

Palliative fever management in Alzheimer patients: Quality plus fiscal responsibility

Aggressive medical treatment of infections does not affect the progressive course of dementia of the Alzheimer type (DAT) and has limited effect on the mortality rate. Utilization of health care resources and discomfort during a fever episode were compared in three differing treatment conditions: in 18 patients in a dementia special care unit (DSCU) who received palliative management, 26 patients in a DSCU who were treated aggressively, and 17 DAT patients in traditional long-term care units who were treated aggressively. Both groups of patients in the DSCU had lower discomfort scores, lower utilization of high-cost health care resources, and higher utilization of analgesics and narcotics. A nursing model of care incorporating hospice concepts into the DSCU is suggested.

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CURRENTLY THERE is no cure or prevention measure for dementia of the Alzheimer type (DAT). Inpatient care in the later stages of the disease is inevitable in most cases,^{1,2} often required for the last 3 years of life,³ and limited in that it can only offer symptomatic treatment and the provision of a comfortable and safe environ-

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ment.⁴ The treatment of disease symptoms in the advanced stage poses ethical and clinical dilemmas⁵⁻⁷ that have both nursing and health policy implications. These dilemmas concern the use of aggressive medical interventions that may or may not extend a patient's life, often cause patient discomfort, increase the risk of precipitating iatrogenic complications, and drive up health care costs. The management of fever episodes in DAT patients is an important issue because most patients ultimately die from an infection.

BACKGROUND

The purpose of this study was to compare discomfort and the utilization of health care resources during treatment of fever episodes in patients with advanced DAT by aggressive medical care (AMC) and palliative managed care (PMC). Increased discomfort associated with the AMC diagnostic workup and treatment, such as temporarily withholding antipyretics or applying restraints, would be acceptable if a positive long-term benefit was achieved. However, the treatment of infection does not affect the progressive and incurable nature of DAT. In addition, treatment of infections in advanced DAT does not affect overall mortality rate and could be considered futile.⁸ In the absence of a long-term benefit, the avoidance of events that invoke patient discomfort and utilize health care resources for futile medical interventions might be a viable approach. In theory, PMC would be better than AMC on both counts.

The care of people for whom cure is not currently possible falls within nursing's domain. The application of the medical model for DAT patients has been criticized be-

cause it adopts an instrumental view of experience that excludes dimensions of meaning, above all the meaning of suffering.⁹ PMC would promote intensive nursing care rather than support the medicalization of late-stage DAT.

The work of Fabiszewski and colleagues has characterized the clinical trajectory of decline in patients with late-stage DAT who developed fevers¹ and examined the survival of AMC and PMC patients.⁸ This nurse-directed research team found no difference in the mortality rate for late-stage DAT patients during the 34-month evaluation period in which 75 of 104 patients developed a total of 172 fever episodes.⁸ The Fabiszewski group recommended that treatment decisions be made individually for each patient, necessitating that both family and staff know the risks and benefits of different strategies.⁸ The 1991 congressional Advisory Panel on Alzheimer's Disease also stated that the decision-making process should "emphasize outcome and allow individualization of care and acceptance of some degree of risk in clinical and everyday care situations."^{10(pxxi)}

Magaziner¹¹ and Warren¹² and their associates cite an abundance of work related to nursing home infections and antibiotic use in the elderly studied from a medical perspective, but there is little specific information regarding treatment strategies for caring for DAT patients with fever episodes. Nevertheless, the clinical manifestations of the progression of DAT place patients at risk for developing fever episodes.⁸ For example, incontinence places patients at risk for urinary tract infections.^{13,14} Moreover, mobility and eating difficulties that predispose DAT patients to aspiration^{15,16} may cause pneumonia, which often has atypical clinical presentations.¹⁷⁻¹⁹

The health policy perspective is the anticipated need to provide 3 years of nursing home care to DAT patients³ who are vulnerable to developing repetitive infections.¹ For some of these patients, antibiotics do not increase survival.⁸ The government's expenditures for nursing home care of individuals with dementia in 1990 was more than \$11 billion²⁰ and the increasing prevalence of DAT in future years is certain.¹⁰

The ethical perspective was articulated in the American Nurses' Association *Code for Nurses with Interpretive Statements*, which states "The nurse assumes responsibility and accountability for individual nursing judgments and actions."^{21(p7)} To make decisions that professional nurses would consider morally right, the ethical principle of autonomy needs to be considered. In this situation, DAT can be considered a terminal illness and patients' autonomy should be maintained by their family or legal surrogate who could decide in advance of a fever episode the scope of medical care to be provided or withheld.⁶

In the absence of cure, quality of life is the focus of care. This belief has been made operational with dementia special care units (DSCUs), which promise to provide better care to patients with DAT than those individuals would receive in traditional long-term care units.²⁰ Promotion of comfort, that is, the alleviation of discomfort, has been suggested as the major goal of DSCUs for patients with late-stage DAT.²² Volicer and colleagues⁷ have argued that patients with DAT should not be denied options for pal-

liative care that are available to patients who traditionally receive hospice care. That is, patients with cancer can decide to forego chemotherapy for comfort care, thus patients with DAT should have the option of palliative care available.

METHOD

Sample

This prospective study extended the work of Fabiszewski and associates^{1,8} by including discomfort and utilization of health care resources. Comparable patients were recruited and characterized using similar scales. Study sites were two Department of Veterans Affairs (DVA) geropsychiatric hospitals located in New England that care for patients with advanced DAT on intermediate medicine units but use different management practices. At one site, patient care is provided on three, 25-bed DSCUs. A patient's legally defined surrogate decision maker meets with the health care team to make an advance management preference.⁶ For the management of fevers, a patient would either be given a full diagnostic workup and subsequent treatment for intercurrent infections, that is, aggressive medical care (DSCU-AMC) or palliative managed care (DSCU-PMC) strategies directed to control symptoms and promote comfort.⁶⁻⁸ At the second site, DAT patients are dispersed among several traditional long-term care (TLTC) units and all are managed by aggressive medical care (TLTC-AMC).

Criteria for subject selection included

- a diagnosis of probable DAT according to the DSM III-R and the criteria proposed by McKhann and associates,²³
- admission for long-term care (ie, not episodic or respite care), and

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- the occurrence of a documented fever episode.

A fever episode was defined as an inter-current illness characterized by a fever that was not caused by a known non-infectious complication such as dehydration or impaction and survived by the patient (ie, the episode was not the terminal event of end-stage DAT). Fever was defined as an observed rectal temperature higher than 100°F for greater than 24 hours,⁸ one increase to 102°F,⁸ or antipyretic therapy for more than 24 hours to reduce a temperature elevation.

Variables

Fever management strategies

The independent variable, designated fever management strategy, was not manipulated by the research team. The clinical staff identified eligible patients. An abstraction form⁸ was used to record patients' observed physical appearance and condition at onset, signs that would potentially lead to a diagnostic workup for the fever, diagnostic tests ordered and their results, organisms identified, treatments carried out, and the diagnosed cause of the fever episode.

Utilization of health care resources

Several costing formulas were used to determine the price of health resources utilized. The formulas used were:

- the DVA cost distribution report²⁴ to compare intermediate and acute medicine bed days prices,
- the DVA formulary price list for assigning costs to medications,
- Medicare national relative value scale, multiplied by a cost factor specific to radiology in suburban-rural areas of Massachusetts²⁵ for costing chest radiographs, and
- Medicare caps for 1991 supplied by Blue Cross of Massachusetts to compare laboratory costs.

Discomfort

The second dependent variable was discomfort, which was defined as a negative emotional or physical state, subject to variation in magnitude in response to internal or environmental conditions. Discomfort was operationalized by the discomfort scale for DAT (DS-DAT),²⁶ which consists of a nine-item behavioral observation scale with a range of 0 (no observed discomfort) to 27 (high level of observed discomfort). Reliability, audited by the alpha coefficient as a measure of internal consistency,²⁷ ranged from 0.86 to 0.88. Interrater reliability, audited quarterly using the correlation coefficient,²⁸ ranged from 0.89 to 0.98. To evaluate a consistent bias across observers²⁹ the paired *t*-test was used to compare mean scores and ranged from 1.6 ($p=0.12$) to 1.3 ($p=0.28$).

Disease severity

To describe the patients, four scales⁸ were used. Overall DAT severity was measured by the Bedford Alzheimer Nursing Scale (BANS) that has been found to vary monotonically with disease progression.³ Two modifications from the original BANS were made for this study. Two items, contractures and rigidity, were combined because one item contributed better to a scale with equally weighted items. Instead of the three-point scale, a four-point scale was used to capture a broader range of variation in DAT progression. The seven-item BANS has a range of 7 (no impairment) to 28 (complete impairment). The alpha coefficient of 0.70 was an adequate indicator of internal consistency for a new scale.²⁷

Dependence in activities of daily living (ADL) was measured by the six-item Katz Index of ADL,³⁰ which has a range of 0 (completely independent) to 6 (completely dependent). When items of the Katz index have been embedded into larger scales of functional assessment, the total scale has been judged valid and reliable.³¹ Coefficient alpha was 0.70 in this study.

Cognitive impairment was measured by the Mini-mental Status Examination (MMSE) in which a score of 30 indicates no impairment and a score of 0 reveals maximum impairment.³² The MMSE has been found to be reliable in a number of studies³³; in the current study it had a coefficient alpha of 0.79.

Speech ability was measured by a four-item speech assessment scale³ with a range of 4 (completely mute) to 20 (all language ability retained), modified from the Boston Aphasia Diagnostic Evaluation.³⁴ In previous work, deterioration in speech varied with disease progression.³ In this study the alpha coefficient was 0.97.

Procedures

Each unit was contacted twice weekly to identify patients who met the inclusion criteria. The DS-DAT was administered monthly to all patients by two trained raters, hired for the project, who alternated between the sites. Five-minute observations were made on patient units during daylight hours, after morning care had been completed. The raters waited at least 15 minutes after any event that might invoke discomfort (such as being turned) before beginning the observation. The DS-DAT was also administered during the typical peak (days 3 to 5) and resolution (days 9 to 11) of fever episodes. The score of the monthly DS-DAT

that preceded the fever episode was used for the baseline (prefever) score.

Nursing staff familiar with the patient at the time of the fever onset completed the clinical section of the fever abstraction form. A research nurse abstracted demographic, diagnostic, and utilization data from the medical record. The clinical staff, who was familiar with the composite of patients' behaviors on all shifts, completed BANS and Katz indices quarterly. A research nurse administered the MMSE and speech assessment scale quarterly. The measures of disease severity collected before the fever episode were used for the analysis.

Patients lacked decision-making capacity (see MMSE scores, Table 1). Informed consent was therefore obtained from patients' legal surrogates. Consent was provided for all 163 of 169 eligible patients who were simultaneously participating in a longitudinal study of DSCUs.²²

RESULTS

Patient characteristics

During the 2 years of data collection, 61 patients had a fever episode with complete data for the observations of discomfort made before, at the peak, and at the resolution of their first documented fever episode. Patients were assigned into one of the three groups—TLTC-AMC, DSCU-AMC, and DSCU-PMC—on the basis of their location

At the onset of fever, half of the patients were described by nursing staff as having had a recent change in behavior with increased confusion, lethargy, or agitation.

Table 1. Characteristics of the study population at time of fever episode (means \pm standard deviations)

	TLTC-AMC (n = 17)	DSCU-AMC (n = 26)	DSCU-PMC (n = 18)	Total (n = 61)
Age at DAT onset (years)	66.6 \pm 10.6	65.2 \pm 8.3	60.9 \pm 6.4	64.2 \pm 8.6
Age at fever onset (years)	72.9 \pm 10.1	72.8 \pm 7.7	70.3 \pm 4.2	72.1 \pm 7.7
Duration of DAT at fever (years)*	5.8 \pm 2.5 [†]	7.6 \pm 3.2 ^{†‡}	9.4 \pm 3.2 [‡]	7.7 \pm 3.2
Duration of hospitalization (months)*	24.6 \pm 15.2 [†]	13.4 \pm 10.1 [†]	42.5 \pm 33.3 [‡]	25.1 \pm 23.8
Initial temperature (°F)	101.8 \pm 1.1	101.6 \pm 1.0	102.0 \pm 1.2	101.8 \pm 1.1
Highest temperature (°F)	101.9 \pm 1.0	102.4 \pm 1.1	102.6 \pm 1.1	102.3 \pm 1.1
BANS*	19.9 \pm 3.6 [†]	16.8 \pm 4.0 [‡]	20.9 \pm 3.1 [†]	18.9 \pm 4.0
Katz ADL scale	5.7 \pm 0.8	5.4 \pm 0.9	5.9 \pm 0.3	5.6 \pm 0.7
MMSE	1.4 \pm 3.1	1.6 \pm 3.4	0.4 \pm 0.9	1.2 \pm 2.8
Speech assessment	7.1 \pm 4.6	8.3 \pm 4.3	6.7 \pm 3.4	7.5 \pm 4.1

*F test significant at $p < .01$.†,‡ Groups not sharing the same superscript are different from each other by Scheffe multiple comparison test ($p < .05$).

and treatment strategy. Demographic characteristics were similar (Table 1) although DSCU-PMC patients had a longer duration of DAT than TLTC-AMC patients and longer hospitalization at the onset of their fever than TLTC-AMC and DSCU-AMC patients. All patients suffered from advanced DAT as indicated by scores on the disease severity measures (Table 1). BANS scores indicated that DSCU-AMC patients were slightly less impaired than the other two groups.

At the onset of fever, half of the patients were described by nursing staff as having had a recent change in behavior with increased confusion, lethargy, or agitation. Eating problems included: refusing food ($n = 23$), refusing liquids ($n = 17$), choking on food ($n = 13$), and choking on liquids ($n = 15$). Given the predisposition of patients to develop urinary tract infections (UTF) and pneumonia, the number of patients with reported genitourinary ($n = 11$) or respiratory ($n = 21$) symptoms was low. The nursing

staff often recognized the presence of infection from atypical symptoms. When further questioned, some typical responses were "I can tell when he has a urinary tract infection, he gets agitated." "[He] gets more confused whenever he is coming down with pneumonia." "We can just tell; his behavior changes."

Fever management strategies

The patients were divided into groups according to planned treatment strategies recorded in their medical records, but diagnostic and treatment strategies actually carried out were not as clear-cut as had been presumed. Empiric management was observed, most likely because the fever episodes examined in this study were not necessarily the first ones suffered by patients since their hospitalization. Not all TLTC-AMC and DSCU-AMC patients received a full fever workup (Table 2). Some DSCU-PMC patients who exhibited signs of cystitis with dysuria had a urine culture or were

treated with antibiotics (or both). Two DSCU-PMC patients had blood cultures drawn and one of those patients received a chest radiograph. The percent of patients given a diagnosis of fever of unknown origin (Table 3) was consistent with previous findings.⁸

Initial treatment by antibiotics was given to 14 of 17 patients in the TLTC-AMC group (6 parenterally, 7 by mouth, and 1 by feeding tube), 24 of 26 patients in the DSCU-AMC group (2 parenterally and 22 by mouth), and 5 of 18 patients in the DSCU-PMC group (all by mouth). In the TLTC-AMC group one patient received double antibiotic therapy (parenteral cephalosporin and clindamycin followed by oral Cipro) and another received triple antibiotic therapy (parenteral cephalothin and gentamicin with oral Bactrim). DSCU-AMC and DSCU-PMC patients received more antipyretics and analgesics than did TLTC-AMC patients (Table 2).

Utilization of health care resources

Anticipated differences in the costs of health care resources utilized were found.

Not surprisingly, the largest differences were found in high-cost items, and these differences were accounted for by a few patients. Thus analysis of statistical variance between groups would not be meaningful. Therefore, those data are described only. Statistical comparisons are made for standard diagnostic tests (Table 2). The data show that DSCU-PMC patients had fewer laboratory tests than either the TLTC-AMC or the DSCU-AMC patients.

Patient transfers to an acute medical unit accounted for the largest cost difference between TLTC-AMC and DSCU-PMC groups. The daily cost of \$267 a day did not include drugs, radiology, laboratory procedures, and the cost of the unused but reserved long-term care bed. No DSCU-AMC or DSCU-PMC patients were transferred to acute medicine. One TLTC-AMC patient was transferred for 4 days during this study. Before this patient's death 5 months later, he was transferred five additional times for a total of 29 days on acute medicine.

Medications were the next highest cost items. Large differences were observed between TLTC-AMC and DSCU-PMC

Table 2. Diagnostic tests and costs

	TLTC-AMC (n = 17)	DSCU-AMC (n = 26)	DSCU-PMC (n = 18)	Price each (\$)	Total (n = 61)
<i>Test counts</i>					
Chest radiograph*	10	19	1	38.46	1,153.80
Blood culture*	6	17	3	14.62	380.12
Urine culture*	10	18	4	3.21	102.72
Mean cost/patient† (\$)	29.67	39.89	5.29		26.83
Total cost/group (\$)	504.42	1,037.06	95.16		1,672.64

* chi square significant at $p < .001$ for differences between TLTC-AMC and DSCU-AMC groups combined and DSCU-PMC group.

† F test significant at $p < .001$.

All groups different from each other by Scheffe multiple comparison test ($p < .05$).

Table 3. Diagnosis and fever management

	TLTC-AMC (n = 17)	DSCU-AMC (n = 26)	DSCU-PMC (n = 18)	Total (n = 61)
<i>Diagnosed cause of fever episode</i>				
Pneumonia	2	5	1	8
UTI	6	12	7	25
Pneumonia and UTI	0	2	0	2
Other	2	1	0	3
Unknown	7	6	10	23
<i>Analgesic use</i>				
Antipyretic*	11	23	13	47
Morphine	0	0	1	1
Antipyretic and morphine	0	2	3	5

*chi square = 5.80, $p = .016$ for difference of antipyretic use between TLTC-AMC and combined DSCU-AMC and DSCU-PMC groups.

groups. Some parenteral antibiotics also required intravenous supplies for administration and laboratory resources to monitor kidney function and peak-trough levels. The formulary cost for 1 day of antibiotic therapy (three administrations of 1 g ceftazidime at \$10.19 each) was \$30.57 for a TLTC-AMC patient. One day of analgesic drug therapy for a DSCU-PMC patient treated with antipyretics (12 325-mg acetaminophen tablets at a cost of \$0.01 each and 6 4-mg morphine sulfate tablets at a cost of \$0.40 each) cost \$2.52.

Discomfort

Observed discomfort levels before, at peak, and at resolution were higher for TLTC-AMC patients than for DSCU-AMC or DSCU-PMC patients (Fig 1). The analysis of variance indicated that discomfort levels across time were similar in DSCU-AMC and DSCU-PMC groups, but significantly lower than the TLTC-AMC group (Table 4). While the mean scores showed an increase from time 1 (before) to time 2 (peak), and there was a decrease from time 2 to time

3 (resolution), this change did not reach statistical significance, most likely due to the small sample size. There was no interaction, that is, there was no difference in the pattern over time by group (Table 4). Separate analysis showed that the DSCU-AMC group had lower discomfort scores [$F(41,1) = 5.58, p=.02$] than the TLTC-AMC group.

DISCUSSION

There are some limitations to be considered regarding these findings. Patients were not randomly assigned to treatment strategy, and they were predominantly male and younger than the typical patient residing in a nursing home.³⁵ The treatment strategy was not determined by a research protocol, but by a sequence of events controlled by clinical staff. The raters were not blind to patients' location, and discomfort was assessed only three times per patient.

Ideal design and methods could not be implemented. Random assignment was not possible for ethical reasons. Patients had es-

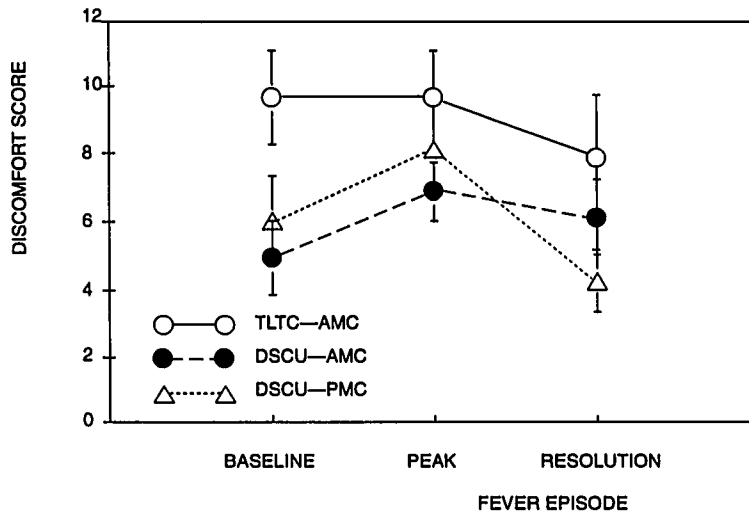


Fig 1. Discomfort during a fever episode.

established relationships with caregivers, their hospital site was convenient to families, and relocation would have been stressful.³⁶ Examination of patients' characteristics (Table 1), however, indicates that there were no significant clinical differences in severity of DAT, a reason for random assignment to achieve equivalent groups.

Designated treatment strategies were based on families' knowledge of patients'

previous wishes or perception of the best interest of the patient and reflected personal value decisions; thus random assignment would have been unethical. Actual treatment strategies carried out were according to the best judgment of the clinicians caring for patients. The magnitude of the differences between AMC and PMC treatment strategies was not as great as anticipated. Type II errors are a risk when studies are

Table 4. Repeated measures analysis of variance for discomfort scores before fever, at peak, and at resolution

	SS	df	MS	F	p
<i>Between subjects</i>					
Groups	350.56	2	175.28	3.80	.028
TLTC vs DSCU	343.43	1	343.43	7.45	.008
AMC vs PMC	0.73	1	0.73	0.02	.900
Within groups	2,672.75	58	46.08		
<i>Within subjects</i>					
Time	135.34	2	67.67	2.87	.061
Time × group	98.81	4	24.70	1.05	.386
Within cells	2,735.88	116	23.59		

SS = sum of squares; df = degrees of freedom; MS = mean squares.

conducted in natural settings where the research team does not have control of the independent variable. Despite this risk, large and anticipated differences were found in costs of health care resources utilized and discomfort.

Practical considerations determined the open nature of the study, data collection in the clinical settings, and 5-minute observation periods to assess discomfort. Privacy and financial and logistical considerations did not allow for the ideal solution of continuous recordings by a high-resolution camera that would enable scoring by raters masked to the setting and illness status of patients. However, a single 5-minute observation period is typically used in clinical settings and from such observation wide-reaching nursing implications for managing aversive procedures have been drawn.³⁷⁻³⁹ Previous work by Patterson⁴⁰ found that the expectancy threat to observer validity in natural settings can be overcome by well-trained raters. This study followed the rater training and evaluation program built into the use of the DS-DAT,²⁶ raters alternated between sites, and interrater reliability levels were acceptable.

The burden associated with fever management strategies needs to be considered in the light of iatrogenesis and benefits. Most patients who develop fevers have multiple episodes and recover with or without using antibiotics,⁸ which can promote resistance, thus necessitating the administration of more potent parenteral antibiotics. The potential for iatrogenic complications, such as the development of delirium or pressure sores due to the use of restraints, is higher when AMC is used. DAT patients cannot understand why they must be taken to another area by an escort they do not know, why they must undergo an examination, and

why restraints must be used prior to administration of intravenous solutions and medications.

The major component of the cost differences between the TLTC and DSCU groups was the cost of acute hospital care. In addition, the transfer of a long-term care patient did not decrease those costs because the bed was left unfilled pending the patient's return. It is clearly more economical to the health care system for DAT patients to remain on their long-term care unit and receive palliative care.

The findings indicate that managing fever episodes on a DSCU results in lower discomfort levels, even for AMC patients, than those observed in AMC patients on TLTC units. This finding was unanticipated as the research team believed that TLTC-AMC and DSCU-AMC patients would have similar discomfort scores and trends, both higher than DSCU-PMC patients. It was not the intent of this study to identify specific components of the DSCU responsible for the observed differences. It may be that liberal use of antipyretics (Table 3) given to both DSCU-AMC and DSCU-PMC patients accounted for lower discomfort scores. The DSCU⁴¹ is a relatively new, multifaceted construct that needs further investigation.

IMPLICATIONS

The advent of the DSCU offers a unique opportunity for nursing to take the lead to shift the paradigm from cure to care of individuals with DAT. The paradigm of intensive care nursing, rather than the medicalization of late-stage DAT, is congruent with contemporary policy recommendations and biomedical ethics. This study supports the

Moody thesis of a nonmedical model to provide more humane and less expensive care as the hospice experience has suggested.⁹

A nursing research agenda would include replicating this study in non-DVA sites with female patients, identifying the concepts within the DSCU that have a causal relationship with discomfort and other outcome variables, examining outcomes for long-term care patients who are transferred to acute units, and addressing infections in the elderly from a nursing perspective. For example, although pneumonia with atypical symptoms has been well described,¹⁷⁻¹⁹ except for a single case study, urinary tract infections are not described in the literature.⁴²

Nursing practice changes would be related to preventing patient discomfort. There is no need for patients to endure invasive treatments that do not treat underlying causes when symptomatic manage-

ment promoting comfort is more appropriate. Low-dose morphine by mouth should be considered as an analgesic because it has few side effects and addiction to narcotics for patients with late-stage DAT is not an issue.

The authors recommend a nursing model that includes concepts described in the hospice model for patients with late-stage DAT,⁶ encompasses instrumental tasks and affective relations as characterized in a caregiving relationship,⁴³ and involves the interdisciplinary team to promote mutual goal setting in collaboration with the family.⁴⁴ Use of a hospice model benefits patients by decreasing discomfort and also saves valuable health care resources. Patients' dignity and individuality, as remembered by the family and preserved by the staff, may be maintained despite the relentless progression of DAT.

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