. This is sometimes difficult because of the family system and the need to be respectful to the elderly person. The family will need to make decisions about work schedules, day-care programs, and, possibly, respite services. The family may need counseling and assistance with legal and financial planning. At this stage, caregivers must learn how to provide cognitive support and investigate the range of services that will help them balance their role as caregiver with other family and work roles.

Stage 3. This stage is quite problematic for the caregiver, because the impaired person can no longer perform any activity without either verbal or physical assistance. The impaired person can still identify familiar persons and usually performs activities appropriately. For example, the person can be taken to the store and out to family activities. Simple tasks can be performed if cognitive support is given. The person cannot do something that involves more than two steps and, if asked, may become anxious or frustrated. The person at this stage needs to be verbally guided through most tasks, unless these tasks have been overlearned. If a safe environment is set aside in which to perform overlearned tasks, the impaired person will usually be able to perform them without assistance. Day-care facilities are critical at this stage, as is access to respite services.

Stage 4. One might think that persons in this final, severe stage cannot do anything for themselves. Often, people in this stage are in nursing homes, but for many reasons (e.g., costs ranging from $24,000 to $40,000 annually) a substantial number remain at home. Persons in this stage can still respond to a one-step command, but the request must take into consideration their physical capabilities. Specific verbal guidance must be provided to elicit every movement. For example, in feeding such a person, the caregiver would have to instruct him or her to (a) hold the bread, (b) put it to the mouth, (c) open the mouth, (d) take a bite, and (e) chew. One can imagine the demand placed on the caregiver who must perform this step-by-step cueing with every activity of feeding, hygiene, and dressing. The impaired person also has the capability to respond when others initiate a conversation, but performance in this area will depend on whether a language impairment is present. In-home assistance would be necessary at the point that the person could no longer attend day care.

The literature suggests strategies that can be helpful in the management of a cognitively impaired person (see Table 1). One important consideration that must be addressed when the family is required to provide care to a cognitively impaired older adult is that caregiving requires the family to develop specific skills in order to provide adequate support. Described below are services...
Table 1
Strategies for the Management of Elderly Persons With Cognitive Impairments

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Author</th>
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<tbody>
<tr>
<td>Behavior modification</td>
<td>Haley, Brown, &amp; Levine, 1987; Zarit &amp; Anthony, 1986</td>
</tr>
<tr>
<td>Organization of a schedule</td>
<td>Cohen et al., 1984; Quayhagen &amp; Quayhagen, 1988</td>
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<tr>
<td>Organization of the environment</td>
<td>Cohen et al., 1984; Quayhagen &amp; Quayhagen, 1988</td>
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<tr>
<td>Exercise</td>
<td>Zarit &amp; Anthony, 1986; Quayhagen &amp; Quayhagen, 1988</td>
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<tr>
<td>Maintenance of interpersonal relationships</td>
<td>Cohen et al., 1984; MacDonald, 1978; Matonko, 1989</td>
</tr>
<tr>
<td>Family included in care plan</td>
<td>Cohen et al., 1984; Quayhagen &amp; Quayhagen, 1988; Quayhagen &amp; Quayhagen, 1988</td>
</tr>
<tr>
<td>Family given resources and readings to back up their need for skills</td>
<td>Cohen et al., 1984; Quayhagen &amp; Quayhagen, 1988</td>
</tr>
<tr>
<td>Education about the disease</td>
<td>Cohen et al., 1984; Quayhagen &amp; Quayhagen, 1988; Quayhagen &amp; Quayhagen, 1988; Rabins, Mace, &amp; Lucas, 1982</td>
</tr>
<tr>
<td>Support groups</td>
<td>Rabins, Mace, &amp; Lucas, 1982</td>
</tr>
<tr>
<td>Activities developed together</td>
<td>Rabins, Mace, &amp; Lucas, 1982</td>
</tr>
<tr>
<td>Training in communication skills</td>
<td>Rabins, Mace, &amp; Lucas, 1982</td>
</tr>
<tr>
<td>Engagement in activities performed previously</td>
<td>Quayhagen &amp; Quayhagen, 1988</td>
</tr>
<tr>
<td>Continuance of normal responsibilities for as long as possible</td>
<td>Zarit, Orr, &amp; Zarit, 1985</td>
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that, if organized into a well-established community social service network, would provide the maximal level of support to caregivers in managing the cognitively impaired elderly person.

A Community Approach to Caring for Persons With SDAT

Instead of using a professional case management approach, the staff of the Memory and Aging Project at Washington University in St. Louis suggests that a professional team train the caregiver to be the case manager. This approach was developed with information identified by Clark and Rakowski (1983) in a study of family caregivers in which they categorized the tasks required of a caregiver in providing assistance to impaired older adults. The approach supports the caregiver in developing the skills, attitudes, and confidence to function in the roles necessary to support the person with SDAT in the community. This approach allows the caregiver to acquire skills in clinical observation, direct care, management, and treatment initiation through a formalized home training program.

Clinical observation. The caregiver needs sufficient understanding of the characteristics of the disease to provide accurate assessment and historical data and to be able to report changes in the condition of the person with SDAT. He or she also needs the skills to report reactions to interventions and treatment to the physician, other professionals, and family members.

Direct-care skills. The caregiver needs to learn to recognize and understand the needs of the elderly person and learn the techniques that the professional team member recommends to solve problems he or she faces on a daily basis. This necessitates that the caregiver acquire specific and unique skills that are required to care for the person with SDAT.

Management. The caregiver must learn what services could be helpful in managing the impaired person. Additionally, the caregiver must learn how to access and coordinate the services to benefit both the impaired person and other caregivers.

Treatment initiation. The caregiver needs to recognize that new situations and unexpected problems are likely to arise constantly. The caregiver must also motivate the impaired person and maintain support so as to enhance function, thus minimizing the burden of care.

The goal of such an approach is to provide the person with SDAT and the caregiver with the resources and skills necessary to achieve a livable situation in the community, where the well-being of both the family and the person with SDAT is maintained without undue burden. The ultimate objective would be to provide the caregiver with the skills and support to function as a case manager. To begin this process, the current approach to care must be expanded.

A professional staff member, for example, a nurse, a social worker, or an occupational therapist, would initiate a case, complete the intake assessment in the home environment, and bring in other professionals to assess identified problems that interfere with either the function of the person with SDAT or the family unit. He or she would coordinate a planning meeting with the professionals involved, including the primary physician and the caregiver, to establish an individualized care plan for the person with SDAT. This plan would identify the services that would be available for care of the impaired person in the community. The care plan might, for example, include training in the provision of cognitive support; recommendations for day care and family or personal counseling; and resources available through community agencies. With this information, the caregiver should have the knowledge and resources to begin to balance the role of caregiver with other family and personal responsibilities. Training of the caregiver will require support for several months, much of which can be accomplished through occasional visits and telephone consultations.

Not all of the services that could assist the caregiver in managing the impaired person would be necessary for each person or family (see Figure 1). The appropriateness of the service would depend on the needs of the impaired person and the resources and knowledge of the caregiver. Many of these services are currently available in
the community, either through community services for the elderly, organizations serving the disabled, or social groups. Ideally, health professionals would locate and work with community resources to build a network with and for the caregiver so that the services needed to manage the cognitively impaired elderly in the community become available. The policy concern is that there currently is no system to help caregivers access these services in the context of an individualized family-centered plan and that the payment for these services is limited.

Occupational therapists must work with community leaders to build a comprehensive system for the management of our cognitively impaired and frail elderly. What follows is a description of the community services that occupational therapists could use or develop to meet the needs of families caring for cognitively impaired elderly persons. This model involves professionals from several disciplines (i.e., occupational therapy, physical therapy, nursing, medicine, social work, family therapy, psychology, and law) working together to address the problem.

### Service and Training Programs

**Patient counseling.** Individual counseling can be provided to the person with SDAT if he or she is capable of developing improved coping mechanisms for facing life changes.

**Couples and family counseling.** Couples coping with the changes in their marriage because of SDAT can receive emotional support and treatment of psychological problems and issues resulting from the effects of dementia. The treatment would include psychotherapy and psychopharmacologic options, when indicated. Families can receive the same kind of counseling to understand the changes that they are facing. Specific training can be provided for adult children who are facing the changing role of managing a dependent parent; some adult children have difficulty with the role-reversal process that must occur.

**Crisis intervention programs.** Crisis intervention programs must be available to provide support when an
emergency occurs in which the person in crisis feels insecure about his or her ability to resolve or handle a given situation. This applies particularly to families of caregivers who have not yet developed the coping skills necessary to deal with unexpected changes. A family member may be experiencing stress or have an acute onset of psychological distress. Some hospitals and community agencies have developed hot lines that support family members.

**Driving evaluation and consultation.** A patient with memory problems may be unwilling to admit that he or she can no longer drive. Family members, often confused as to when a person should no longer drive, may not know how to intervene. A driving program offers help with this dilemma. The occupational therapist evaluates the elderly person's vision, perception, hearing, reaction time, problem-solving ability, coordination, attention span, and memory. If the person passes a prescreening assessment, he or she is scheduled with a certified driving instructor and an occupational therapist for an on-the-road evaluation. In the early stages of SDAT, a patient can sometimes **continue to drive** under limited conditions but should be reevaluated at regular intervals. The information provided by a driving assessment is given to the primary physician, who then has objective information to discuss in planning with the family.

**Exercise and recreational group treatment.** An exercise and recreation program can combat the effects of a sedentary, isolated life-style. Persons in such a program meet in two 2-hr sessions per week. The routine involves stretching, **walking**, engaging in group activities, receiving refreshments, and socializing. Activities include 20- to 30-min units of activities such as modified volleyball, croquet, bowling, sing-alongs, or dancing, followed by a relaxation period. A second session with **more** gentle exercise and activity serves those requiring a lower level of exertion.

**Home-delivered meals.** For persons that qualify, Meals On Wheels can assist families with this need.

**Home health services.** Specialized services in the home can be provided, however, the regulations would need to be expanded to allow a 6- to 8-week in-home period of training under Medicare. Some of the services could be implemented in a **limited** way under the current regulations if other conditions initiated the referral. Nurses could provide medical management, drug monitoring, and bowel and bladder management. Occupational therapists could provide specific life-skills training to caregivers, such as techniques to modify the environment, cuing training to assist with self-care, and the setting up of routines that would promote the highest level of performance. Additionally, therapists could recommend and train the caregiver in the use of specialized equipment to support independence and could set up in-home workstations that use the impaired persons' overlearned or job-related skills to engage them in familiar tasks, thereby freeing up some of the caregiver's time. The goal of this particular approach is to determine a way to tap overlearned skills to create an in-home work environment that allows the person with SDAT to engage in familiar tasks for periods of time during the day without placing demands on the caregivers. This may involve the use of music or the use of a **trade**. Examples include plumbers with plumbing stations, electricians with electrician stations, and homemakers with designated cleaning and folding tasks. This approach has allowed for persons with SDAT to engage in meaningful activity, thus enabling other family members to carry on with their activities without interruption. Physical therapists could provide mobility assessment and training, including equipment use; enhanced safety in the home and community; **training of the caregiver** in safe and efficient transfer techniques; and home exercise programs to maintain appropriate movement to support the patient's performance. Through the design of an exercise program for both the impaired person and the caregiver, a joint activity could reduce stress on both parties. Speech pathologists could evaluate and treat the patient's communication skills in the home, including training the person with SDAT in the use of an emergency telephone line and developing a specialized augmentative method of communication for the family to use for life tasks if verbal communication has broken down. Specific strategies can often promote communication, which brings increased satisfaction to both the impaired person and the caregiver.

**Mental health services.** Caregivers can be referred for emotional support, treatment of psychological problems, and counseling on stress resulting from dealing with patients with SDAT. Treatment would include dynamic-oriented psychotherapy, cognitive therapy, supportive therapy, and psychopharmacologic treatment, as indicated.

**Transportation.** Voluntary transportation can be provided to take a family member to the doctor or to day care, when feasible. If that is impractical, several agencies provide transportation at a cost. Many day-care facilities include transportation as part of their services.

**Respite Services**

**Adult day care.** A respite care program in the form of adult day care includes social activities and a meal furnished to participants. Day care is designed to present a meaningful, structured environment in which the SDAT patient can retain skills. The program usually operates for 8 hr a day, and arrangements can be made for a program that runs either 2 or 3 days per week; special provisions can be made for half-day programs. These arrangements allow the caregiver respite and continued employment. Some progressive corporations are beginning to explore
this type of service as part of an employee benefit package.

*Aides, homemakers, and companions.* Homemakers and companions can be provided through private-duty nursing facilities to help with household chores and personal services. Some agencies are training their employees to address the needs of the SDAT patient.

*Community programs.* Some communities have programs that provide services to both impaired elderly and their families that are organized through the county health department or that fulfill the intent of the Older Americans Act (Public Law 89–73). These programs should be identified and made available as resources to families with special needs. For example, in St. Louis, two such programs have been developed: the STAES (i.e., System To Assure Elderly Services) Program and the Older Volunteer Service Bank. The STAES Program uses older volunteers who are recruited and trained to assist needy elders in their neighborhoods. Monthly support groups for the volunteers reinforce participation and continued training. Volunteers provide telephone reassurance, friendly visits, in-home services, and information and referral. Professional staff provide backup and assistance for volunteers encountering difficult situations. The Older Volunteer Service Bank was initially developed for the purpose of having seniors help other seniors and themselves at the same time. In this program, persons 60 years of age and older volunteer to provide respite care to other persons in the same age bracket. The number of volunteer hours are banked and can then be drawn on by the volunteer if he or she needs similar services in the future. As part of a senate bill passed in 1987, this service was expanded to a statewide program to allowed younger volunteers to provide respite care and donate their banked hours to a person 60 years of age or older. Because respite care for persons with SDAT has been a critical issue, the expansion of this program will help more caregivers. At the time of this writing, however, this particular program has not been successful statewide.

*Weekend respite.* Some nursing homes provide respite care on the weekends for older adults with SDAT. This allows families to continue with family activities.

*Extended overnight respite.* Some nursing homes provide temporary nursing home care for a minimum of 7 days for patients with SDAT still residing in the community. The program includes medications, meals, bathing, nursing assistance, and activity-based programs designed to sustain the patient’s level of performance.

**Caregiver Support**

*Support groups.* Support groups of the Alzheimer’s Disease and Related Disorders Association can be the basis of help for caregivers who need to gain understanding of and learn techniques for dealing with common problems. Support focuses on caregiving and its difficulties. Support groups are sponsored by various agencies in many metropolitan areas, and although rural areas do not have as many formalized support groups, churches often fulfill this function.

A 24-hr hot line. The State of Missouri, through the Missouri task force of the Alzheimer’s Disease and Related Disorders Association, has established a 24-hr hot line staffed by the Missouri Division of Aging. Hot-line personnel have received special training in handling Alzheimer information and referrals. Currently, most calls are referred to the association. This service differs in each state, but it should be investigated.

**Educational Programs**

*Time management.* The caregiver can be encouraged to identify those behaviors on the part of the person with SDAT that trigger a stressful situation. The caregiver is then provided with coping strategies that use resources, other family members, and new skills to provide support for stress reduction. The principles of time management are shared on an informal basis within the context of the person’s environment and family structure, in the hopes that the caregiver will develop routines and methods of managing a complex set of activities and yet retain some individuality and opportunity for personal achievement.

*Accessing and choosing resources.* Caregivers can be given a thorough understanding of local resources, including sources of payment from the Social Security Act, Public Law 89–73, and local nonprofit and private payment options.

*Medication and personal care issues.* Updates on advances in Alzheimer research can be provided. Caregivers can be assisted to reexamine their role expectations through discussions and the completion of questionnaires. Physicians can be called on to conduct education programs on medication use. Areas that have Alzheimer research centers are encouraged to provide this type of assistance to the community.

*Financial planning.* The caregiver may need assistance in reviewing his or her assets, liabilities, health and life insurance, and investments. Families can be assisted in developing short-term and long-term budgets in anticipation of increased costs and decreased income. Creative planning early in the disease process should alleviate stress.

*Legal planning.* The family often needs help with making decisions about personal and financial affairs while the person with SDAT is still competent. For persons who are no longer competent, caregivers may need to be counseled about legal concerns and remedies. Attorneys have been cooperative in participating in educational sessions to review the guardianship laws, probate issues, creative use of durable power of attorney, and living trusts. The goal of caregiver education is to help
families see the advantage of promptly seeking educational assistance before the loss of legal competence. Otherwise, legal guardianship and cumbersome supervision of a probate court are unavoidable.

Preparing for nursing home placement. This program focuses on the effect of necessary home placement on the patient and caregivers. Family members will review the relative benefits and problems associated with long-term care. Topics will include the easing of the transition, guilt, and anxiety; the reestablishment of social activities; and the facilitation of the involvement of other family members.

Policy Implications

The categories of public policy affecting persons with SDAT cut across many public policy arenas, including tax policy, regulatory policy of health and social welfare programs, research policy, and mental health and long-term care policies. Although a coherent set of national priorities guiding public action does not exist, the demands created to care for persons with cognitive loss bring the pros and cons of family policies into sharp focus (Kane, 1986). The industrial revolution and the urbanization that it engendered required a transfer of services from the home to an industrialized or commercial setting. Some such services that have made the transition are those involved with schools, hospitals, and food and clothing production (except in isolated cases). In this transfer, we have changed the nature and function of the family, because many family activities have been transferred from the household to society (Bergmann, 1986). Previously, when female workers were needed for the war effort, both the federal government and private employers were willing to provide the necessary services to allow women to participate in the labor force (Bloom, 1986). The demand for productive workers may promote this effort again.

I am proposing a series of recommendations that will produce a maximum effect for a given investment of resources and allow choices so that citizens could maximize their personal preferences. Programs to serve this population should do the following:

- Use an individualized family-centered care plan to maximize the performance of the person with SDAT and minimize family disruption.
- Provide alternative strategies that families can choose among to assist in the management of their cognitively impaired family member. This would allow the caregiver the option of remaining on the job while still fulfilling his or her filial responsibilities without having to place the impaired person in custodial care. An additional objective would be to avoid putting most of the burden of care on the female family member.
- Develop methods that encourage industry to provide services to workers and provide services that the elderly and family could purchase with discretionary income. Both of these approaches would require a tax incentive to make them attractive.

Review of Current Policies

Policies exist that provide support to caregivers, but the bulk of the care of the impaired elder is provided by the informal network. I will review current policies in the context of the goals of the proposed policy.

Medicare and Medicaid are public programs that have a strong institutional bias—Medicare toward hospital reimbursement and Medicaid toward nursing home reimbursement. Although Medicare pays for the initial diagnosis, it will then pay only for care related to an acute episode of illness. Only those Medicare beneficiaries who are confined to their home and need skilled nursing care are eligible for home health services under Medicare. No provisions for personal or custodial care are provided, which is the type of care that is needed by the cognitively impaired elderly. If a person is receiving Medicare coverage for a related condition and the family needs to supplement the service by paying for additional hours of nursing, then the care may not be deemed intermittent, and Medicare can deny all home health care benefits (Kane, 1986, Select Committee on Aging, 1987). Additionally, no provision for the training of caregivers in the skills necessary to manage a cognitively impaired elder are provided, nor is a mechanism by which caregivers can become acquainted with available resources.

Under Medicaid, the state can apply for waivers to provide community-based care. By 1986, 46 states had received waivers to cover personal and respite care. Although this is a start in assisting the poor (the government asks persons to impoverish themselves in order to qualify for Medicaid), these programs are not statewide, thus access is limited. These programs would not help people who are struggling to remain in the labor force, because, if working, the person would virtually be denied access due to his or her assets. Fewer and fewer nursing homes will accept persons with SDAT. Providers seem to reject such clients, thereby forcing the family to search for help. When a facility is found, the family is often dissatisfied and may have to travel long distances to get there (Kane, 1986).

Through Public Law 89–73, in-home care, such as homemaker, home health aide, and chore services, are available. This program also provides Meals On Wheels. The total appropriations for this program nationwide in fiscal year 1989 were $1.6 billion (O'Shaughnessy, 1988). The objective of this act is to set broad policy guidelines to improve the lives of older Americans in the areas of health, housing, and long-term care. In 1987, Public Law 100–175 amended Public Law 89–73 to include grants to
states to provide such programs as in-home care for the frail elderly, elder abuse prevention programs, and long-term-care ombudsman services. The act is broad in its goals but limited by the small level of funding.

The Federal Supplemental Security Income program is a federal program of retirement benefits for disabled persons. The regulations require that an elderly person living in another person’s household must receive a one-third reduction in monthly benefits. This provision acts as a deterrent to families who may want, or who find it necessary, to provide care to an impaired elderly person (Select Committee on Aging, 1987).

The 1986 tax reforms created deterrents for families who care for an elderly impaired person. Under the old law, an impaired elderly person could claim a personal exemption and at the same time be claimed as a dependent on a son’s or daughter’s tax return. According to the new law, the elderly person cannot claim an independent exemption. In addition, when the medical expense deduction was raised from 5% to 7.5% of the taxpayers’ gross income, families found it more difficult to claim the child and dependent care credit, because this credit requires that they spend more money in order to take advantage of the credit (Select Committee on Aging, 1987). With people on very limited incomes, the choice may be difficult.

Public policies can promote informal caregiving by supporting the development of services that are targeted to assist impaired elderly persons. The little information that is available on use of services indicates that caregivers purchase services only when the tasks become too difficult to handle, and when they do request services, they are modest in their request, never asking for all of the support that professionals would recommend (Select Committee on Aging, 1987). Policymakers are concerned that if more services were available, caregivers would substitute paid care for informal care. Perhaps substitution would provide the support necessary to the caregiver to alleviate the burden associated with the provision of daily, routine care. In a study of caregivers, McKinlay and Tennstedt (1986) found that families using formal service provided the same amount of help to their parents but in different tasks. Other researchers examining the effect of the use of homemaker services in New York found that families shifted their responsibilities to other activities that assisted the impaired elderly person (Frankfather, Smith, & Caro, 1981).

Selecting the Best Policy

The types of services that will best serve the family managing a cognitively impaired elderly person are not generally available. The model suggested (see Figure 1) is a community service network, which uses the total pool of community services, for example, home health care, meal programs, and day care, and a comprehensive social and functional evaluation of both individual and family resources. By including the expectations and skills of the caregiver, a team of professionals can set up individualized training programs based on the needs of the family and provide ongoing consultation to caregivers to meet their needs for information and support as the disease progresses. The desired outcome would be to have community assessment and training centers that families could use to learn about the resources available in a community to help them manage their cognitively impaired or frail elderly parent. This type of service would make entry into the system easy. Unfortunately, access continues to be a serious problem, particularly with so many impoverished elderly persons. Currently, entry into the system would be through multiple points, including hospitals, physicians, older adult centers, day-care facilities, and industry. The occupational therapist will be challenged to build, coordinate, and market the program that contributes to the community’s resources.

This approach is suggested because it allows families to make choices according to their own needs. A family member who chooses to provide the majority of care would only need social support and consultation on the skills needed to provide care, whereas a working caregiver would need many different services, including day care.

Several possibilities for payment for these services exist:

1. Some elderly persons could avail themselves of such services. Nearly one third of elderly households have a net worth of over $100,000 (Cashell, 1989).
2. Some families are in the position to purchase the services from their own resources.
3. Employers, in an effort to attract and retain qualified employees, could offer a range of services and educational programs that include establishment of the individualized care plan. This, coupled with payment for day care and respite service, should attract and retain qualified employees. By offering this program in addition to day care for employees with young children, companies would be offering benefits that would span the age range of the employees. Payment for such services could tap the Dependent Care Assistant Plan. Some major corporations, such as Travelers Insurance, Con Edison, Mobil, and Ciba-Geigy, have implemented educational programs and are developing strategies for sharing the costs of respite care and work-sponsored adult day care (Select Committee on Aging, 1987). The use of flextime could also allow families to provide the care themselves. Although this is an impressive start, more needs to be done to ensure that employers have productive workers.
4. Medicare could expand its coverage to allow 6 to 8 weeks of in-home support and training of caregivers for persons with SDAT as a preventive health measure. Whereas SDAT was once classified as a mental health problem, it is now defined as a neurological problem. By allowing an in-home training program under specifically defined criteria, the family, whether working or not, would benefit from acquiring the skills needed to manage the problem. This approach could be coupled with family leave to give working caregivers access to the benefit. To accomplish this objective, we must change the Medicare law and lobby to enact legislation such as the Family and Medical Leave Act, which was proposed but not approved in 1990.

5. Medicaid could be expanded to cover this type of program for the poor as an alternative to institutional placement for families that want to maintain the impaired person in the community. This approach would take advantage of a less-expensive model of care as well as tap the resources of the family in providing informal care. Studies would need to be conducted, perhaps under a waiver program, to demonstrate the cost-benefit ratio of such an approach. The fact that there are not enough nursing home beds to serve this population even now would be a good incentive for such an approach. This approach would require a change in Medicaid regulations.

6. An additional method of support to the working caregiver is the Dependent Care Assistance Plan. This is an employee benefit plan allowed under the Internal Revenue Service that excludes the value of employer-provided dependent care from an employee's gross income. The employer can deduct the cost of care as a business expense. In 1986, an estimated 1,000 employers offered such a plan for child care, and none reported using it for elder care. The major reason it was not used for the elderly was that for tax purposes, the elderly person must be a dependent of the employee. Although this plan could help some people, the regulations must be modified to address the issue of dependence (Select Committee on Aging, 1987). Additionally, the cost of services must be realistic to encourage families to spend their limited resources on services that will minimize their burdens, because they themselves are currently providing care for their elderly parents and relatives.

7. Congress considered, but did not adopt, the Family and Medical Leave Act in 1990. This act would have required all but the smallest companies to grant unpaid leave to care for a newborn, a newly adopted baby, a sick child, or a sick parent who requires medical attention. President Bush opposed this legislation because he thought that employers and employees should work out the problems on an individual basis instead of relying on mandated benefits. Supporters argued that this act would establish a minimum labor standard for leaves that would create a societal interest in helping families. Certainly, the family must be considered in the formula for providing informal services. It will be interesting to watch this debate unfold in the decade ahead as families request benefits that allow them to have time to manage the needs of their parents.

The current political climate is a good one in which to begin addressing these issues. Currently, 35 states permit some form of payment to the elderly client's relative for the provision of home care. This financial incentive is restricted to persons who are at high risk of institutionalization. Some of these programs grant the elderly person total discretion in hiring a caregiver. In states that supplement the federal Supplemental Security Income benefit, elderly care recipients may be permitted to use this supplement to reimburse a caregiving relative.

The expansion of the child and dependent care credit under the 1986 tax law is a start. More and more businesses may be forced to adopt this benefit when they realize the effect it will have on a stable work force.

In 1986, the Respite Care Act was established to develop a statewide respite care demonstration to test the efficacy of providing short-term and extended respite to families caring for disabled elders. This demonstration, administered by the state's health department, gives priority to Medicaid recipients but offers other families these services based on a sliding scale (Select Committee on Aging, 1987).

The Alzheimer's Disease and Related Disorders Research Act of 1986 asks agencies to estimate the costs borne by families to ascertain the best combination of informal and formal services; to evaluate ways to sustain family caregivers in order to reduce the psychological, social, and physical burdens of caregiving; and to identify the best methods of providing outreach, case management, home care, and respite services (Select Committee on Aging, 1987). It is hoped that the results of these studies will offer some policy guidelines.

The private sector is beginning to respond to the problem, due to the conflicts experienced by the family caregiver, who must juggle family and job responsibilities. A recent survey by the Business Group on Health found that 70 New York companies, more than half were aware of the problems that their employees were having with balancing their caregiving and work demands, yet only 15% of these companies had programs to assist working caregivers (Warshaw, Barr, Rayman, Schachter, & Lucas, 1986). Within the next decade, innovative em-
employee-sponsored programs will be developed that will teach workers (a) how to manage their impaired parents and (b) where to get access to resources that will minimize their stress. Only with this kind of approach will businesses retain workers on a permanent basis. We are already seeing the benefit of flexible schedules. I believe that this benefit will be an important option for both women and men who have to deal with the realities of managing parents in the community rather than placing them in institutional care.

Summary

The family will be critical in the future of the management of our nation’s elderly (Caserta, Lund, Wright, & Redburn, 1987). Research shows that families do provide support, even if it complicates or compromises their own lives. We are faced with the challenge of designing and implementing programs that will reduce the caregivers’ burdens. To be effective caregivers, spouses and children need skills and information. This requires an assessment and training approach and ongoing consultation. For the working population, the best approach would be for corporations to sponsor such programs and to provide day-care facilities. For poor persons, a community service could be established as a joint effort of hospitals and social service agencies. If community assessment and training centers were available, persons who need and want help would know where to get it. The goal of this type of approach would be to minimize admissions to nursing homes and at the same time provide resources to caregivers so that they could continue with their families’ activities without further erosion.

I have presented a socially oriented approach, rather than a strictly medical approach, for the management of the elderly without compromise of the family. The purpose for this was to leave as much responsibility with the family as they are willing to assume. A medical approach usually institutionalizes the problem and drives costs up. We must, however, address the social consequences of the medical condition. If we take a medical approach only, we will fail to consider the caregiving relationship and the conditions that cause stress for both the caregiver and the impaired elderly person (Lyman, 1989). We must recognize that the complexity and intensity of this problem require that some resources are going to be necessary if the family is to shoulder the burden. Not only must our corporations respond with strategies to meet these problems head on in order to have productive workers, but also, our current policies in the social service system and tax program must be evaluated and expanded to address these problems as well. Otherwise, the family is going to undergo even more disruption. We as occupational therapists have a body of knowledge to bring to this problem: We can not only help caregivers acquire the skills for their role in caregiving, but also help caregivers balance their activities to maintain a more healthful role for themselves.

The political climate may change as more and more people face the dilemma of managing their elderly frail or impaired parents. The issue of protecting the family from further erosion can be used as a positive force in the resolution of the problems associated with the management of older adults.

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