

Palliative Care for Advanced Dementia: A Model Teaching Unit-- Practical Approaches and Results

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As baby boomers age, the prevalence of Alzheimer's disease and other dementias is expected to increase dramatically in the coming years. While research continues at a fast pace to find the cure for Alzheimer's and other dementias, care for persons with dementia has become a top priority. Yet, many family and professional caregivers struggle with the caregiving essentials as individuals' progress through the dementia disease trajectory, particularly in long-term care settings. The purpose of this article is to present an overview of the Palliative Care for Advanced Dementia: A Model Teaching Unit at the Beatitudes Campus, to describe the "best practices" for persons in the final stage of dementia, and to discuss the preliminary findings related to the impact of this Program.

Background

The Alzheimer's Association estimates that over 10 million baby boomers will develop Alzheimer's disease. With over 5.2 million Americans currently living with the disease, it is expected that by 2010 there will be a half million new cases of dementia. Alzheimer's disease is the most common type of dementia, accounting for 50 to 70 percent of cases.¹ The disease is projected to strike one in eight persons and effective treatment could still be a decade or more away. In addition, as a person ages, there is an increased likelihood that he or she will be afflicted with the disease. Alzheimer's disease alone (excluding the other types of dementia) is presently the sixth leading cause of death in the country.² While death from other major diseases, such as heart disease, stroke, and breast and prostate cancer is on the decline (2004-2005), death from Alzheimer's disease is spiraling upward at a rate of 45 percent during this same period.¹ In Arizona alone, the number of persons with Alzheimer's disease is projected to grow from 78,000 in 2000 to 94,000 in 2010-- a 24 percent increase.³ While research continues at a fast pace to find the *cure* for Alzheimer's and other dementias, *care* for persons with dementia has become a top priority. Yet, many family and professional caregivers struggle with the caregiving essentials as individuals progress through the dementia disease trajectory, particularly in long-term care settings. The purpose of this article is to present an overview of the *Palliative Care for Advanced Dementia: A Model Teaching Unit* at the Beatitudes Campus, to

describe the “best practices” for persons in the final stage of dementia, and to discuss the preliminary findings related to the impact of this Program.

The Person with Advanced Dementia

The person with advanced dementia suffers from significant losses, including the inability to communicate effectively, execute activities of daily living, meet personal care needs, and achieve personal and social comfort.⁴ As independence becomes compromised, individuals become less capable of caring for themselves. They suffer from increasing deficits in all aspects of their lives and struggle with the almost insurmountable challenge of staying connected with the world that surrounds them. The inability to verbally communicate their needs to others may be overlooked as they become increasingly reliant on caregivers to meet their entire essential physiological, psychological, spiritual, social, and comfort needs. The decline is progressive, resulting in loss of independence, cognitive demise, and poor overall functional ability. Persons progress from the mild stage with impaired memory, personality changes, and spatial disorientation to the moderate stage exhibiting aphasia, apraxia, confusion, agitation, and insomnia. By the time they reach the severe stage they will exhibit restlessness, incontinence, eating difficulties, and motor impairment. In the terminal state, individuals can become bedfast, mute, dysphagic, and may develop intercurrent infections.⁵ Persons with advanced dementia, including late-stage Alzheimer’s disease, comprise the severe and terminal categories.

An individual can live up to 20 years after the diagnosis of Alzheimer’s disease has been made and typically remains in the advanced stages of the disease from one to three years. More than two-thirds of persons with dementia die in a nursing home compared to 70 percent of those with cancer who die at home or in the hospital.¹ It is suspected that death due to dementia is drastically underreported as the cause of death may actually be attributed to an event that led to the death, such as an infection, or a co-existing primary disease. Individuals are more likely to be placed in a long-term care facility as their disease progresses to the moderate and advanced stages and as caregiving needs increase. The number of individuals residing in long-term care facilities in Arizona in 2007 was 40,272. Of these, 45 percent were without cognitive impairment, 23 percent were considered to have very mild to mild impairment, and 32 percent were classified as having moderate to severe dementia.³ Caregivers across the continuum of care, and particularly in long-term care facilities, must attend to the complexity, challenges, and the potential of unmet needs for persons in this progressive decline.

While persons are in the moderate stage and progressing toward advanced dementia, they may undergo a myriad of curative or restorative interventions or suffer from a lack of comfort interventions. Staff may not know how to adequately care for these most vulnerable elders since persons with advanced dementia may not be able to verbally communicate their needs. Within any given facility, a palliative care approach may be nonexistent.⁶ Staffing, fiscal, and other organizational factors in the facility along with resident characteristics may play a role in the decision to forgo hospitalization for a person with advanced dementia,⁷ or to forgo artificial nutrition and hydration.⁸ In fact, restraint use, the lack of pain management, the inappropriate use of psychotropic medications, the use of tube feedings, repeated hospitalizations and emergency department visits may create more discomfort, especially when individuals are unable to verbalize their preferences. Advance directives may not be specific enough, and the

inevitability of the terminal disease process may also not be acknowledged.⁹ Volicer hypothesizes that the distress caused by these questionable interventions not only affects the individuals themselves, but their families as well.¹⁰

The Model Teaching Unit Program

The Beatitudes Campus Health Care Center has had a special care unit for dementia since 1998. Called the Vermilion Cliffs (Cliffs), individuals, known as residents, in the moderate to advanced stages of dementia reside in the facility unit, known as a neighborhood, until their death. Potential residents are screened by the staff social worker before their admission to the unit. The average resident length of stay is two years and three months. The maximum census on the Cliffs is 46 and it runs at full capacity with a waiting list. The average age is 87 with females outweighing males three to one. The primary dementia diagnoses include Alzheimer's disease, frontotemporal dementia, Lewy body dementia, and vascular dementia. The average Mini-Mental Status Evaluation (MMSE) is 9 with a range of 0 to 18. The average Functional Assessment Staging Tool (FAST) score is 6d with a range of 6a through 7f, which is consistent with moderate to advanced dementia.

There are many practices in place that promote comfort. "I Care Plans" are care plans written from the perspective of the person (and not the staff member), identifying key aspects of care such as maintaining communication and connections through activities, recognizing delirium and mood disorders, and managing fall risks. There are no physical restraints used on individuals residing in the neighborhood. There is a 24-hour open restaurant which functions as the primary dining room and snack area. The dining program is customized to address individual dietary needs, resident choice of food with marginal use of nutritional supplements, and a milieu that is conducive to a pleasurable eating experience. As a result, minimal weight loss is seen among residents. There is a continuous activity program around-the-clock, and sundowning does not exist since there is a balance of sensory-calming and sensory-stimulating activities that is individualized to each resident. Pain is aggressively treated and there is minimal use of psychotropic medications. Residents sleep on their own schedule and they can eat and enjoy activities at their own pace. Bathing is a pleasurable experience and the towel bath method is an option for those who no longer enjoy a shower. When residents fall asleep in their chairs, they are laid down to rest. When residents are up, they are positioned in a chair in proper alignment to promote comfort and safety. In essence, comfort is the primary goal for these elders.

Direct caregivers are trained in comfort-management principles during orientation and at regular intervals. The staffing ratio is 1: 8 for Certified Nursing Assistants and 1: 22 for the licensed nursing staff. All staff come to know the residents individually and can therefore anticipate their needs. Reactive approaches to behavioral challenges are thus minimized. Instead of resorting to standard responses such as "that is just the way s/he is...", the staff embraces an investigative mentality. They look for signs, symptoms, and gestures indicative of displeasure, pain or distress and modify their approaches to the residents accordingly.

In 2005, the Beatitudes Campus and Hospice of the Valley, both in Phoenix, Arizona received generous financial support from the BHHS Legacy Foundation to institute a training program for qualified and interested facilities to learn these best practices in dementia care. To date, four

long-term care facilities have participated in the program. Over two years, there were 525 individual staff education contacts with the Model Teaching Unit education team. In addition, 225 persons attended the training programs and 102 caregivers received advanced dementia care training at the Cliffs. Four facilities, two long-term care and two assisted living facilities, are participating in the 2007-2009 program.

A variety of materials have been developed to facilitate the Model Teaching Unit program. The actual training spans six months. Individuals representing all disciplines caring for persons with advanced dementia are afforded didactic training both onsite at their home facilities, and at the Cliffs, which has become a living clinical laboratory. Table 1 lists the primary training components of the Palliative Care for Advanced Dementia program.

Table 1. Core Training Program

1. Key Concepts in Dementia Care
2. One to One Direct Care Experience Peer Training at the Cliffs
3. Self-Study Program that includes audio-visual training materials for continuing education
4. Targeted Training Program:
 - Comfort-Focused Behavior Management
 - Assessing and Addressing Pain
 - Meaningful Moments for Persons with Advanced Dementia: Stimulation of the Senses
 - End-of-Life and Hospice Care
 - Medical Provider Education and Support

In addition, medical care providers are educated on palliative principles of medical management of persons with advanced dementia, addressing issues such as simplifying daily medications and treatments, and assessing for pain and depression. Providers are also offered guidance to effectively discuss health care decisions with the resident's power of attorney. Facility participants receive a tool box with a variety of audio-visual materials and the Palliative Care for Advanced Dementia Guidelines and Standards.¹¹

A significant and vital part of the *Palliative Care for Advanced Dementia: A Model Teaching Unit* program is the data collected to ascertain the significance and impact of the program related to the knowledge and commitment of caregiving staff and changes in resident outcomes. Facilities participating in the program agree to participate not only in the standard evaluation surveys, but also in the research studies which are part of this demonstration project. All of the research studies were approved by the Institutional Review Board (IRB) at Hospice of the Valley. The overall purpose of the research was to ascertain if the training program had made a difference in the knowledge and commitment of caregiving staff and in the overall care of residents. The following research questions were addressed: 1) What are the resident outcomes or processes of care which changed as a result of the training program? And 2) Do facility caregiving staff acquire knowledge, improvement of skills, or experience a change in their beliefs, perceptions, and team-building as a result of the training program?

Analysis and Results

The study employed a quasi-experimental design, and data was collected at the beginning of the training program and six months later. The convenience sample included consenting resident and staff participants from three nursing care facilities that were part of the *Palliative Care for Advanced Dementia: A Model Teaching Unit* program at the Beatitudes Campus from 2005 through 2007. Descriptive and inferential statistics were employed. A brief summary is provided.

Residents

Thirty residents with advanced dementia were consented by their legal decision-makers to participate in the study to evaluate change in practice and outcomes pre and post training program. Twenty-four of the participants had a MMSE of 0 and all of the residents had a FAST score of greater than 7, indicating profound cognitive and functional impairment. Data was collected from the medical record for each resident's history of hospitalization, emergency department use, advance directives, evidence of pressure ulcers, weight trends, and the medication administration record (MAR). Charts of twenty-five residents were initially retained in the study; however over the six-month course of the study, nine persons (36%) became deceased. Ultimately, medical records for 16 residents in three facilities were included in the analysis. Fifteen of these residents were female, the average age was 87, the mean FAST score was 7c, and the mean MMSE score was 1. Hospice was provided to 63% (n = 10) of the residents.

T-tests were computed to determine differences between the means of the variables of interest. There was no statistical significance over the six-month time interval for the following measures: repeat hospitalizations, multiple emergency room visits, weight trends, the incidence of pressure ulcers, and the type of advance directive. However, further analysis revealed compelling findings related to weight loss. Using the Minimum Data Set data, persons with significant weight loss are defined as follows: those experiencing a weight loss of 5 percent or more at the 30 day review interval, 7.5 percent at the 90 day interval, or 10 percent at the 180 day or six-month interval. For the 16 residents that were retained in the study over six months, 56.3% (n = 9) of them maintained or gained weight, one with significant weight gain; 43.8% (n = 7) lost four pounds, two (12.7%) with significant weight loss. Two residents gained weight even though they were on hospice services. Overall, the training program thus appeared to be instrumental in weight maintenance and stability for the sixteen residents on the dementia units participating in the study.

The MARs were reviewed for the 16 residents with respect to total medication use over the six months of the study, relevant medication classifications of interest, and related costs based on the average wholesale price index (Table 2).

	Category of Medication	% Change in Cost	%Change in Usage
1.	Antipsychotics	-25.99	-7.95
2.	Antidepressants	6.07	29.50
3.	Sedatives	-38.96	-9.40
	Combined psychotropics listed in 1, 2 & 3	-17.66	1.73
4.	Non-opioids	31.23	29.96
5.	Opioids	75.72	504.35
	Combined pain medications listed in 4 & 5	64.71	43.53

For the 16 residents whose MARs were examined at the six-month interval, the cost per day at the beginning of the study was \$217.29 and at the end of the study \$169.37 for an overall 22.05% decrease in the drug cost per day and a statistically significant difference in the reduction in cost ($t = 2.14, p = .02, df = 15$).

Facility Staff

Eighty-six staff members from three long-term care facilities consented to participate in the study to complete the Questionnaire of Palliative Care for Advanced Dementia (qPAD). The qPAD measures the attainment of knowledge related to advanced dementia, beliefs regarding end-of-life care, and perceptions of staff related to their involvement in the unit decision-making and resident care-planning process. The qPAD was developed by a team of dementia practitioners to include questions similar to the Modified Knowledge of Alzheimer's Test (mKAT),¹² and also staff perception and belief questions related to end-of-life care and team-building.¹³ Part 1 of the qPAD consists of twelve questions related to staff knowledge about approaches to care, pain management, behavior, and other fundamental advanced dementia practice principles. Part 2 includes twelve questions addressing the following: beliefs about whether or not their education and training can make an impact in end-of-life care discussions; perceptions about how they collaborate with team members and families; and overall feelings of job satisfaction. Only those staff members who completed the Key Concepts and 1:1 Direct Care Experience or peer training received the qPAD at the six-month interval. Of the 86 participating staff members, 50 were eligible to complete the qPAD both at the beginning of the study and six months later.

The primary job categories of those who participated in the study included certified nursing assistants, licensed nurses, activity professionals, and dietary professionals; and most of the staff ($n=45$) were full-time employees. Preliminary results indicated that there was a statistically significant difference in knowledge and beliefs, perceptions, and satisfaction over the 6-month interval. Using a Mixed Model Analysis, staff acquired increased knowledge during the training program ($F = 9.638, p = .002$). The interaction effect was not significant, meaning that the extent to which there was a change or improvement over time did not differ between the three facilities that participated in the study. Thus, the knowledge acquired was a function of time only, and not related to the facility in which they were employed.

Again, using a Mixed Model Analysis, the staff improved in their level of agreement related to their beliefs about end-of-life and palliative care and perceptions of team building ($F = 7.857, p = .006$). A General Linear Model analysis and tests of within-subjects effects validated the

Mixed Model Analysis supporting the premise that knowledge about advanced dementia care improved over six months ($F = 13.511$, $p = .001$) as did knowledge and understanding of end-of-life issues and palliative care as well as positive perceptions of team-building ($F = 9.357$, $p = .004$). Similarly, staff knowledge, beliefs, perceptions, and satisfaction were strengthened over time. No facility effect or interaction effect of time and facility were appreciated. Additionally, analysis of the Beliefs, Perceptions, and Satisfaction subscale (Cronbach alpha = .859) suggests that these questions are useful in ascertaining a staff member's beliefs about end-of-life care, perceptions of teamwork in the facility, and overall satisfaction at work.

Discussion

This demonstration project, grounded in the palliative care for advanced dementia training program, generated several relevant findings. Overall, measures to ascertain changes in major attributes of care related to hospitalization, emergency department use, advance directives, pressure ulcers, weight loss and hospice use revealed no statistically significant difference for the residents that participated in the study. Overall, the lack of findings in this part of the study could be due to the relatively small sample size, low numbers for each variable, and lack of statistical power to compare data at two different time intervals. A six-month period may not have not been long enough to witness statistically significant findings or any substantive trends positively or negatively. In addition, recent statewide efforts through quality improvement and other education programs may have provided an impetus to promote some initial comfort care principles such as the re-examination of acute care interventions for persons who are terminally ill. Recent efforts to increase awareness about advance directives may have also had an impact.

There were other clinical outcomes that were generally positive. Overall, although not statistically significant, weights remained relatively stable, when progressive weight loss is generally expected. The overall cost of medications decreased dramatically over the six-month observation period. Positive trends in appropriate medication use were also seen, as antipsychotic and sedative use decreased while the use of pain and antidepressant medications increased.

For staff members who participated in the program, there was a statistically significant difference over six months that indicated not only that they learned the principles of advanced dementia care, but also that they believe they can have a positive impact in end-of-life care and effect a positive culture change on the unit. The Beliefs, Perceptions, and Satisfaction subscale may, in fact, be more important in promoting change and sustainability of the palliative care for advanced dementia principles than specific knowledge measured in a test. Additional analysis is expected over the coming months to determine the instrument reliability and validity for further testing and instrument revisions in the future.

Although the findings cannot be specifically attributable to the project itself, the data suggest that the changes in practice, care, and knowledge and attitudes of the staff are related to the educational intervention. Anecdotal reports indicate that *comfort care* strategies are beginning to take hold as a standard of practice in caring for persons with advanced dementia.

Summary

The *Palliative Care for Advanced Dementia: A Model Teaching Unit* project has provided extensive training to the facilities that have enrolled in the project. There has been overall enthusiasm for the Program, as evidenced in the number of committed staff from Beatitudes and from the learning facilities that have participated thus far. Evaluations of the program have been extremely positive and onsite qualitative observations in each of the facilities have revealed tremendous strides in changing dementia care practices overall, and particularly for persons with advanced dementia. With continued funding, additional effort will be made to solidify the program by incorporating stronger evaluation measures and additional studies to quantify differences in outcomes or processes of care for residents and for staff in caring for persons with advanced dementia.

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