Palliative Care for Advanced Dementia
Approaches that Work
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ABSTRACT
Advanced dementia is a terminal condition; however, research has revealed that affected individuals are subjected to multiple intrusive and burdensome interventions. Individuals with advanced dementia require palliative care long before their death. This article reviews selected approaches that support personhood, explain behavior management principles, assure meaningful connections for activities of daily living, minimize weight loss, and explain advance directives and medical management best practices in palliative care for advanced dementia.

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Mrs. Green (pseudonym) is in the advanced stage of dementia. She has Alzheimer’s disease with vascular involvement. She is incontinent, confined to a geriatric chair, and unable to ambulate. She has a history of osteoarthritis throughout her spine and all of her joints. She is being treated with risperidone (Risperdal®) for behaviors and trazodone (Desyrel®) for sleep. She is up in the geriatric chair by 6:00 a.m. and remains there through lunchtime, often asleep or crying out—can she be helped?
Alzheimer’s disease, the most common form of dementia, is now the sixth leading cause of death in the United States and the fifth leading cause for those age 65 and older. The disease is expected to affect one in eight Americans, and no treatment or cure is on the horizon. While death from other major diseases, such as heart disease, stroke, and breast and prostate cancer is declining (2000-2006), death from Alzheimer’s disease is spiraling upward at a rate of 47.1% during this same period (Alzheimer’s Association, 2009). Alzheimer’s disease and related dementias are fatal, with death occurring 4 to 6 years after diagnosis (Xie, Brayne, & Matthews, 2008). It is suspected that death due to Alzheimer’s disease is drastically underreported, as the cause of death may be attributed to an event that led to the death, rather than the dementia that caused it. Researchers estimate that the actual number of Alzheimer’s-related deaths is twice the number reported on death certificates (Alzheimer’s Association, 2009).

**THE PERSON WITH ADVANCED DEMENTIA**

Advanced dementia is often referred to as late-stage dementia and includes the severe and terminal stages of the disease. Typically, individuals with advanced dementia have a score of 10 or less on the Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975), 7 on the Global Deterioration Scale (Reisberg, Ferris, de Leon, & Crook, 1982), and 7 on the Functional Assessment Stage Test (items a through e) for those with Alzheimer’s disease (Reisberg, 1988).

Individuals with advanced dementia experience significant physical losses, such as the inability to communicate and perform activities of daily living. Their memory is severely impaired for both recent and past events. As independence becomes compromised, the person becomes less capable of caring for himself or herself and relies on caregivers for ambulation, dressing, grooming, feeding, and bowel and bladder care (Long, 2006). The person becomes resistive, dysphagic, incontinent, and experiences significant motor impairment while gradually losing touch with the world around him or her, becoming oriented to only himself or herself. The person becomes increasingly reliant on caregivers to meet his or her entire essential physiological, psychological, spiritual, and social comfort needs.

Individuals are more likely to be placed in a long-term care facility as their disease progresses to the moderate and advanced stages, and more than two thirds of those with dementia die in a nursing home, compared with 20% to 28% of those with cancer or other related conditions (Alzheimer’s Association, 2009). As such, caregivers in nursing homes and assisted living facilities must attend to the complexities and challenges related to these individuals and their end-of-life care needs (Alzheimer’s Association, 2007).

**THE MODEL TEACHING UNIT PROGRAM**

In 1998, the Beatitudes Campus Healthcare Center developed a special care unit known as the Vermilion Cliffs. This unit or “neighborhood” is home to 30 people experiencing moderate to advanced dementia. Basic guidelines for relocating to the Vermilion Cliffs include a diagnosis of dementia, an MMSE of 18 or less, and impairment in activities of daily living. The Vermilion Cliffs was founded on the principle that achieving comfort is non-negotiable for the older adults who reside there. The individuals sleep and wake as they desire, eat foods that are acceptable to them without focusing on traditional nutritional requirements, have their physical pain managed, and are offered multiple opportunities to make daily positive connections with their world through their five senses. There are no restraints and there is no sundowning. The neighborhood operates much like a small town with a 24-hour restaurant and has enjoyed a waiting list for many years.

With a grant in 2005, the Beatitudes Campus and Hospice of the Valley instituted a training program for qualified and interested nursing facilities to learn best practices in dementia care. Outcomes from the training program have revealed a reduction in the use of psychotropic medications and physical restraints, decreased weight loss, less hospitalization and emergency department use, improved facility milieu, and increased comfort for those with dementia.
and improved staff knowledge, beliefs, and attitudes about end-of-life care (Long & Alonzo, 2008). The approaches to care, described below, are used in the classroom and clinical setting as staff from nursing homes and assisted living facilities learn best practices in advanced dementia care.

**BEST PRACTICES IN ADVANCED DEMENTIA CARE**

“Help me! Help me!” It’s 11:00 a.m., and Mrs. Green calls out her usual cries. The nursing staff remark, “That’s how she always is. We really can’t do anything about it; she has Alzheimer’s disease, you know!” What if Mrs. Green’s experience didn’t have to be this way? Is there a better way? The approach is palliative care, and all individuals with dementia in the final years of their lives have a need to be comfortable. What are the best practices that promote comfort? Can her geriatric nurse practitioner help in any way?

**Support Personhood**

Personhood refers to the state of being human (Kitwood, 1997). Dementia can rob an individual of personhood if caregivers do not actively pursue and assure a holistic approach toward the individual. Caregivers need to support biological, individual, and sociological personhood; personhood can be maintained in a palliative care program that aims to satisfy the primary self, social self, and inner self with meaningful connections (Buron, 2008; Kovach, 1997). As the disease progresses in the person with advanced dementia, preservation of self and personal identity must be acknowledged and sustained; thus, person-directed care dominates practice.

Therefore, it is important to truly know the person. This requires a detailed physical, psychological, social, and spiritual history, gathered in a biosketch or “life story,” that is actively incorporated into the individual’s care plan and made available for the entire interdisciplinary team. The one-page form “About Me” (©2006, Hospice of the Valley) is posted at the bedside of the person who is terminally ill (Dougherty, Gallagher, Cabral, Long, & McLean, 2007). This consolidated form allows the hospice and nursing facility care team to personalize this individual's care and honor who they are and what brings them joy (Hospice of the Valley, 2006, p. 1). The “What Caregivers Should Know” form (©2007, Beatitudes Campus) (Table) is used by staff at the Beatitudes Campus when a person is newly admitted to the neighborhood. As part of a care plan meeting, family members or the responsible party—and the person with dementia if he or she is able—participate in this “getting to know you” session. This information will direct the overall care needs of the person, even more so when he or she becomes unable to verbally communicate his or her needs, desires, and wishes. The Table provides an abbreviated list of items retrieved during the session.

A person-directed approach necessitates a warm and home-like milieu (i.e., the person’s living space and general nursing unit). The milieu should support positive tactile, acoustic, olfactory, visual, and thermal stimulation (Calkins, 2005). Adequate lighting, temperature and noise control, appropriate music, effective color differentiation, and personal items at the bedside will

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**TABLE**

**EXAMPLES OF ITEMS ON THE “WHAT CAREGIVERS SHOULD KNOW” FORM**

| 1.     | Name the person prefers to be called                  |
| 2.     | Where the person was born                             |
| 3.     | Names of the person’s parents and siblings and important things to know about them |
| 4.     | Favorite past job                                     |
| 5.     | Name of spouse                                       |
| 6.     | Military background and branch, if applicable        |
| 7.     | Names of the person’s children and important things to know about them |
| 8.     | Individuals the person was, or is now, close to      |
| 9.     | Religious preference                                  |
| 10.    | Favorite spiritual song, hymn, or reading             |
| 11.    | Favorite music                                        |
| 12.    | Favorite holiday                                      |
| 13.    | Vision and hearing quality or deficits               |
| 14.    | Favorite and least favorite foods and drinks         |
| 15.    | Comfort foods when sick                              |
| 16.    | Bathing schedule and preference (e.g., shower, bath, at the sink) |
| 17.    | Morning, afternoon, and evening routines             |
| 18.    | Clothing preferences                                 |
| 19.    | Things most proud of                                 |

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promote a milieu that is pleasing and comfortable. These kinds of surroundings are associated with positive behaviors and less agitation for the person and greater satisfaction among caregivers (Edvardsson, Winblad, & Sandman, 2008).

**My Behavior Is My Communication**

Individuals in the advanced stage of dementia lose the ability to verbally communicate. Their behaviors become the conduit for their needs, pleasures, and frustrations. Behavioral disturbances may result in the use of psychotropic agents and often physical restraints. For individuals with advanced dementia, behaviors are assessed and managed as a symptom of discomfort. Thus, it is important to address the most primary of needs: hunger, thirst, wet briefs, feelings of being too cold or too warm, a need to move, and many more. It is better to anticipate needs than wait for a behavior to occur. Staff should use the basic comfort principles such as a gentle or soft approach, engagement, and distraction when appropriate to the situation and move from a reactive mode to an anticipatory mode. Finally, comfortable people do not hit, scream, pound on tables, or call out. If this behavior is present, the caregiver must identify the root cause of the behavior and intervene to remove the antecedent cause.

Often, pain is the cause of the behavior. It is imperative to ascertain whether the person has a history of pain. In the advanced stage of the disease, individuals with dementia are unable to use typical pain intensity scales to describe or rate their pain. Thus, it is important to use a reliable and valid pain rating scale to assess pain. Pain must be treated aggressively. A trial dosage of acetaminophen (Tylenol®) is recommended to treat the pain, progressing to opioid drugs if needed (Chibnall, Tait, Harman, & Luebbert, 2005). In many circumstances, the behaviors will diminish if pain is attended to.

**Assure Comfort in Activities of Daily Living**

A person with advanced dementia cannot verbally share that he or she is hungry or thirsty, hot or cold, bored or lonely, incontinent or not. Thus, it is incumbent on caregivers to routinely offer food and drink, anticipate bowel and bladder needs by regularly escorting individuals to the bathroom—on the person’s schedule, and assuring other comfort needs are met, such as adequate and appropriate sensory stimulation. Staff should consider the person’s past routine and best time of day for activities. Over time, showers may yield to the towel bath or Bathing Without a Battle method, if it provides more comfort for the person (Rader et al., 2006). Caregivers should always provide a dignified approach to the caregiving experience, using a calm pace, gentle, and respectful approach.

It is important to ensure all activities are meaningful with the opportunity to make connections with individuals with advanced dementia. This can be achieved through music, aromatherapy, and food, as a few examples. Spirituality can be promoted through meaningful religious traditions, prayers, and song. The outdoors can be used to create connections with the wind, bird songs, and sunshine. Transportable multisensory bags or kits can be created to be used with selected individuals or in small groups (Gallagher, 2006).

Finally, weight loss is not necessarily inevitable if attention is paid to the meal environment and routines (Mamhidir, Karlsson, Norberg, & Kihlgren, 2007). Weight loss can be mitigated by providing “comfort food,” which is any food the person can accept, eat, and tolerate, and...
“dementia-friendly foods,” such as pudding and ice cream, which are soft and sweet. The dining environment should be homelike with casual conversation and a reduction in noise related to dishes and silverware. Loud and inappropriate music should be discouraged, and staff should be encouraged to eat with the residents. A liberalized diet should be the norm for all meals and snacks (American Dietetic Association, 2005), with food and drink offered frequently throughout the day.

Advance Directives and Medical Management
When in place, advance directives honor the choices of individuals when they can no longer convey their health care decisions. If the person with dementia did not make his or her wishes known when he or she had the mental capacity to do so, family members will support what the person would have wanted. Yet typically, many individuals with dementia or their family members are unaware of the terminality of this disease, the primary causes (Morrison & Siu, 2000), and the uncomfortable interventions (described below) (Mitchell, Keily, & Hamel, 2004), or these health care decisions occur too late in the disease, creating greater dissatisfaction among family members (Engel, Keily, & Mitchell, 2006; Mast, Salama, Silverman, & Arnold, 2004).

Aggressive medical management may have limited benefits and cause greater discomfort for individuals with advanced dementia and may accelerate health decline and even death (Volicer, 2005). Nonpalliative, and often aggressive, care is common for those in the late stages of dementia and includes tube feedings, chemical and physical restraints, and the wide use of invasive laboratory tests and intravenous therapy (Birch & Draper, 2008). Individuals may be repeatedly hospitalized for infections or eating problems. Often, individuals with advanced dementia die within 6 months of admission to a nursing home, yet few are referred to hospice (Volicer, 2005) when that Mrs. Green’s behavior is communicating distress. You notice she has not moved from the same position all morning and wonder whether she can no longer reposition herself. Being restrained in a geriatric chair further complicates her ability to move. Her history of osteoarthritis suggests she may be experiencing pain. A team meeting is held, and staff members review their observations. The staff agrees that a trial dosage of acetaminophen will help, along with regular trips to the bathroom, repositioning in a more comfortable chair, and returning her to bed when she looks tired or has pain. The staff discovers that when Mrs. Green is allowed to sleep until 8:00 a.m., she appears much more comfortable and her calling-out behavior ceases. On the basis of Mrs. Green’s response, you and the team decide to review the effectiveness of these interventions over the next 3 days, looking for signs of comfort or discomfort, and consider whether tapering her dosage of risperidone is a possibility.

CONCLUSION
The greatest challenge in dementia care today is assuring that comfort and palliative care needs are addressed for individuals with this terminal condition. That comfort-focused care is a guiding principle for change.

You are the new geriatric nurse practitioner assigned to the nursing home, and Mrs. Green is your patient. Having attended dementia training programs, you are aware

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REFERENCES