Helping Families With End-of-Life Care in Alzheimer's Disease

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Objective: Alzheimer's disease is a chronic process of gradual deterioration of cognitive ability. While this is clearly a tragedy for the individual and the family, the prolonged nature of the disease allows the clinician an opportunity to plan for progressive stages of the disease including the final stages of care. This article reviews opportunities for assisting families in the care of their ill relatives with Alzheimer's disease.

Data Sources: Review articles on end-of-life care and Alzheimer's disease obtained on a search from Ovid on March 2, 2006. Only English-language review articles were included in the search.

Study Selection: Articles were included in the review if they offered clinically relevant material for assisting families in end-of-life care in Alzheimer's disease. Articles between 1998 and 2006 were included. Approximately 10% of the articles listed were included in the review.

Data Synthesis: Clinicians should discuss with family members choices to be made at the end of life in Alzheimer's disease care and work with the family to ensure these wishes are followed. The geriatric psychiatrist plays a central role in these discussions. Other members of the health care team, including nursing care, hospice care, and social work coordinators, all coordinate efforts to deliver optimal end-of-life care. This leads not only to better and more humane care, but also to a cost savings in America's burgeoning health care budget.

Conclusion: Geriatric psychiatrists can play a central role in assisting families in managing end-of-life care in Alzheimer's disease.

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As baby boomers age, they will leave yet another legacy to America. Living longer than their predecessors, many will develop Alzheimer's disease in their elder years. As the American life span increases, more Americans will live to be old enough to develop the chronic deterioration of this disorder. It is estimated that by the year 2050, 13.2 million people will be suffering from Alzheimer's disease in the United States.[1] Among the many challenges of caring for this group will be helping families manage the inexorable decline associated with the disease. Any physician who has a patient with Alzheimer's disease has more than one patient. The victims of the disorder include not only the patient, but his or her family as well.

While the tragedy of Alzheimer's disease is that it represents a slow decline of abilities, the chronic nature of the disorder offers caregivers the chance to plan for the future needs of the patient, including decisions about end-of-life care. These decisions include plans for additional help, nursing home care, medications, and the use of hospice care. The geriatric psychiatrist can be central in assisting the family with these decisions. Years are available for this work. For individuals diagnosed at age 65, there is an average survival of 8.3 years, and even for those diagnosed at age 90, there is a 3.4-year average survival time available to make decisions.[2] For all of those who suffer from Alzheimer's disease, the mean survival time from diagnosis to death is 3 to 5 years.[3,4] Families should be encouraged to begin planning early in the course of the disease, or even before the disease starts, so that patients can be included in decision making. If another family member has suffered from Alzheimer's disease, patients may be especially willing to discuss their own wishes for end-of-life care.

While many diseases require consideration of end-of-life care, Alzheimer's disease care is a bit different. Alzheimer's disease presents a chronic and slow deterioration over years. With Alzheimer's disease, there is no cure or even treatment that stops the disease. If cure is not available, the focus must be on care, including end-of-life care. As the number of elders with Alzheimer's disease grows, stretching the health care system, and as health care costs escalate, this planning is essential to ensure that each patient receives only wanted care.

Despite the chronic nature of the disease, physicians often do not take the opportunity to discuss end-of-life care with either the patient or the family. In one survey of physicians, only 47% said they discussed end-of-life care with patients suffering from mild to moderate Alzheimer's disease.[5] This is indeed a failure. As the years of this chronic illness pass, many decisions must be made about care. Ignoring this aspect of disease management creates the potential for suboptimal decision making, leading to increased costs and needless suffering for the patient and the family.

Opportunities abound to plan for the future needs of Alzheimer's patients. Toward the end of life, those with Alzheimer's disease receive care in either a nursing home or hospital. Currently, 24% of all deaths occur in nursing homes.[6] Those with advanced Alzheimer's disease are also more likely to be admitted to the hospital compared with other elders without dementia.[7] In fact, infectious disease is a more common discharge diagnosis for patients with Alzheimer's disease[7] than elders of similar age. These admissions present the opportunity to discuss with families the prognosis of the dementing illness, as well as the management of problems to come.

WORKING WITH FAMILIES

Most Alzheimer's disease care is delivered by families. In fact, 70% of those with the disease live at home.[8] Those families are burdened not only by the time it takes to provide the extra care, but also with the financial costs of health care or the financial costs of abandoning their own livelihood to care for their ill relative.[9] In one survey of family members providing end-of-life care, more than half had to end or reduce employment because of the demands of caring for their ill relative.[10] These caregivers also suffer an increased risk of depression and physical illness.[9]

Rabow and colleagues[9] outline 5 key opportunities to prepare for the end stages of the disease: promoting excellent communication with the family, encouraging appropriate advanced care and decision making, supporting home care, demonstrating empathy for family emotions and relationships, and attending to family grief and bereavement.

Of these, communication with the family is the most essential.[11] This communication not only allows us to understand the wishes of the family, but also enables them to get to know and trust us. One qualitative survey of patients with end-stage medical illnesses in Canada showed that the most important factor for patients and their family members was having trust and confidence in their doctors.[12] Through this discussion, physicians too can better understand their patients' families and their wishes. The wants of families of those with Alzheimer's disease are not always based on measurable medical outcomes. In a survey of 113 consecutively admitted patients to a geriatric psychiatry unit, the severity of dementia did not predict what families would decide for resuscitation status. The average Mini-Mental State Examination[13] score of patients whose families wanted full resuscitation efforts in an emergency was 14. The average Mini-Mental State Examination score of patients whose families wanted no resuscitation was the same—14.[14]

Cultural differences play a role in end-of-life decision making. Patients in rural areas may show more acceptance of death and place fewer demands on practitioners. Patients in urban areas may insist on more aggressive medical care in advanced dementia.[15]

Ethnic background may also influence end-of-life decisions. African American caregivers, in one study, were less likely to decide to withhold medication, tube feeding, or other medical interventions.[16] However, in this study, African American patients with Alzheimer's disease were more likely to die at home as families shouldered more of the burden of end-of-life care.

The issue is further complicated by the fact that there is not a uniform set of guidelines for end-of-life care in Alzheimer's disease. One survey showed that only 2% of physicians would want to be resuscitated from a cardiac arrest if they were suffering from Alzheimer's disease.[17] Families choose resuscitation far more often. In fact, there is not uniform agreement of when "end of life" is in Alzheimer's disease. One survey of critical care program directors showed that 29% of them did not feel that Alzheimer's disease qualified as a terminal illness at all.[18]

The issue is further complicated by deciding who should give informed consent or refusal for treatment. Physicians in practice do not use a uniform standard for assessment of decision-making capacity.[19] Early in the course of the illness, patients may be able to give advanced care directives. However, later in the course of the disease, and certainly in the end stages of the disease, patients cannot give consent. Proxy decision makers, usually family members, take on this role. There is general agreement that proxy decision making is ethically sound and can improve patient care.[20]

Even if the patient has left a living will, families are faced with most medical decision making at the end of life. Because families are typically unfamiliar with the medical decisions being made, let alone the complex decisions made at the end of life, they will need support from their physicians.[8] Families seldom reach a unanimous decision. Here again, physicians can use their skills to negotiate family conflicts, recognize reasonable questions, and support the final decision made by families. Physicians can also continue to focus on the medical decision-making questions at hand.[11] By focusing on the questions at hand, acknowledging the deteriorating state of the disease, and supporting family decisions, the physician serves an essential role in the process.

It is best to remember a simple fact. The task for families is not to decide what they would want for themselves, or what they would wish for the ill individual. The task rather is to decide what the individual would have wanted for if he or she were capable of making the decision. In helping the family make the decision, it is helpful to ask them, "If 10 years ago, you described this situation to your relative and asked, 'what would you want me to do?' what would his or her response have been?" Having family members understand that their job is to follow the wishes or presumed wishes of their elder relative in the situation can simplify decision making.

COMMON CLINICAL PROBLEMS IN DECISION MAKING

As Alzheimer's disease progresses, the individual often loses weight. To make matters worse, in end-stage disease, the patient often develops neuromuscular dysmotility of the tongue and pharynx. Choking and aspiration are common problems, often leading to the terminal event of the dementing illness—a fatal pneumonia. So, should a feeding tube be placed to avoid this problem?

Risks for placing the tube are substantial, and there is no clear evidence that gastric tube placement and feeding prolongs quantity or quality of life.[21] Thus, families can be reassured that "doing everything" is not better care. Because key decision makers in nursing homes may encourage tube feedings despite the lack of data of their efficacy,[22] physicians will need to educate families and help in their decision.

Another frequent question is whether cholinesterase inhibitors should be removed from the patient with advanced Alzheimer's disease, or whether they should be offered in the first place. One survey of patients admitted to a geriatric psychiatry unit showed that families tended to accept cholinesterase inhibitors if their family member had less severe dementia, and families also showed a nonsignificant tendency to accept this medication if the patient could return home after the admission.[23] While available evidence suggests that cholinesterase inhibitors mildly prolong life for those with Alzheimer's disease, at what point should the medications be withdrawn? There is no clear answer for this question, and certainly no answer that fits all situations. Here again, families need to make this difficult decision. Perhaps the best way to address this to families is to advise them that these medications prolong life and ask whether the patient's current state should be prolonged. In end-stage dementia patients, any medication that decreases short-term suffering should be given, and use of any medication should be questioned when it does not affect the patient's outcome or even prognosis.

Patients with Alzheimer's disease also continue to suffer from chronic disorders such as heart disease or diabetes. Hurley and Volicer[8] contend that these chronic diseases should be treated conservatively, with the goal of reducing short-term complications of the disease. With end-stage Alzheimer's disease, it is reasonable to argue that long-term disease manifestations, such as the effects of high cholesterol, may be ignored. With this terminal condition, long-term health problems are not the priority; therefore, it may be reasonable to withdraw medications such as statins or medications for the long-term effects of osteoporosis. Decreasing the number of medications would simplify medication side effects as well as the patients' drug regimen, reducing the chance for drug interactions. Costs for the family would also be reduced.

Most would agree, however, that it is essential to make sure that medications are offered that would help to control pain.[1] More than half of family members providing end-of-life care in dementia felt that their ill relative had frequent pain.[10] Providing adequate pain relief can make a large difference in quality of life at the end stages of the illness.[24] Reducing pain may also reduce agitation, hopefully limiting the intervention of nursing home care.

In terminal stages of Alzheimer's disease, infections often occur. The use of antibiotics is again an open question for families, since treating the infection does not alter the course of the dementing illness. One survey of hospitalized, incurably ill patients showed that those with dementia were more likely to receive antibiotics than those with metastatic cancer.[25] In terminal stages of dementia, it is reasonable for families to refuse antibiotics as well.

ROLE OF THE GERIATRIC PSYCHIATRIST

The geriatric psychiatrist plays a central role in assisting families in end-of-life care in dementia. Foremost among the skills a psychiatrist brings to any clinical situation is the ability to communicate with families and convey the family's concerns to the treatment team.[24] The geriatric psychiatrist frequently acts as a "translator" for the family and the treatment team.

More than simply conveying information, however, the geriatric psychiatrist can use psychotherapeutic skills to reduce depression in caregivers and identify family dysfunction. Family therapy skills can help to rally the family to the task of caring for the ill relative. In Alzheimer's disease, the patient is not the only patient, and the geriatric psychiatrist is frequently asked to provide care for depressed family members as well. Using therapeutic skills to improve communication among family members and between the family and the treatment team is essential. Coming to a final decision or "insight" is key in the decision-making process and will call upon all the therapeutic skills the geriatric psychiatrist possesses.

Unfortunately, as the disease progresses, behavioral problems including agitation, psychosis, and depression emerge. Appropriate psychiatric management of these symptoms enables the patient to remain at home longer.[26] The geriatric psychiatrist manages these problems as well as any medication treatment they require. Often during this time, the geriatric psychiatrist earns the family's trust for managing other difficult medical problems and situations.[24] These problems provide the geriatric psychiatrist an opportunity to begin discussions about end-of-life care and decisions that may confront the family in the future as they care for their ill relative.

The geriatric psychiatrist also typically manages the use of cholinesterase inhibitors or memantine for patients. Knowledge of the dementing illness and the medications available enables the geriatric psychiatrist to assist the family in deciding when is the proper time to use and stop these medications. The geriatric psychiatrist's medical background also helps the family in understanding and deciding about using pain medications.

The geriatric psychiatrist is frequently called upon by the medical team to assess decision-making capacity of the patient and assists the family in understanding the importance of assigning power of attorney or getting a guardian for the patient.[24] In addition to being a communicator with the treatment team, the geriatric psychiatrist serves as an arbiter for these difficult issues. At times, there can be friction among the attending physician, consultants, and the family. The geriatric psychiatrist with expertise in both medicine and family dynamics can be an essential consultant to ease the process for all.

IS HELP AVAILABLE TO FAMILIES?

Hospice care, which offers either alternatives to institutional death or additional services in homes, hospitals, and nursing homes, provides subspecialty care for those at the end of life. Geriatric psychiatrists can be essential in establishing hospice care.[27] There is a growing need for hospice care for end-stage Alzheimer's patients. Family members of those who receive hospice care are more satisfied with the overall quality of care for their loved ones[29]; yet, patients with Alzheimer's disease are seldom referred for hospice care. Only about 8% of patients in hospices suffer from Alzheimer's disease.[1]

The physician should not feel that he or she must carry the burden of counseling about end-of-life decisions on his or her own. An interdisciplinary team with an array of expertise is best able to offer help.[30] Nursing staff know the 24-hour needs of the patient best, and social workers are best attuned to services in the community. Access to community mental health services is frequently required for family members who suffer the understandable depression associated with not only managing the illness, but also the constant grieving of seeing your loved one slowly dissipate over years.

Physical care needs for those in the final stages of Alzheimer's disease can also be overwhelming. The combined problems of incontinence, decreased sensation, and poor food intake can lead to skin pressure sores. Nursing expertise is essential to identify and care for these lesions, but even more to design care systems to prevent their occurrence.[31] Because immobility is commonly a problem in the end stages of the disease as well, contractures can be a difficult and painful problem. Nursing care with the combination of colleagues in physical therapy and occupational therapy can help to prevent contractures and increase mobility.

Obtaining community services for hospice care, home nursing care, or physical therapy can be a daunting task. The local Alzheimer's Association usually has lists of available services and can also refer families to home care agencies, attorneys competent to manage elder issues, and geriatric physicians in the community. Perhaps more importantly, the Alzheimer's Association also hosts monthly support groups for families. These meetings supply a backbone of support to provide information to families and support them through this most difficult time of progressive grief.

End-of-life decisions are often intertwined with religious beliefs. Family members and patients who have found religion a guide throughout life may feel guilty about not "doing everything" or may simply look to religious leaders for support. Clergy members in hospitals can provide comfort for the family, and generally support the medical team's advice for the family. Hospital chaplains, who are more used to medical decisions and the medical environment, are especially helpful for families. Including chaplains as part of the "end of life team" can provide an added measure of comfort for families.

Making the complex array of decisions at the end of life can be complex, confusing, and frightening. Family members may well be overwhelmed or afraid of what other family members may think of them. It is often helpful when scheduling a family meeting to include not only family members in the area but also relatives dispersed across the country. Conference telephone calls are a convenient way to link family members across the country and to assist communication for the family present in the area making the decision. The cost for these calls is about 9 cents per minute per phone connection. This is inexpensive indeed when the costs of extensive unwanted medical care can be avoided. Very likely, it also offers inexpensive malpractice insurance to have family members agree and support the medical care plan for the patient.

In the future, more end-of-life care will be shifted to the home. The growing number of elders and the limited resources of Medicare to fund all their needs will mandate this change.[32,33] Integrated home health care services are evolving to meet the needs of patients with Alzheimer's disease.[34] The physician who is able to take advantage of these supports will be able to offer the most comprehensive care to ease the suffering of patients and their families.

CONCLUSION

End-of-life care for those with Alzheimer's disease may be viewed as being sad and demoralizing. However, for medical caregivers, it offers an opportunity to make use of essential communication skills, making a clear difference for the patient, family, and even for the growing cost of health care for elders. Geriatric psychiatrists have a special role in end-of-life care utilizing their complex skills. While cure cannot be attained, better care almost always is achieved by working with the family in the end stages of Alzheimer's disease. Few aspects of medicine are as challenging or rewarding as this high level of care. The chronic nature of Alzheimer's disease offers the repetitive opportunity for physicians to discuss and manage these events as the disease progresses. End-of-life care in Alzheimer's disease should occur long before the end of life. Just as planning for care is essential for all chronic illnesses, it is also essential for care of the individual and family suffering with Alzheimer's disease.

As America ages, these issues will become even more important. Clearly, more research is needed in an array of issues. Do the cholinesterase inhibitors or memantine add anything toward the end of life? When should they be optimally withdrawn? How do families make end-of-life decisions, and how can psychiatrists best deliver this information? What information do families require to best make decisions, and how should this information be conveyed? What are the key ingredients to make home care succeed at the end of life? What is the best way to manage pain or agitation? What is a more clinically useful way to establish a "living will" in Alzheimer's disease? What is the best way to record this "living will" in a medical chart so that it is followed? In addition, there is a need to include end-of-life issues in educating medical students and residents so they can manage them responsibly throughout their careers. Policy decisions need to be made to ensure home health care and associated home health services to be an option in delivering end-of-life care in Alzheimer's disease. These and many other questions concerning end-of-life care demand better answers.

In the meantime, until a cure is found for Alzheimer's disease, guidance for end-of-life care for families is essential.

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