

Managing Families of the Demented Elderly

Burton V. Reifler, MD, MPH, and Suzanne Wu, PhD
Seattle, Washington

Dementing illness affects about 10 percent of people over 65 years of age, and families encounter many problems as they attempt to care for these relatives. Physicians can assist in several ways, beginning with establishing an accurate diagnosis, as terms such as "senility," "dementia," and "hardening of the arteries" are imprecise and may convey an attitude of hopelessness. A psychiatric, medical, and laboratory evaluation usually leads to a specific diagnosis. About one half of all cases are due to Alzheimer's disease, but there is frequently a treatable component to the demented patient's condition.

In addition to making an accurate diagnosis and treating reversible problems, physicians can assist the family in having the patient do all he or she is capable of including increasing specific activities, can help the family understand that even their best efforts may not lead to improvement, can point out ways for the family to balance the patient's needs with their own, and can teach the family how to communicate more effectively with the patient.

There is little doubt that families continue to assume the burden of caring for their impaired older relatives. Most of the support services to the elderly are provided by the family,¹ and neglect is a rare cause of admission to geriatric units.² Butler and Lewis³ have commented on many of the myths concerning old people and their families, pointing out that families neither abandon their el-

derly relatives nor deny them financial support. Thus, helping demented old people includes helping their family cope with the situation.

The task of caring for a demented relative is, even in the best of circumstances, a very difficult one for a family. In recognition of this, Geriatric and Family Services, an outpatient clinic at the University of Washington, was established. Described in detail elsewhere,⁴ this clinic provides a psychiatric, medical, social, and environmental assessment and treatment program for the patient while concurrently offering his or her family advice, support, and information.

The evaluation phase of the program requires four visits: a psychiatric assessment, a physical examination with appropriate laboratory and x-ray

From the Department of Psychiatry and Behavioral Sciences, University of Washington, Seattle, Washington. At the time this paper was written, Dr. Wu was a Geriatric Fellow in the Department of Psychiatry and Behavioral Sciences, University of Washington, Seattle. Requests for reprints should be addressed to Dr. Burton V. Reifler, Geriatric and Family Services, Department of Psychiatry and Behavioral Sciences, RP-10, University of Washington, Seattle, WA 98195.

studies, a home visit by the clinic social worker, and a conference at which the findings and recommendations are discussed. During the pilot year (1978-79) capacity was 100 new assessments, after which the clinic expanded to accommodate 250 new assessments a year. The waiting period for entry has averaged about one month; despite this, the broken appointment rate is only 2 percent. Follow-up treatment is provided as needed. The most common diagnoses are Alzheimer's disease and depression.

In this report, the authors describe some problems frequently seen in families who are attempting to assist a demented relative and offer some suggestions for physicians who are treating such families.

Common Problems Involving Families of the Demented Elderly

Family Does Not Let Patient Do What He or She Is Able to Do

There are many reasons why a relative might step in and do something the patient can do for himself. It is painful to see a relative suffer from mental deterioration, for example. One husband could no longer tolerate watching his wife cut vegetables; the erratic slices were reminders of her illness.

Letting the patient do what he or she can may bring criticism from others. Dementing illness is not well understood by the public, and a friend who sees a woman letting her husband edge the lawn in a haphazard way may think she is too lazy to help. The friend does not realize that when the wife does help her husband, he immediately withdraws, feels less confident about his own abilities, and becomes more dependent; moreover, he may feel angry and resentful toward his wife for treating him "like a child."

Exasperation is another reason for taking over for the patient. How long can a daughter watch her mother attempt to button her coat, and how many times can the family look on as the patient sets the table for the number of people she was serving 40 years ago?

Whatever the reason, routinely assuming the responsibility for activities the patient is still able to do, albeit not so well as previously, may cause a decline in independence. Garraway and co-workers⁵ noted that some aspects of in-hospital progress among stroke patients tended to disappear after discharge and suggested that a contributing factor may have been overprotection by their families.

Family Tries to Protect Patient by Limiting Activities

Along with taking over chores and responsibilities that the patient is still capable of performing himself, families often attempt to protect the patient by drastically reducing his social, recreational, and intellectual activities. One family stopped taking the patient to church because the patient could no longer comprehend the sermons. What the family failed to recognize was the value to the patient of the religious ritual and the social contact with friends.

Often activities outside the home are reduced in an effort to avoid embarrassing the patient who is "not his old self," or to avoid embarrassing family members who find it difficult to explain the changes in the patient to their friends. Frequently the spouse of the patient makes a unilateral decision to withdraw from usual social functions. One couple used to enjoy dancing. After his wife developed Alzheimer's disease, her husband stopped taking her out, even though her disease did not affect her ability to dance.

In another situation, a woman became embarrassed when her husband's friends commented that he could not keep his own golf score. She protected him by finding reasons to keep him from playing golf with anyone except her, despite the friends' willingness to keep him in their usual group.

Family Always Puts Patient's Needs First

Feelings of duty, responsibility, and guilt may lead families to rearrange their work and leisure

schedules to accommodate the perceived needs of the patient. This perception often includes around-the-clock surveillance, companionship, and attention. This situation is especially stressful when the patient lives with a married son or daughter, as the caregiver feels caught between the parents' needs and those of his or her spouse and children. A daughter switched to working swing shift so she could keep her mother company during the day while her husband kept the patient company at night. The daughter's husband grew increasingly unhappy with this situation, even though he had initially concurred with the daughter's priorities.

Spouses of demented individuals may sacrifice their independence in order to be at home with the patient 24 hours a day, believing that this is the best and right thing to do. They stop going to club meetings, stop having lunch with their friends, stop recreational pastimes, and stop window shopping. The extremity of this sacrifice stresses even the most devoted of partners, who alternate between feelings of resentment and guilt.

Family Uses Logic and Reason to Excess

Frequently in an attempt to treat the demented relative as an "adult," family members will exhaust themselves by repeating lengthy explanations to repetitive questions. Typical of this pattern is the patient who asks every five minutes, "What happened to my house?" The family member again explains that the house was sold several months ago, that the money from the sale of the house had been put into a bank account for the patient, and that the patient's new home is with her daughter and son-in-law. The family member is frustrated and tired of answering the same question over and over again, but believes that the patient deserves a complete answer every time.

Family Believes Environmental Change Can Lead to Patient's Happiness

A woman from Seattle visited her mother on the East Coast. As her mother's memory was failing, the daughter urged her to move, offering to take care of all the arrangements. After the move, the

daughter became upset when her mother kept complaining about missing her old home.

Most families have a wish to see their ailing relative return to normal, and one aspect of this is a desire to see the person cheerful and even appreciative of the family's efforts. This often fails to occur in dementing illness. Instead of the family recognizing the problems as a result of both the disease and their own needs, they may increase their efforts and periodically try out a new living arrangement for the patient, usually with no improvement. Daughters seem particularly prone to accept the notion that if they could somehow set up the perfect situation, just the right combination of living accommodations and activities, then their mother would be happy and content. This usually leads to disappointment as the patient's problems of depression, inactivity, and dependence persist.

Unrealistic Expectations by Family

Many individuals who care for their impaired relatives have very high expectations of themselves. A daughter had spent two hours with her mother to get her bathed and dressed for a medical appointment, then got angry when her mother put her sweater on over her coat. She criticized herself for not being more tolerant. Another woman said she felt bad after she snapped at her husband when he asked yet again when supper would be ready.

The cycle of becoming angry and then feeling guilty occurs in virtually every family member attempting to care for a demented relative. This cycle is similar to the one that occurs with parents and small children, but has important differences as well. A parent can more easily comfort a small child than an adult relative and can often justify punishing or scolding the child as part of parental responsibility. It is much harder to justify being short tempered with one's own parent, as it may be contrary to a lifetime's experience and may violate cultural expectations of parental respect.

A pathological problem is a child's desire to gain the parent he or she never had. A daughter may see the mother's illness as an opportunity to provide kindness and devotion, finally securing the warmth, love, and appreciation her mother had previously withheld. Since personality changes in senile dementia of the Alzheimer's type usually

lead to the patient becoming "more of the way they always were," the cold, critical parent becomes more demanding and impossible to please. If the child's response has usually been depression, this may reoccur.

Management Suggestions

Establish a Diagnosis

Mental illness of old age may be interpreted by both laymen and physicians as part of the normal aging process. The terms "senility," "dementia," and "hardening of the arteries" carry no diagnostic precision and may convey an impression of hopelessness. These descriptions are scarcely of more value to families than what a physician told a man about his cognitively impaired father, that he "just isn't clicking like he used to."

The cause of an elderly patient's dementia can usually be diagnosed by a thorough clinical evaluation. The most frequent causes of dementia are shown in Table 1. It is also fairly common to discover a potentially treatable aspect of the patient's condition, as seen in Table 2.

While there is no precise definition of an adequate diagnostic work-up for dementia, the assessment at Geriatric and Family Services includes history from patient and family; mental status examination; complete blood count; a chemistry battery including glucose, electrolytes, creatinine, calcium, and hepatic enzymes; chest x-ray examination; electrocardiogram; urinalysis; thyroid function studies; a VDRL serology test; and erythrocyte sedimentation rate. Investigations ordered, if indicated by the history and physical examination, include folate and B12 levels, thyroid stimulating hormone, computed tomography of the brain, and electroencephalogram.

The most common cause of irreversible dementia is Alzheimer's disease (primary neuronal degeneration), which is a clinical diagnosis. The DSM III criteria for this disorder consist of presence of dementia, a gradually progressive course, and exclusion of all other specific causes of dementia.⁷

Even when the cause of the dementia is irre-

Table 1. Causes of Dementia (n = 222)

Diagnosis	Percent
Alzheimer's disease	51
Vascular disease	8
Normal pressure hydrocephalus	6
Alcoholism	6
Intracranial masses	5
Huntington's	5
Depression	4
Drug toxicity	3
Creutzfeldt-Jacob	1
All other causes plus diagnosis uncertain	11

Adapted from Wells (1977)⁶

Table 2. Potentially Treatable Illnesses in Demented Patients Detected During Diagnostic Evaluation at Geriatric and Family Services (n = 76)

Diagnosis	Number Detected
Depression	16
Folate deficiency	10
Parkinson's disease	5
Urinary tract infection	5
Drug toxicity	4
Myxedema	1
Subdural hygroma	1
Subarachnoid cyst	1
Metastatic carcinoma of colon	1
Metastatic carcinoma of breast	1
Temporal lobe epilepsy	1
Rheumatoid cerebral vasculitis	1
Total	47

versible, as in Alzheimer's disease, establishing the diagnosis is useful. First, it reassures the family that they have met their responsibility of ruling out reversible causes. Second, it provides an opportunity to discuss the disease, including prevalence, theories of cause, genetic aspects, complications, opportunities for treatment, and

course. Many people can cope best with the problem if they have such facts at their disposal. Finally, it allows both patient and family to benefit from aspects of the sick role, in which the patient can be seen as having a problem not of his or her own making that entitles both patient and relative to certain services and privileges. For example, a neighbor who is annoyed at a patient may be more sympathetic if told that the patient is being followed for Alzheimer's disease rather than told the patient is senile.

Let the Patient Do All That He or She Is Able to Do

The husband, who became distraught when his wife could no longer slice vegetables neatly, urged her to take it easy while he fixed supper. He gradually assumed more responsibility for routine tasks in the mistaken notion that this was the best approach. In another situation, a husband whose wife was slow to answer because of memory impairment would answer questions for her. The patient's reliance on her husband became so great that she gave up trying to speak for herself and always looked to her husband to provide her responses.

If the reasons for the family's reluctance to let the patient do what he or she can are openly discussed, family members frequently realize that they have been too zealous. Whether the motive is avoidance of a reminder of the patient's illness, fear of criticism from others, desire to help the patient who is no longer functioning well, or exasperation and frustration at the patient's decreased ability, discussion with the family usually results in the patient resuming his or her old activities. Besides helping the patient maintain as much independence and self-sufficiency as possible, this approach may help to bolster a diminishing self-confidence and decrease resentment toward the family for "taking over."

Encourage Family to Increase Patient's Activities

Social, emotional, and intellectual stimulation are as important to the demented patient as they are to any cognitively intact individual. Like the

adage, "if you don't use it, you lose it," withdrawal and isolation beget greater withdrawal and isolation. Families should be encouraged to allow the patient to continue as many activities as possible outside the home. Even though the patient's facility with or comprehension of the activity may be diminished, the stimulation provided by the activity is generally helpful. For the patient whose level of impairment precludes participation in most premorbid activities, the highly structured environment of the adult day center provides a good alternative.

Again, reluctance on the part of the family to encourage the patient in activities outside the home can usually be dissipated through open discussion of their motives. Feelings of embarrassment or desire to protect the patient can be aired, and ways to cope with those feelings suggested.

Advise Family That Best Efforts May Not Lead to Improvement

One of the certainties in Alzheimer's disease is that new problems will occur. If the family believes that these problems indicate they have somehow failed, it can be demoralizing, as problems can arise in virtually every aspect of daily life. The patient may have trouble figuring out how to put on or fasten clothing, neglect bathing and cleanliness, wander off, become overtly paranoid, demand not to be left unattended, insist on retaining access to bank accounts or vault boxes, and reject helpful efforts from others.

The wife of one patient commented that the problems in Alzheimer's disease are like gnats. Although each one is small, in large numbers they are maddening.

When the problems are approached individually, there is usually some partial remedy for each. Examples of such partial solutions include replacing clothing snaps with velcro strips, prescribing antipsychotic drugs for paranoia, installing a photoelectric device at the front door (such as those used in stores) to make an alerting sound when the patient tries to leave the house, and replacing negotiable documents with photocopies while moving the originals to a different vault box (the patient never noticed the difference).

The physician's strategy should be to prepare the family for the new problems that will occur and to make him or herself available for consultation when needed.

Help Family Balance Patient's Needs with Own

The needs of the patient are generally assumed by the family without consulting the patient. The physician who facilitates an open discussion about expectations between family members and patient will often find that their respective needs are not in conflict and can be readily accommodated. In fact, patients frequently express the desire not to interfere with their family's lifestyle. The importance of respite for family members also needs to be emphasized. The physician can help relieve the family's guilt about taking a few days off by advising them that if they are rested, the patient will be better off also.

Families sometimes have the misunderstanding that any demented individual requires 24-hour supervision. Although this may be true in some cases, it is by no means the general rule. The physician, guided by information provided by the family, can offer advice about whether the patient is capable of spending time unattended and can advise the family that it is never possible to eliminate all risks. There are situations in which the patient cannot be left unattended, perhaps if he needs assistance going to the bathroom or has a tendency to wander off. Families should be encouraged to utilize community services such as chore workers and in-home assistants. The patient can also attend an adult day center, which provides stimulation for the patient and allows the family the time for their other responsibilities.

Urge Family to Refrain from Logical Arguments when These Are No Longer Effective

One of the more exasperating problems identified by families of demented patients is their tendency to ask the same questions repeatedly. While a complete, albeit simplified, answer is warranted

the first few times the question is asked, continued questioning on the same topic suggests that the information is unlikely to be retained. In this situation a different strategy can be taken; the family can respond to the emotional tone of the message rather than the content. For example, the woman who wanted to know what happened to her house was clearly worried. A response to her affective message might be in the form of reassurance that everything is fine and that she need not worry. In addition, it is helpful to then distract the patient's attention by switching the discussion to another topic of interest to the patient. This allows the patient to get a response to the affective component of the question (which may be more important than the literal content) and helps to decrease the family's frustration.

Conclusions

While families wish to do all they can to help cognitively impaired elderly relatives, they face numerous problems in obtaining accurate information and establishing a satisfactory plan. Even though the physician is usually unable to reverse the impairment completely, he or she is able to offer substantial help by establishing an accurate diagnosis and by advising the family on realistic expectations for both the patient and themselves.

References

1. Brody EM: Long Term Care of Older People: A Practical Guide. New York, Human Sciences Press, 1977, p 306
2. Issacs B: Geriatric patients: Do their families care? *Br Med J* 4:282, 1971
3. Butler RN, Lewis MI: Aging and Mental Health. St. Louis, CV Mosby, 1973, pp 106-119
4. Reifler BV, Eisdorfer C: A clinic for the impaired elderly and their families. *Am J Psychiatry* 137:1399, 1980
5. Garraway WM, Akhtar AJ, Hockey L, Prescott RJ: Management of acute stroke in the elderly: Follow-up of a controlled trial. *Br Med J* 281:827, 1980
6. Wells CE: Dementia. Philadelphia, FA Davis, 1977, p 250
7. Diagnostic and Statistical Manual of Mental Disorders, ed 3. Washington, DC, American Psychiatric Association, 1980, p 126