

Hospice Approach to the Treatment of Patients With Advanced Dementia of the Alzheimer Type

Ladislav Volicer, MD, PhD; Yvette Rheume, BSN, RN; June Brown, LCW;
Kathy Fabiszewski, RN, MS; Roger Brady, MDiv

A program that limits the extent of medical treatment in patients with advanced dementia of the Alzheimer type was initiated on an intermediate medical ward. Five levels of care were designed to define options that stress maintenance of patient comfort without striving for a maximal period of survival (hospice approach). An optimal care level for each patient recommended by the staff correlated highly with the severity of dementia, but care levels assigned during meetings of family members with the multidisciplinary team for 40 patients correlated poorly with the staff recommendations and the severity of dementia. Intensive nursing care and comfort measures, which included antipyretics, analgesics, and (if necessary) oxygen and anticholinergics, were provided during the terminal phase. Preliminary results indicate that the mortality did not increase significantly during the first year of this program, although the extent of medical care was limited in all patients, and 62% were not treated with antibiotics if they developed symptoms of pneumonia or urinary tract infection.

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RECENT advances in medical technology necessitate increased consideration of ethical issues in health care decisions. Progressive dementia of the Alzheimer type (DAT) is an example of a disease in which ethical dilemmas play a crucial role in medical treatment decisions. At present, no effective

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treatment exists to reverse or arrest the progression of this disease.¹ Treatment of DAT consists exclusively of the symptomatic management of behavioral problems, insomnia, seizures, and

intercurrent illnesses. Aggressive medical treatment of patients with advanced DAT poses an ethical conflict between the obligation to prevent death and the obligation to prevent suffering. Many interventions aimed at postponing death may also increase patient discomfort.

Despite some important contributions that have addressed the question of withholding medical interventions in patients with advanced dementia,^{2,5} there are still areas where no consensus has developed. These areas include the desirability of treatment of infections⁶ and the acceptability of withholding food and liquids in patients with advanced dementia.⁷ Some of this controversy is reflected in recent court decisions that differ in the interpretation of the nature of various treatments and in designation of an authority to make decisions regarding withholding of treatment.^{8,9} This report describes a hospice approach to the

treatment of patients with advanced DAT and a process used to make decisions to withhold treatment. The reaction of the staff and families of patients who were involved in this program and our experience during the first year of its implementation are also presented.

DESCRIPTION OF THE PROGRAM

We began with the premise that because we are unable to influence the pathogenesis of DAT, our treatment efforts should focus on providing maximal comfort for our patients. Therefore, we considered a hospice approach, which provides maximal comfort without striving for maximal survival time, as an appropriate treatment strategy. Five levels of care were defined to specify optimal treatment for each individual patient. The first four levels are similar to those described by Besdine,² and the fifth was added to specify handling of feeding difficulties. These levels of care are as follows.

1. The patient receives aggressive diagnostic workup, treatment of coexisting medical conditions, and transfer to an acute-care unit if necessary. In the event of a cardiopulmonary arrest, resuscitation is attempted. Tube feeding is used if normal food intake is not possible.

2. The patient receives complete care as defined above but resuscitation is not attempted in the event of cardiac or respiratory arrest ("do not resuscitate" [DNR]).

3. This level involves DNR and no transfer to an acute-care unit for medical management of intercurrent life-threatening illnesses. This eliminates use of respirators, cardiovascular sup-

From the Geriatric Research Education Clinical Center, E. N. Rogers Memorial Veterans Administration Hospital, Bedford, Mass (Dr Volicer, Father Brady, and Mss Rheume, Brown, and Fabiszewski); and the Departments of Pharmacology, Psychiatry, and Medicine (Dr Volicer), Boston University School of Medicine.

Reprint requests to GRECC, E. N. Rogers Memorial Veterans Administration Hospital, 200 Springs Rd, Bedford, MA 01730 (Dr Volicer).

port, etc, which are available only in an acute medical setting.

4. This care level includes DNR, no transfer to acute-care unit, and no workup and antibiotic treatment of life-threatening infections (pneumonia, urinary tract infection [UTI]). Only antipyretics and analgesics are used to ensure patient comfort. Partial isolation techniques are used for staff protection.

5. Supportive care is given as defined above but eliminating tube feeding by a nasogastric tube or gastrostomy when normal food intake is not possible. Fluids necessary for hydration are provided orally only if the patient is not comatose.

Patients are assigned a level of care when the family member(s) meet with the multidisciplinary team. Prior to this conference, nursing staff and the attending physician develop a consensus regarding optimal level of care. This consensus is used as a guideline for discussion with the family. The multidisciplinary team includes the head nurse and/or other nurses from the unit, a social worker, a nurse practitioner, the attending physician, and a chaplain. Family member(s) are asked about any previous wishes the patient might have expressed regarding his survival in a mentally debilitated state or with the help of machines. The staff recommendation is then presented in terms of decisions regarding resuscitation, intensive support of failing physiologic functions, use of antibiotics, and use of artificial feeding. The decisions reached at the family conference are summarized in a written format, signed by all staff participants and sent to the family for review. The family is asked either to sign the summary or to suggest a revision. The summary states that the family members may change their decision about the choice of optimal treatment at any time. This signed summary is included in the patient's medical chart, and the level of care is specified on the physician's order sheet. This order is reviewed and renewed monthly and the family conference is repeated if the patient's condition changes substantially and/or at the request of the family.

PATIENTS AND METHODS

The program was initiated on a 46-bed intermediate-care ward that constituted an inpatient component of the Alzheimer's Disease Research Program at the Bedford (Mass) Division of the Boston Geriatric Research, Education, and Clinical Center. The patient population on this ward consisted of 43

patients with advanced DAT admitted for long-term care and two patients admitted for two-week respite care; one bed was reserved for diagnostic evaluation. The diagnosis of DAT was made by a neurologist according to *DSM-III* criteria and fulfilled the criteria for probable DAT specified by McKhann et al.¹⁰ The team taking care of these patients included a part-time physician (L.V.), a nurse practitioner (K.F.), a social worker (J.B.), 31 nursing personnel (15 registered nurses, two licensed practical nurses, and 14 nursing assistants), a dietitian, and physical, occupational, and recreational therapists.

The intellectual and functional progression of DAT in each patient was evaluated every three months by a physician and the nursing staff assigned to the ward. The evaluation included administration of the Mini-Mental State Test¹¹ and the Blessed Information Test¹² in communicative patients, the Bedford Alzheimer Nursing Scale (L.V., B. Seltzer, MD, Y.R., K.F., L. Herz, MD, et al, unpublished data, 1986), the MACC Behavioral Adjustment Scale,¹³ and the Language Assessment Scale. The Language Assessment Scale is an adaptation of the Boston Diagnostic Aphasia Examination¹⁴ and consists of four items rating spontaneous speech, verbal comprehension, naming, and repetition capabilities of patients. Each item has five specific levels of performance, with 5 being normal and 1 being nonresponsive. The MACC Scale and the Language Assessment Scale correlate with duration of disease and therefore can be used to denote severity. Results were analyzed by the Statistical Program for Social Sciences-X programs using the Spearman rank-order correlation.

Forty patients with DAT (mean \pm SD age, 66.8 \pm 6.0 years) were initially included in this hospice-approach program. All were men; 37 were married, two were widowers, and one was divorced. The initial symptoms of DAT had been observed in 29 of these patients prior to age 65 years and in 11 at the age of 65 years or later. The mean duration of the disease was 7.9 years (range, two to 15 years). At the time this program was initiated all patients were severely demented; Mini-Mental State Test score was 0 (normal, 27 to 30) in 39 patients and 1 in one patient. Fourteen patients were completely mute; 18 were able to ambulate independently, and 12 of them paced most of the time. Eleven were able to feed themselves (five only occasionally), and four were able to dress themselves. Twenty-four patients were

Relationship of Report of Patient's Previously Expressed Wishes to Limit Treatment With Level of Care Assigned by Family Conference

| Level of Care | No. of Patients | |
|---------------|---|-----------------------------|
| | Previous Wishes to Limit Treatment Reported | No Previous Wishes Reported |
| 2 | 0 | 1 |
| 3 | 2 | 12 |
| 4 | 4 | 2 |
| 5 | 12 | 7 |
| Total | 18 | 22 |

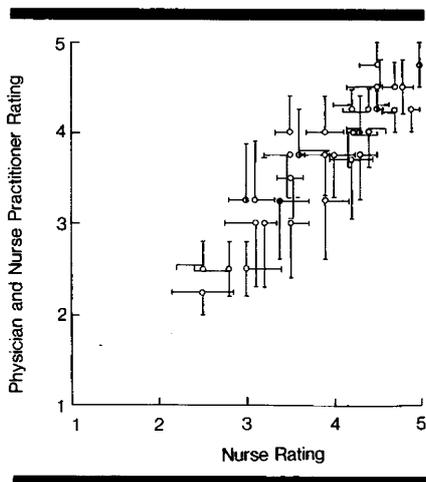
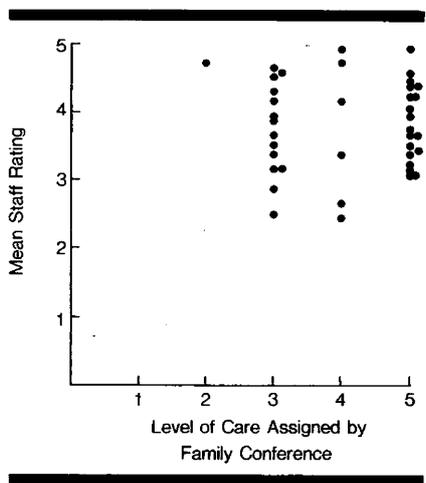


Fig 1.—Correlation between mean optimal care level recommendations by nursing staff and those by physicians and nurse practitioner. Each circle indicates recommendation for an individual patient; bars, SEM; half-closed circles, two patients recommended same level of care; and closed circles, three patients recommended same level of care.

Fig 2.—Lack of correlation between recommendation of optimal care level by staff and assignment of care level by family conference. Each circle indicates recommendation for individual patient.



rigid on passive movements, 15 had flexion contractures, and five had no meaningful eye contact with caregivers. Two patients were fed by nasogastric tubes and two by gastrostomies. Most of the patients were treated for insomnia or hyperactive behavior with benzodiazepines; some of them also received low doses of antipsychotics (usually haloperidol).

RESULTS

At the beginning of the hospice-approach program, a questionnaire was distributed to all members of the nursing staff. This questionnaire included a description of the principles of the hospice approach, a draft of definitions of levels of care, and questions about their acceptance of the hospice approach and their willingness to recommend an optimal level of care for individual patients. Of 31 questionnaires, 25 were returned; two registered nurses and four nursing assistants did not return the questionnaire. Twenty-three respondents believed that the hospice approach was appropriate in caring for patients with advanced DAT; two nursing assistants did not agree. Ten staff members offered suggestions for revisions of the level description. We revised the description as delineated above.

Nineteen staff members stated that they would be willing to recommend an optimal level of care for individual patients. However, when asked to do the actual ratings on the 40 patients included in this study, only nine (eight registered nurses and one licensed practical nurse) responded. Six nursing assistants expressed willingness to recommend optimal treatment but only one responded, by a letter explaining that he/she did not feel qualified to make a judgment. The same rating was also performed by the nurse practitioner assigned to the ward and by three physicians who were familiar with the patients. The ratings varied widely, but there was a significant correlation between the mean care levels recommended by the nursing staff and the mean care levels recommended by the physicians and the nurse practitioner (Fig 1; $r=.928$, $P<.001$). The mean level of care calculated from all staff recommendations correlated with the severity of DAT assessed by the Language Assessment Scale ($r=-.540$, $P<.001$) and by the MACC Behavioral Adjustment Scale (social contact, $r=-.692$, $P<.001$; cooperation, $r=-.666$, $P<.001$; communication, $r=-.536$, $P<.001$; and mood, $r=-.535$, $P<.001$).

As a result of individual family conferences concerning these 40 pa-

tients, one patient was assigned to level 2 care, 14 patients were assigned level 3, six patients were assigned level 4, and 19 patients were assigned level 5. In five cases the family member(s) modified their decision after reviewing the family conference summary (one from 2 to 3, one from 3 to 2, one from 4 to 3, and two from 5 to 3). In 36 cases the next of kin or legal guardian was the wife of the patient, in two cases a son, in one case a daughter, and in one case a brother. Nineteen conferences were attended by more than one family member; 15 by children of the patient, three by siblings of the patient, and two by family friends. During 19 conferences family members indicated that the patient had expressed wishes regarding his or her survival in a mentally debilitated state or with the help of machines, and 21 families stated that the topic was never discussed. Eighteen families believed that the patient would want to limit some medical procedures. Evidence for this belief varied from direct statements the patient made before he became demented to the patient's decisions about another family member in a similar situation. Treatment level 5 was assigned more often in family conferences where previous wishes were reported (66.7% of cases) than where no previous wishes were known (31.8% of cases; Table; Fisher's exact test, $P=.03$). One family reported that the patient had believed that any kind of life was worth living but decided that, because he could not have anticipated his present debilitated state, level 5 care was the most appropriate.

Assignments of care levels reached during the family conferences did not correlate with the mean level of care assigned by the whole staff ($r=-.051$, $P=.377$; Fig 2). Despite this discrepancy, the staff was able to comply with decisions of the family conferences. Only one registered nurse and one nursing assistant continued to disagree with the hospice approach and consequently transferred to another ward. Six months after the initiation of the hospice program, the staff was asked again to recommend the optimal level of care for individual patients. Seven registered nurses, three nursing assistants, one licensed practical nurse, and the attending physician participated in the ratings. The ratings were generally higher than the first ones and varied less (mean level of care for 35 surviving patients, 4.39 ± 0.05 vs 3.79 ± 0.11 ; paired $t=7.92$, $P<.001$). There was a strong correlation between the first and second ratings ($r=.792$, $P<.001$).

Of the 40 patients initially included

in the hospice-approach program, 13 died during the first year of the program. Autopsy was performed in 11 cases; pneumonia was the cause of death in seven cases, sepsis resulting from UTI in two cases, and myocardial infarction and gastrointestinal bleeding in one case each. Eight of the 13 patients were in care level 5, one in level 4, three in level 3, and one in level 2. The duration of stay in the hospital (43 ± 28 months) was similar for level 2 and 3 patients (43 ± 35 months) and for level 5 patients (43 ± 26 months). This duration also was not significantly different from the duration of stay of 23 patients with DAT (32 ± 24 months; $t=0.43$) who died in our hospital before initiation of the hospice approach.

COMMENT

Although the right of patients to refuse treatment is generally recognized, no consensus has been reached regarding the most appropriate procedure for obtaining approval of decisions to limit treatment of incompetent patients. Some authors and courts believe that such a decision should be made only by the courts.¹⁵ We believe that a decision-making procedure that involves both family and professional caregivers is preferable. Input in this process is provided by individuals who know best the patient's preillness lifestyle and attitudes and his or her present condition. These individuals either dealt or are dealing with the patient on a daily basis and can appreciate the extent of his or her suffering inflicted by the disease.

Several objections can be raised concerning this process. It could be argued the conference "intimidates" families to accept staff care level recommendations. The staff's professional status, knowledgeability, and number could be viewed as establishing a coercive climate that strongly influences family decision making. We believe a number of factors make this unlikely. The relationships among patient, family, and staff usually evolve over years of contact through participation in our outpatient services, support groups, and a respite program. The long-term nature and quality of this relationship supports open communication. Moreover, the process of the family conference encourages the family to give further consideration to care levels outside the conference and in consultation with other family members, friends, clergy, and advisors. The strong influence of the family views on optimal care level assignment is also supported by the poor correlation between staff recommendations and

the actual-care levels assigned (Fig 2). At the family conference we attempt to create an atmosphere of mutual empowerment in which the staff defers to family member(s) for the final decision, which then provides the staff with the authority for patient management in an acute situation.

Another possible objection is that family motives are suspect. For example, a family may have opted for a less aggressive level of care to avoid financial consequences of extended institutionalization. In our program, there is no financial liability to patient/family for long-term inpatient care. Actually, the family often is faced with loss of funds when the patient dies, because the death terminates some military and disability benefits. Despite this financial threat, most families agree that limited medical treatment for their relatives is preferable.

All patients involved in this program would not be resuscitated in the event of cardiac or respiratory arrest because none of them was assigned level 1 care. We believe that the aftermath of a cardiopulmonary resuscitation produces undue stress and discomfort for a patient who is severely confused. Similarly, we suggest that transferring a patient to an acute medical ward is not desirable. Patients with DAT have a decreased adaptability to a new environment and are often exposed to increased use of restraints in an open ward environment. Resources on our ward provide for both oral and parenteral antibiotic treatment, intravenous hydration, administration of oxygen, and suctioning. We believe that advanced cardiovascular or respiratory support, cardiac monitoring, or long-term intravenous treatment would considerably increase the discomfort of the patient.

The most common life-threatening complications of DAT are pneumonia and UTI. Pneumonia is usually a conse-

quence of sustained dysphagia resulting in aspiration of liquids or solids. The incidence of UTI is increased in patients with incontinence.¹⁶ Therefore, it can be argued that both pneumonia and UTI are indirect extensions of the DAT disease process. Because of the terminal nature of advanced DAT, it is not justifiable to treat a part of the disease process when treatment does not improve the general condition of the patient.

Treatment of infections with antibiotics does not necessarily increase patient comfort. Optimal treatment requires an invasive diagnostic workup including blood withdrawal and sputum suctioning. An empiric treatment without such a workup cannot ensure effectiveness and is, therefore, a poorly defined limitation of medical care.⁵ Patient comfort can be ensured by liberal use of antipyretics and analgesics even if the infection is not treated with antibiotics. In addition, our preliminary data indicate that the hospice approach does not significantly increase the mortality of patients with DAT. A prospective study measuring the effect of the hospice approach on mortality is in progress.

Another intervention that increases the discomfort of patients with DAT is the use of artificial feeding. Feeding and hydration by nasogastric or gastrostomy tube may decrease the incidence of aspiration pneumonia in patients with dysphagia, but it also removes the possible pleasure derived from tasting food. In our experience, the patient's ability to swallow food and liquids is adequate even in very advanced DAT unless the patient develops a serious infection. We recommend that artificial feeding not be initiated unless there is a hope for recovery of normal swallowing because we found it very difficult to stop this feeding. Although a recent court decision specified conditions under which a

tube feeding can be terminated,¹⁷ none of our four families agreed to terminate tube feeding. The limited acceptance of the decision to terminate tube feeding can be attributed to clearly defined consequences of food and liquid deprivation, while the decision not to use the tube feeding defers to the natural progression of the disease.¹⁸ Patients who were assigned level 4 optimal care were either those in whom artificial feeding was initiated before the development of the hospice approach or patients who did not have dysphagia and, therefore, the issue was not discussed at the family conference. However, we initiated nasogastric feeding for a patient assigned to level 2 of optimal care who developed swallowing difficulties.

Although our environment is different from that of a standard hospice, we use similar techniques to ensure patient comfort. These include maximizing the quality of life by use of recreational and occupational therapies, meticulous nursing care, oral hygiene, use of low doses of morphine if the patient is restless, atropine to decrease pulmonary secretions, and oxygen if the patient is dyspneic. We believe that the hospice approach to advanced DAT minimizes patient suffering and provides a compassionate environment for those in the terminal stages of this disease. A similar approach might be beneficial for patients in terminal stages of other progressive diseases, eg, chronic obstructive pulmonary disease and amyotrophic lateral sclerosis, who are currently excluded from most formal hospice programs.

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References

1. Volicer L, Herz LR: Pharmacologic management of Alzheimer-type dementia. *Am Fam Phys* 1985;32:123-128.
2. Besdine RW: Decisions to withhold treatments from nursing home residents. *J Am Geriatr Soc* 1983;31:602-606.
3. Bayer R, Callahan D, Fletcher F, et al: The care of terminally ill: Morality and economics. *N Engl J Med* 1983;309:1490-1494.
4. Wanzer SH, Adelstein SJ, Cranford RE, et al: The physician responsibility toward hopelessly ill patients. *N Engl J Med* 1984;310:955-959.
5. Rango N: The nursing home resident with dementia. *Ann Intern Med* 1985;102:835-841.
6. Hilfiker D: Allowing the debilitated to die. *N Engl J Med* 1983;308:716-719.
7. Lo B, Dornbrand L: Guiding the hand that feeds. *N Engl J Med* 1984;311:402-404.
8. Suber DG, Tabor WD: Withholding of life-sustaining treatment from the terminally ill incompetent patient: Who decides? *JAMA* 1982;248:2250-2251, 2431-2432.
9. Mariner WK: Decision making in the care of terminally ill incompetent persons: Concerns about the role of the courts. *J Am Geriatr Soc* 1984;32:739-746.
10. McKhann G, Drachman D, Folstein M, et al: Clinical diagnosis of Alzheimer's disease. *Neurology* 1984;34:939-944.
11. Folstein M, Folstein S, McHugh PJ: 'Mini-Mental State,' a practical method for grading the cognitive state of patients for clinicians. *J Psychiatr Res* 1975;12:189-198.
12. Blessed G, Tomlinson BE, Roth M: The association between quantitative measures of dementia and of senile changes in cerebral grey matter of elderly subjects. *Br J Psychiatry* 1968;114:797-811.
13. Ellsworth RB: *The MACC Behavioral Adjustment Scale: Revised 1971 Manual*. Los Angeles, Western Psychological Services, 1971.
14. Goodglass HC, Kaplan E: *The Assessment of Aphasia and Related Disorders*, ed 2. Philadelphia, Lea & Febiger, 1983.
15. Baron C: The case for the courts. *J Am Geriatr Soc* 1984;32:734-738.
16. Johnson ET: The condom catheter: Urinary tract infection and other complications. *South Med J* 1983;76:579-582.
17. Curran WJ: Defining appropriate medical care: Providing nutrients and hydration for the dying. *N Engl J Med* 1985;313:940-942.
18. Volicer L: Need for hospice approach to treatment of patients with advanced progressive dementia. *J Am Geriatr Soc* 1986;34:655-658.