

**Quality End of Life Care for Individuals with Dementia
in Assisted Living and Nursing Homes and Public
Policy Barriers to Delivering this Care**

Jane Tilly, DrPH, Alzheimer's Association

and

Abel Fok, BSc, LLB Candidate Queen's University Faculty of Law

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Summary

In 2005, the Alzheimer's Association began developing a series of dementia care practice recommendations for assisted living and nursing homes. To date, we have developed recommendations on the basics of good dementia care, food and fluid consumption, pain management, social engagement, wandering, falls, and physical restraints. Each set of recommendations is evidence based and this paper addresses a forthcoming set of recommendations on end of life care.

This paper extends the knowledge gained from an Association-supported literature review on end of life care for people with dementia in residential care settings¹, by 1) determining what practitioners, providers, professionals and researchers believe constitutes quality end of life care for residents with dementia, and 2) describing perceived public policy barriers to delivery of this care.

Methods

To complete this research we interviewed 49 experts, including professionals, providers and researchers from assisted living residences, nursing homes, hospices, the Veterans Affairs medical system, and academia. We asked the experts a series of open-ended questions related to the following three topics:

1. What are the key elements of quality end of life care for people with dementia in nursing homes and assisted living residences?
2. What are the key elements of quality care for both groups' family caregivers?
3. What are the public policy barriers to delivery of quality end of life care for people with dementia in nursing homes and assisted living residences in the US?

Results

The interview results were striking in that there was little disagreement about the key characteristics of quality end of life care for dementia residents. Overwhelmingly, the most important issues for the majority of experts are communication and decision-making about care. These issues underlie all other key characteristics of quality end of life care. One expert stated that "communication and advance planning are critical to a dignified, comfortable death."

¹ Volicer, Ladislav, *End-of-life Care for People with Dementia in Residential Care Settings* The Alzheimer's Association, 2005, available at <http://www.alz.org/national/documents/endoflifelitreview.pdf>

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Communication and Decision-Making

In the opinion of experts, physicians and other practitioners, such as nurses and social workers must be prepared to discuss the resident's care goals, the progressive and inevitable decline toward death that must be expected with a diagnosis of dementia, and the advantages and disadvantages of different medical interventions. Communication about these issues should start as soon as possible, ideally at diagnosis of dementia because individuals with dementia eventually lose the ability to make independent decisions about their care.

Most experts agreed that it is important to “plant the seed” for discussions about care goals for residents and which medical interventions residents and families will accept as early as possible so that residents who are able to understand care options can express their preferences. The care decisions that need to be discussed include a range of medical interventions that studies have shown to produce either little or no benefit or even could have detrimental effects on people with advanced dementia. These interventions include resuscitation, hospitalization, tube feeding, use of antibiotics, use of intensive care units, and invasive medical tests.

Symptom Management

Many experts cited residents' aphasia as posing a particular challenge for practitioners in the assessment and treatment of the resident's physical symptoms. According to the experts, there are three key elements to managing these symptoms – identification and assessment of physical symptoms: continual monitoring of the resident's condition, and practitioner skill.

For physical symptom management, a majority of interviewed experts believe that both non-pharmacological and pharmacological avenues should be pursued as needed. Non-pharmacological interventions may be the most appropriate first step for control of some symptoms. If these approaches fail to manage the resident's symptoms, a conservative trial of medication should be pursued. Medication may be the only treatment option for certain symptoms.

Taking care of the physical needs of a dying resident can be quite labor intensive and requires staff to be creative in their approaches to meeting residents' needs. Some experts mentioned that good end of life care can only be delivered with sufficient staff resources and by staff who are experienced and educated in the care of dying residents.

Dementia residents' behaviors should be viewed as a means of communication rather than behavior to be discounted or dismissed. The most commonly cited behavioral symptoms for residents with dementia at the end of life are: agitation, psychosis, delirium, restlessness, and depression.

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Experts agree that it is always preferable to first use non-pharmacological approaches to deal with behavioral symptoms. Appropriate medication can be used to treat symptoms if practitioners determine that the source of a resident's behavioral response is physical distress. However, if the source of distress is psychosis and non-pharmacological interventions fail, then experts believe anti-psychotic medications should be employed as a last resort. Many of these experts also cautioned that the person with dementia should be demonstrably much better by taking such medication in order to justify its use due to the associated side effects.

Psycho-Social and Spiritual Support

Experts largely agree that psycho-social and spiritual support can be beneficial to both the resident, regardless of cognitive status, and to the family. A key component of psycho-social support for the resident is the interaction between the facility staff and the resident. Staff interaction with residents should not be limited to care. Staff members should converse and interact with the resident. This would be facilitated by staff learning more about the resident, including, who they were and what they enjoyed in the past. Dementia residents also are able to derive a sense of comfort and familiarity from music or religious rituals that they enjoyed prior to the onset of disease. For residents who participated actively in their religion prior to admission, experts indicate that the facility should find out which religious practices or rituals are significant to the residents and help them practice to their capabilities.

The experts agreed that providers should play a role in supporting the family caregivers throughout their prolonged grieving process over the loss of the person with dementia. Families face a unique two-part grieving process since dementia first robs a resident of his or her cognitive abilities before taking the resident's life. Providers can help family through ongoing education and communication about the disease and how the loved one is faring. Individual gestures of kindness can also help caregivers.

In addition, family members often look for a way to contribute to the resident's comfort and need suggestions about how to interact with a dying resident with dementia. Among the suggestions that experts made were for staff to suggest that family bring music the resident likes and teach family how to perform comfort care for the resident.

When a resident is actively dying, perhaps during the last 24 to 48 hours of a resident's life, families need someone who can explain what is happening to the resident so as to minimize the family's distress. The support provider must be readily available to the resident and family, the family must have a means of contacting the provider when needed, and the provider must be responsive to the family's needs.

Bereavement

All experts agree that a facility needs to recognize the death of a resident and to provide some form of bereavement support for the family after the resident's death. The most commonly reported method of remembering a resident's death is through onsite

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memorial services conducted by the facility staff. Model facilities often call family after a resident's death to inquire about "how they are doing" and to assess whether any family members are at risk of "complicated grief" -- having severe depression or other emotional complications after the loved one's death. While not all experts addressed the issue, some experts believe that many nursing homes and assisted living residences do not have the requisite time and resources to provide adequate bereavement services for families.

Provider Training and Skills

There is a general consensus that providers who care for residents with dementia need to be specifically 'dementia-trained' because of the unique challenge this group of residents presents. Training content should include knowledge of disease trajectory, symptoms, approaches to care, goals of care (cure or comfort), palliative care measures, end of life issues, signs of impending death for persons with dementia, and how to interact with residents and families.

Critical knowledge also includes assessment, symptom management, and communication. Good assessment skills are critical, particularly in working with those who cannot communicate verbally. Individuals with dementia at the end of life are often at high risk for pain, depression, and other conditions that complicate assessment. Managing these symptoms requires specific knowledge of non-pharmacological and pharmacological treatments of conditions at the end of life.

Public Policy Barriers

Experts agreed about the major public policy barriers to delivery of quality palliative care in nursing homes and there was some discussion of the barriers to delivery of such care in assisted living residences. Experts identified four major public policy barriers in the following order: use of the Medicare Part A skilled nursing facility benefit, Medicare hospice eligibility criteria, certain aspects of the quality assurance system, and inadequate provider reimbursement.

Under Medicare's Part A skilled nursing facility benefit, beneficiaries cannot have hospice care while they are in this type of facility. This prevents them and their families from having access to certain types of care at the end of life.

The requirement that a beneficiary receiving hospice have a prognosis of dying within 6 months also limits access to palliative care in the view of approximately two-thirds of the experts. Another problem with the hospice benefit is that residents with dementia can go on and off of hospice because their conditions improve or their health stabilizes while receiving hospice. This revolving door makes delivering coordinated palliative care very problematic.

About half of the experts mentioned some aspect of the quality assurance system being a barrier to provision of quality care. These aspects included: an adversarial tone to

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nursing home surveys, and certain nursing home quality indicators than can penalize nursing homes when they serve dying residents with dementia.

Experts familiar with assisted living residences raised several public policy issues. One is that some states limit the number of residents who can be on hospice or do not permit hospice in assisted living residences at all. Other states require residents to leave assisted living if they have serious pressure ulcers, which they can acquire after hospital stays. Individuals living in some residences are also required to leave if they cannot manage their own medications.

Many experts raised inadequate funding as an impediment to provision of good end of life care. This underlies the perception among many research experts that nursing homes cannot hire sufficient staff to provide quality end of life care. In addition, experts stated that Medicare and Medicaid payments do not cover the time needed to accurately determine what problem a resident with dementia is experiencing, and practitioner time needed to educate or counsel families about their loved ones with dementia or to make bereavement calls.

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Quality End of Life Care for Individuals with Dementia in Assisted Living and Nursing Homes and Public Policy Barriers to Delivering this Care

Introduction

For more than 25 years, the Alzheimer's Association has been committed to advancing research on Alzheimer's disease and enhancing the care, education, and support for individuals affected by the disease. In 2005, we launched the *Alzheimer's Association Campaign for Quality Residential Care* to improve the quality of care for residents with dementia in assisted living residences and nursing homes. The knowledge base for the Campaign is the Association's *Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes*. Phase 1 of these recommendations addresses the basics of good dementia care, food and fluid consumption, pain management, and social engagement, while Phase 2 addresses wandering, falls and physical restraints. During Phase 3, the Association is focusing on end of life care because:

- 67% of dementia-related deaths occur in nursing homes.²
- 71% of residents with advanced dementia died within 6 months of admission, yet 6% were referred to hospice.³
- Non-palliative care is quite common in residents with dementia. This includes tube feeding, laboratory tests, restraints, and intravenous therapy.⁴

This paper builds on a review of the literature -- *End-of-life Care for People with Dementia in Residential Care Settings*, by Ladislav Volicer, MD, which describes current research evidence relevant to end of life care for residents with dementia. To extend the knowledge gained through this literature review, Association staff carried out qualitative research designed to:

- Determine what practitioners, providers, professionals and researchers believe constitutes quality end of life care for residents with dementia
- Describe perceived public policy barriers to delivery of this care.

So that readers better understand our use of three key terms in this, we provide the following definitions. In this paper:

1. *End of life care* means health and/or long term care, which may include palliative and hospice care, provided during some time period preceding death. There is no

²Mitchell SL, Teno JM, Miller SC, Mor V. A national study of the location of death for older persons with dementia. *Journal of the American Geriatric Society* 2005; 53(2):299-305.

³Mitchell SL, Morris JN, Park PS, Fries BE. Terminal care for persons with advanced dementia in the nursing home and home care settings. *Journal of Palliative Medicine* 2004; 7(6):808-816.

⁴ Volicer L. *End-of-life Care for People with Dementia in Residential Care Settings* The Alzheimer's Association, 2005.

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agreed upon time frame, since predicting time to death for most fatal conditions, including dementia, is inexact.

2. *Palliative care* is designed to alleviate physical, emotional, or psychosocial suffering and enhance the quality of life, rather than to cure a disease or medical condition. Palliative care focuses on the comfort of the suffering individual and his or her family. People who receive palliative care may or may not be dying.
3. *Hospice care* in the US is palliative care that agencies provide to individuals who are terminally ill, generally with an expected survival of six months or less. Hospice is a benefit of Medicare, most state Medicaid programs, and many private health insurance plans.

Methodology

The first step we took was to identify experts who could discuss quality end of life care for residents with dementia and the public policy barriers to delivering this care. We accomplished this by identifying people who had published relevant articles in peer-reviewed journals. We also contacted key national organizations representing nursing homes, assisted living residences, hospices, and professional organizations and asked them to nominate experts for us to interview. A third method of identifying experts was to ask those we interviewed for nominations. Any individual who was identified by two or more experts was asked to participate in this qualitative research project.

We conducted interviews, primarily by telephone, with 49 experts representing providers and researchers from assisted living residences, nursing homes, hospices, the Veterans Affairs medical system, and academia. Experts interviewed include medical directors, physicians, nurses, social workers, counselors, health consultants, researchers, and members of religious orders. Interviews lasted approximately 1 hour. Experts were informed that they would not be quoted by name and all agreed to have their names and affiliations listed in Appendix 1.

We asked the experts a series of open-ended questions related to the following three topics:

1. What are the key elements of quality end of life care for people with dementia in nursing homes and assisted living residences?
2. What are the key elements of quality care for both groups' caregivers?
3. What are the public policy barriers to delivery of quality end of life care for people with dementia in nursing homes and assisted living residences in the US?

Two researchers independently kept notes during each interview and the notes were summarized on the same day interviews were conducted. We analyzed the summary reports by examining trends, themes, and note-worthy examples of points that experts made.

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Results

The interview results were striking in that there was little disagreement about the key characteristics of quality end of life care for dementia residents of assisted living residences and nursing homes. There were, however, differences of opinion on a few clinical issues.

Based on expert interviews, the key characteristics of quality care can be broken down into several different areas. Overwhelmingly, the most important areas to the majority of experts are communication and decision-making about care. These areas underlie all other key characteristics of quality end of life care. One expert stated that “communication and advance planning are critical to a dignified, comfortable death.”

1. Communication

Communication about critical topics occurs among residents, family, providers, frontline staff, and practitioners. In the opinion of experts, physicians and other practitioners, such as nurses and social workers must be prepared to discuss the resident’s care goals, the progressive and inevitable decline toward death that must be expected with a diagnosis of dementia, and the advantages and disadvantages of different medical interventions.

Communication about these issues should start as soon as possible, ideally at diagnosis of dementia. Communication needs to continue throughout the course of the disease. Families in particular need ongoing education because they can make better decisions about care when they understand that dementia is a terminal illness and how the disease is affecting their loved ones. Families must also be educated to understand the effects of different medical and care intervention options in a balanced way.

Experts did caution that communication must be tailored to individual families’ understanding of the disease and expectations for the resident. For example, some families think people with dementia can improve. It is critical that they understand the progress of the disease before professionals begin discussions about the advantages and disadvantages of interventions.

Communication with residents is important to determine their views on care as early in the course of the disease as possible. Even when residents have become non-verbal, they communicate through behaviors and emotional reactions to care. Staff needs to “listen hard” to this type of communication and use methods that a person with dementia can understand such as comforting touch, direct eye contact, smiles, and a pleasant tone of voice. In addition, staff should take care to ensure that their body language, mood, and facial expressions are pleasant.

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2. Decision-Making

Most experts agreed that it is important to “plant the seed” for discussions about care goals for residents and which medical interventions residents and families will accept as early as possible so that residents who are able to understand care options can express their preferences. One expert suggests an approach that would alert the family at the initial care planning meeting that the end of life discussion will be coming and follow-up with the family to begin the discussion two weeks after the resident’s admission to the home. This expert recommends ascertaining and confirming previous advance care planning efforts during the initial care planning meeting.

Some experts indicated that decision-making and planning discussions may not work close to admission since it is a stressful time for the families and residents need time to adjust to a move to a new living environment. These experts generally recommend waiting 4 to 6 weeks after admission and staff has begun to develop a relationship with the resident and family to have discussions about interventions.

The care decisions that need to be discussed include a range of medical interventions that studies have shown to produce either little or no benefit or even could have detrimental effects on people with advanced dementia.⁵ These interventions include resuscitation, hospitalization, tube feeding, use of antibiotics, use of intensive care units, and invasive medical tests. Almost all experts discussed resuscitation and hospitalization decisions first, followed by tube feeding and use of antibiotics.

It is interesting to note the differences in acceptance of care practices. For example, informants from one assisted living residence discharge residents if their families choose to use a feeding tube. Experts stated that in a couple of states, the standard of care for nursing homes is to provide feeding tubes for residents who begin to lose weight, unless residents have explicitly stated in an advance directive that they do not want this intervention.

Experts indicated that making care decisions in advance can be very difficult since residents’ situations vary widely. Therefore, it is critical for the resident to have a proxy decision-maker who can make the decisions as he or she believes the resident would have made them. If the proxy decision-maker does not know what the resident would have wanted, then decisions need to be made in what the proxy decision-maker believes is the resident’s best interest. For the decision-maker to carry out resident wishes, the resident needs to impart his or her philosophy regarding end of life care through discussions with the decision-maker. The decision-maker also needs to understand the advantages and disadvantages of various interventions for someone with dementia at end of life. Further, these proxy decision-makers must consider the goals of care which involve balancing prolonging life versus maximizing comfort. The tradeoff between these two goals depends upon the state of dementia and the intervention being

⁵ Ibid.

³ Volicer, op cit

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contemplated. These goals must be reconsidered after every medical crisis in terms of “what the loved one would want” or what would be in his or her best interest.

To promote discussions of end of life care options and decisions, several experts offered specific recommendations. A few mentioned using advance directive tools such as the “Five Wishes” document, which asks people a series of questions designed to prompt discussion of their wishes about what type of care they will receive at the end of their lives. The Veterans Affairs (VA) care system has a goal of getting every veteran aged 75 or older to specify their care wishes in advance directives. The state of Oregon has advance directive forms that follow patients from home to hospital to nursing home and other states are considering the adoption of Oregon’s approach. Maine has developed a brochure to help families learn about and plan for end of life care in dementia. Some facilities require a “palliative care order” form at admission that forces discussion of specific advance directive issues.

Decisions should not be made without an objective assessment of the resident’s functional status. This should occur before the initial meeting to discuss care goals and then several times a year after admission. The frequency of assessment depends upon the rapidity of the resident’s decline and whether or not the resident experiences a medical emergency.

Experts also noted some common problems associated with a change from curative to palliative care at the end of life. One particular problem is when family members disagree on care goals and yet there is no clearly authorized proxy decision-maker. The most difficult situations appear to be when a distant family member decides to get involved in a resident’s care only during a crisis. Due to fear of liability under situations like this, the system often “defaults” to “doing everything,” including aggressive medical interventions.

One expert cited the VA’s hierarchy of next of kin as being a good approach to determining who the decision-maker should be in the absence of an authorized representative. This hierarchy states that the following family members can act as proxy decision-makers in order of priority: spouse, child, parent, sibling, grandparent, and grandchild. VA policy also indicates that if no relatives are available then a “close friend” can be a proxy decision-maker. A close friend is defined as an adult who “has shown care and concern for the resident’s welfare and is familiar with the resident’s activities, health, religious beliefs, and values.” It is important to note that states vary in their approach to establishing a hierarchy for decision making responsibility in the absence of a designated decision maker.

3. Physical Symptoms and Pain Management

The experts recognize that physical problems and pain management are particularly important for persons with dementia. Many cited the residents’ aphasia as a barrier to practitioners who are assessing and treating pain. These difficulties often result in the under-treatment of dementia residents for osteoarthritic pain, pressure sores, and

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many other sources of physical distress. The experts agree that the goal at the end of life should be to minimize pain and suffering, and to maximize comfort, rather than prolonging life at all costs.

The most commonly cited physical problems that dementia residents suffer include dyspnea (difficulty breathing), aspirations, pneumonia, pressure sores, immobility, incontinence, dysphagia (difficulty swallowing), and weight loss. Immobility is also a source of much pain and discomfort for residents. It plays a crucial role in the frequent development of skin breakdowns as a result of prolonged pressure from sitting or lying down for a long time. Dysphagia may be a particularly troubling symptom because it may lead to dehydration, weight loss and recurrent pneumonia, resulting in a progressive decline and death.

Other physical symptoms that were mentioned by the experts include the ‘death rattle’, constipation, dehydration, urinary tract infections, chest pain, and nausea. Several experts emphasized that constipation is a significant issue for residents at the end of life since they are more prone to bowel impaction due to immobility. The death rattle occurs as a result of the accumulation of respiratory secretions in a dying person’s throat. It is a symptom that usually marks the active dying process. Although the gurgling and rattling noises of the death rattle are very distressing for the family, there is currently no evidence to suggest that residents find this condition disturbing.

The interviewed experts agree that due to dementia residents’ cognitive impairment and non-verbal status, the onus is on the practitioners to accurately assess and manage the resident’s physical symptoms. In analyzing the interview results, it is clear that there are three key elements to managing symptoms – identification and assessment of physical symptoms: continual monitoring of the resident’s condition, and practitioner skill.

Practitioners need to monitor residents for any signs of pain or discomfort since persons with dementia are not able to bring such distress to the attention of practitioners. To keep residents clean, dry, moisturized, repositioned, and pain free, some experts advocate the use of mandatory checklists for common symptoms. Others stress the need for pre-emptive treatment with the goal of uncovering and treating problems early to prevent a condition from occurring in the first place, or to prevent downstream ‘secondary’ problems. Pressure ulcers are an example of a problem that can be mitigated with careful monitoring of the resident’s skin condition and ensuring that they are repositioned periodically. Treatment of incontinence can prevent secondary urinary infections and skin breakdown through early intervention. One expert advocated an increased use of silicone catheters for incontinent residents since such material lessens the probability of infections.

A few experts mentioned that it is important to ask the family for their opinions about the resident’s symptoms. One expert said that the VA encourages family members to provide their evaluation of a resident’s level of comfort. Family members are also asked to join with staff in formulating treatment plans.

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Many experts advocate the use of assessment tools to aid in the assessment of residents' pain and behaviors. Some facilities employ tools and scales that have been tested and proven effective in-house. For example, they may use pain scales that are specifically designed for persons with dementia. Some experts were not certain how well assessment tools work for persons with dementia.

Practitioners must have the skills and training to identify and manage residents' physical symptoms. For example, practitioners need to be trained to look for signs of pain such as facial grimacing, moaning, withdrawal to a fetal position, and resistance in response to being repositioned.

A majority of interviewed experts believe that both non-pharmacological and pharmacological avenues should be used to address physical symptoms. A minority of experts think that non-pharmacological approaches should be tried prior to the consideration of administering medicines that can have potential side effects. Non-pharmacological interventions can be as simple as providing relaxing music, pleasant smells, or sounds of nature to calm and soothe the resident. These interventions can also be targeted to the resident's symptom. For example, oxygen can be provided to help a resident who is experiencing dyspnea. Ice chips, frequent oral swabbing and cleansing, or artificial saliva spray can be used to address a resident's dry mouth. Hand-feeding and increasing the viscosity of liquids can be used to address dysphagia.

If the non-pharmacological interventions fail to manage the resident's symptoms, a conservative trial of medication should be pursued. Practitioners can administer doses of analgesics (e.g., Tylenol) at a low dosage, when indicated. The dosage should be increased incrementally until the lowest maintenance dose is achieved. Some experts encourage the use of opioids (e.g., morphine) to treat more severe pain symptoms. Others cautioned that opioids can make a resident's mental status worse, as well as exacerbate constipation, so these side effects must be managed when opioids are used. Interestingly, one expert suggested that nurses and doctors are not administering enough pain medication due to the nature of their training, unjustified fears of resident addiction to pain medications, and for fear of legal liability.

Medication may be the only treatment option for certain symptoms. This is true in the case of bacterial infections. Use of oral antibiotics may be an appropriate course of action for residents who can still swallow. Many experts cautioned that antibiotics are considerably less effective at treating infections at the end of life because residents with dementia are frail and have limited mobility, poor nutrition, and co-morbid illnesses. Some experts suggest use of anti-cholinergic drugs to reduce the secretions causing the death rattle.

Taking care of the physical needs of a dying resident can be quite labor intensive and requires staff to be creative in their approaches to meeting residents' needs. Some experts mentioned that this can only be done with sufficient staff resources and staff who are experienced and educated in the care of dying.

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4. Behavioral Symptoms and Management

As discussed in the physical symptoms section, dementia residents' behaviors should be viewed as a means of communication rather than behavior to be discounted or dismissed. Most of the experts agreed that behavioral problems are difficult to assess and resolve. Only one expert indicated that behavioral symptoms are not an issue at the end of life.

The most commonly cited behavioral symptoms for residents with dementia at the end of life are: agitation, psychosis, delirium, restlessness, and depression. Anxiety and confusion were also mentioned. Since the interview discussions were about dementia care at the end of life, a stage in which most dementia residents can no longer ambulate, it is not surprising that only a handful of experts mentioned wandering as a behavioral problem. Several experts singled out agitation as a serious behavioral issue for dementia residents. Others indicated that delirium is experienced by the majority of persons with dementia at the end stages and that it may not be reversible.

From our analysis of interview results, it appears that part of the difficulty in assessing behavioral symptoms derives from inconsistent definitions and usages of various medical terms in describing behavioral symptoms. Some experts seem to use the terms 'psychosis' and 'delirium' interchangeably. Others have taken the terms 'restlessness' and 'agitation' and incorporated them into each other's definitions. Further, it is unclear whether an expert's mentioning of behavioral symptoms such as anxiety and confusion in fact point toward behaviors such as restlessness or delirium.

As with the assessment of physical symptoms, experts agree that practitioners must investigate and make sense of a resident's behavior. One expert suggested the use of checklists by frontline care providers to assess and document behavioral symptoms on a daily basis. Where appropriate, practitioners should identify whether a particular resident behavior is due to a previously known cause or a new medical problem.

Experts agree that it is always preferable to first use non-pharmacological approaches to deal with behavioral symptoms. This approach can be as simple as providing a resident with a snack or a drink or providing company for a resident who feels lonely and isolated, providing a resident with some needed "downtime" if he or she requires it after certain activities, or merely managing the facility's noise level to minimize resident agitation. Sensory calming activities such as comforting music were also mentioned as a way to soothe agitation.

Appropriate medication can be used to treat symptoms if practitioners determine that the source of a resident's behavioral response is physical distress (eg: pain medication for pressure sores, antibiotics for pneumonia). However, if the source of distress is psychosis and non-pharmacological interventions fail, then experts believe anti-psychotic medications should be employed as a last resort. Several experts have cited psychotropic medicines as relief for severe agitation and delirium, if no identifiable

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physical distress can be found. Many of these experts also cautioned that the person with dementia should be demonstrably much better by taking such medication in order to justify its use.

Several experts make a distinction between management of a resident's behavioral symptoms for the resident's sake versus management for the sake of others (e.g., the family or staff). One expert gave an example of a resident having a pleasant conversation with news anchor Tom Brokaw while he was on television. Although the family was evidently bothered by the event, the resident seemed to be enjoying himself. Hence, the expert advocated that behavioral symptoms should be managed only if they are distressing for the resident himself. Another expert gave the example of sedating a resident to quell screaming for the staff's sake, and said that a better approach is for staff to "listen hard" to the resident and assess his or her needs and address them.

As with management of physical symptoms, many experts also noted that facilities need sufficient staff and resources to provide the kind of care that dying residents with dementia require.

5. Residents with a Secondary Diagnosis of Dementia

Most experts indicated that the general approach to care for a resident with dementia who is dying of another primary chronic condition—such as congestive heart failure, or chronic obstructive pulmonary disease—is similar to the care that a resident with a primary diagnosis of dementia should receive. However, depending on the level of the resident's cognitive and verbal abilities, the resident may be able to be more involved in his or her own care decisions. Several experts added that it may be easier for practitioners to assess and manage symptoms of residents with a secondary diagnosis of early-stage dementia. Such residents are perhaps able to tell practitioners what is bothering them so that practitioners can target treatment in response to the resident's needs and preferences. However, other experts felt that having a secondary diagnosis of dementia can potentially complicate the assessment and treatment of symptoms since there may be mixed care goals between the co-morbid conditions. For example, a practitioner would have difficulty treating an individual if he or she has a palliative care goal for one condition but a restorative care goal for the other. Some of these experts suggested use of holistic care goals in which the secondary diagnosis of dementia can influence care decisions for the primary diagnosis and vice versa.

Interestingly, several experts indicated that the prognosis of death is easier for residents with dementia suffering from another primary terminal diagnosis (e.g., cancer). Prognosis is a key criterion for hospice access; Medicare requires physicians to declare that a resident will likely die within six months for a resident to be eligible for the services. It is difficult to determine the transition to end of life for a long term, progressive illness such as Alzheimer's disease.

6. Psycho-social and Spiritual Support for the Resident

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Although there is not a lot of evidence in the literature on the effectiveness of having residential facilities offer psycho-social and spiritual support for residents with dementia, experts largely agree that such support can be beneficial to the resident, regardless of cognitive status. Most of the experts believe that dementia residents are able to derive a sense of comfort and familiarity from music or religious rituals that they enjoyed prior to the onset of disease. A few experts did indicate that their psycho-social and spiritual support is usually directed more toward the family than the resident. However, these experts would also agree that the resident him or herself can derive comfort from such support.

Psycho-social support can take the form of ensuring that residents with dementia and their families have appropriate expectations of the trajectory of the disease. Uncertainty is a source of great anxiety for residents and families who are uninformed about the progression of dementia. Hence, many experts advocate for nursing homes and assisted living residences to educate the residents and their families about the disease in order to replace misconceptions and anxiety with appropriate expectations and care goals.

A key component of psycho-social support for the resident is continued interaction between the facility staff and the resident. Staff interaction with residents should not be limited to medical care. Staff members should converse and interact with the resident. This would be facilitated by staff learning more about the resident, who they were and what they enjoyed in the past. This knowledge would give staff ideas for talking with residents during care and other activities. Activities can be built around a resident's individual preferences based on the assumption that he or she will still respond positively to activities that he or she considered enjoyable in the past. For example, staff could employ a "high touch" approach for a resident who comes from a family with frequent physical contact. Some experts suggest talking about a family album with the resident. Others suggested that psycho-social support can even take on the form of providing residents some time alone if they require the inner retreat after a period of stimulating activities.

With regard to spiritual support for the residents, one expert suggested that spiritual support can be thought of as whatever gives the person meaning in life. The expert provided the example of a farmer who finds it spiritually fulfilling to be beside an open window because he loves the outdoors. As for residents who participated actively in their religion prior to admission to a residential care facility, experts indicate that the facility should find out which religious practices or rituals are significant to the residents. The staff members can then help the residents practice to their capabilities or ensure that certain religious iconography are available in the facility. For example, a Catholic resident may want to have a priest come to perform last rites. Many of the interviewed experts from nursing homes and assisted living residences indicated that they offer an onsite chapel with clergy visits at the request of the resident or family.

Attending to a resident's psycho-social and spiritual needs can be time consuming. Nursing home frontline workers are often fully occupied with the day-to-day challenges of providing adequate care for the residents. Hence, many experts recommend

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including counselors, social workers, volunteers, chaplains, or psychologists in the resident's care team to ensure that the resident's psycho-social and spiritual needs are met in addition to their medical needs. VA nursing homes often include chaplains and psychologists as part of the care team. Many experts also say that hospices are useful resources because they provide good psycho-social and spiritual support due to their expertise and extra staffing.

7. Support for Family Caregivers

Aside from psycho-social support for the residents, all experts agreed that providers should play a role in supporting the family caregivers throughout their prolonged grieving process over the loss of the person with dementia. Families experience a unique two-part grieving process since dementia first robs a resident of his or her cognitive abilities before taking the resident's life. Providers can help family through ongoing education and communication about the disease and how the loved one is faring. Individual gestures of kindness can also help caregivers. Such support is especially important for dementia caregivers because of the tremendous amount of guilt that they sometimes feel in their role as decision-makers.

Upon admission and throughout the resident's stay at the facility, the family needs to be educated about dementia being a terminal diagnosis and what to expect as the disease progresses. Some facilities have welcome packages filled with fact sheets that explain the disease trajectory. During communication with family, the staff members need to solicit the family's expectations and concerns and work closely with them to develop a care plan that respects their input.

The family (especially the health care proxy) needs to be continually updated on the resident's health status so they can make the best possible decisions on behalf of their loved ones. In addition to regular care planning meetings, one way to handle information sharing is for the facility to provide a logbook for the family to ask questions to the staff—who may be busy and cannot immediately address the family's questions.

Families need to understand the advantages and disadvantages of different interventions so they can make informed decisions about various treatments, comfort care options, or no action at all. As explained previously treatment of symptoms need not occur if the resident is not suffering. Whatever decisions the family makes, reminders that they are doing what the resident would have wanted can help alleviate any guilt they may be having about their decisions.

When a resident is actively dying, perhaps during the last 24 to 48 hours of a resident's life, families need someone who can explain what is happening to the resident to minimize the family's distress. One expert suggests that there are three critical elements to providing good psycho-social and spiritual care for the family during this time. The support provider must be readily available to the resident and family, the family must have a means of contacting the provider when needed, and the provider must be responsive to the family's needs.

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Family members often look for a way to contribute to the resident's comfort and need suggestions about how to interact with a dying resident with dementia. Among the suggestions that experts made were for staff to encourage the family to bring music the resident likes and teach family how to perform comfort care for the resident. Such comfort care can include moistening the resident's lips, massaging hands or feet, and reading aloud favorite passages from books.

Families also need comfort and privacy. Many experts from care facilities noted that they offer "comfort carts" to families that contain such items as snacks, coffee, inspirational passages, spiritual books, a listing of churches in the area, or a CD player with comforting music. Other measures to provide comfort and welcome to the family that experts cited were a recliner for the family member who decides to stay the night with the resident, access to a refrigerator for the family, family participation in meals, provision of blankets during the night, an umbrella if it is raining, and providing magazines. Some facilities provide a private room for the resident who is actively dying to offer the family a private place to grieve. Visiting hours at some facilities are also extended to 24 hours a day, 7 days a week to accommodate the grieving family's needs.

Some providers also either encourage families to develop support networks composed of other families who have loved ones with dementia, or help in connecting families to existing education and support groups. Experts commented that it is comforting for caregivers to know that there are other people who have to make the same end of life decisions on behalf of their loved ones.

Most experts agreed that involving hospice in end of life care is particularly helpful for families. Aside from providing extra staff who can spend time with families, hospice can provide bereavement counseling under Medicare for 13 months after a resident's death. Facility staff is limited in the time and resources that they can devote to residents' families.

8. Bereavement Services and Recognition of Resident Death

All experts agree that a facility needs to recognize the death of a resident and to provide some form of bereavement support for the family after the resident's death. The most commonly reported method of remembering a resident's death is through onsite memorial services conducted by the facility staff. Model facilities often call family after a resident's death to ask "how they are doing" and to assess whether any family members are at risk of "complicated grief" -- having severe depression or other emotional complications after the loved one's death. While not all experts addressed the issue, some experts believe that many nursing homes and residences do not have the requisite time and resources to provide adequate bereavement services for families. However, the capacity of facilities varies. Most experts said that bereavement services are another area in which hospices offer additional help.

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Experts mentioned a number of different ways of recognizing a resident's death in a facility. Some facilities will alert staff to the fact that a resident has just passed away to avoid the surprise of walking into the resident's room without knowing that he or she has died. Other facilities place a 'hold' on the resident's bed for a certain amount of time after the resident's death. Some VA nursing homes hold the resident's bed for 24 hours after death. Other methods of recognizing death are: sending condolence cards from staff to residents' families, creating memorial books containing names and pictures of residents who have died and leaving this book in the lobby or foyer, and placing photographs of residents on a special "recognition wall" for one week after death. One expert cautioned that the federal Health Insurance Portability and Accountability Act's privacy provisions may prevent the posting of a resident's picture after death. Some experts from the VA mentioned that certain facilities have a standard practice of getting permission to use resident photographs.

Periodic, in-house memorial services that recognize and celebrate the residents' lives occur in many facilities on a semi-annual, quarterly or monthly basis. Staff helps plan and participate in these services by doing such things as telling anecdotes from the resident's life. Most experts consider these memorial services to be beneficial for staff members who often grieve about the passing of residents with whom they have developed close relationships. However, the experts disagreed about how helpful these memorial services are for families.

The staff needs to be given adequate time to grieve and to say goodbye to the resident that they have cared for over the years. Some facilities will allow staff some time off to attend a former resident's memorial or funeral service of a former resident that is offsite. Experts also mentioned that staff needs emotional support from supervisors related to their grief.

9. Provider Skill and Knowledge

Interestingly, five interviewed experts indicated that even practitioners need to be educated or reminded that dementia is in fact a terminal condition. And, there is a general consensus that providers who care for residents with dementia need to be specifically 'dementia-trained' because of the unique challenge this group presents. Training content should include knowledge of disease trajectory, symptoms, approaches to care, goals of care (cure or comfort), palliative care measures, end of life issues, signs of impending death for persons with dementia, and how to interact with residents and families.

Critical knowledge also includes assessment, symptom management, and communication. Good assessment skills are critical, particularly in working with those who cannot communicate verbally. Individuals with dementia at the end of life are often at high risk for pain, depression, and other conditions that complicate assessment. Managing these symptoms requires specific knowledge of non-pharmacological and pharmacological treatments of conditions at the end of life. Providers must be able to

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communicate respectfully with residents, no matter what their remaining functional or communication abilities are.

Some experts pointed out that while formal training is important, much of what a staff member needs to know regarding dementia care can be learned by watching how experienced staff handle end of life issues while caring for those who are dying. In addition, it is important for supervisors to positively reinforce training and reward good end of life care.

10. Palliative Care and Hospice Services

Experts were asked whether nursing homes should be providing palliative care as a matter of routine. Almost all experts queried said yes but qualified their responses. Most experts believed that there are some advantages to involving hospice in end of life care for nursing home residents with dementia.

Although the majority opinion was that the option of palliative care should always be provided to the resident, whether good care can be provided is dependent on the facility and its level of resources. A substantial minority of experts believe that nursing homes lack the resources and staff level to provide good palliative care. Some believe that nursing home staff does not have sufficient training to be able to provide good end of life care and that staff does not have the time and expertise to deal with family support issues. This subset of experts believes that bringing in hospice staff is helpful due to their expertise on end of life and dying. Hospices also add staff that can devote the time and care that a resident at the end of life requires. Additionally, hospice staff can offer support to family caregivers during the grieving process.

Among the respondents who addressed end of life care provision in assisted living residences, several said that it is difficult for assisted living residences to provide good palliative care at the end of life without the presence of a hospice. Some assisted living experts mentioned that they make affirmative efforts to involve hospices at the end of life.

11. Public Policy Barriers to Delivery of Quality End of Life Care

Experts agreed about the major public policy barriers to delivery of quality palliative care in nursing homes and there was some discussion of the barriers to delivery of such care in assisted living residences. Experts identified four major public policy barriers in the following order: use of the Medicare Part A skilled nursing facility benefit, Medicare hospice eligibility criteria, certain aspects of the quality assurance system, and inadequate provider reimbursement.

Medicare benefits largely focus on medical interventions and rehabilitation, rather than on comfort or palliative care. This problem presents itself in the Medicare skilled nursing facility benefit. The nursing home and the resident's family have a financial incentive to transfer an individual with dementia to the hospital because after a three-day

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stay in the hospital, a resident is provided with skilled nursing care coverage under Medicare. Medicare payment levels are generally higher than Medicaid and beneficiaries do not have to pay out of pocket costs or room and board costs for the first 20 days of the benefit. Unfortunately, Medicare beneficiaries receiving the skilled nursing facility benefit cannot have hospice care at the same time. Experts mentioned this financial incentive first and most frequently when asked about public policy barriers to delivering quality end of life care.

The requirement that a beneficiary receiving hospice have a prognosis of dying within 6 months also limits access to palliative care in the view of approximately two-thirds of the experts. Another problem with the prognosis criterion for hospice referral is that residents with dementia can go on and off of hospice because their conditions improve or their health stabilizes while on this benefit. This revolving door complicates delivery of coordinated palliative. Experts who did not complain about the prognosis requirement used the general frailty of the dementia resident to justify use of the hospice benefit. Interestingly, one expert from an assisted living residence works closely with hospice agencies and said 85% of its residents with dementia die while receiving hospice services.

About half of the experts mentioned some aspect of the quality assurance system being a barrier to provision of quality care. A few, mostly providers, said that there is an adversarial tone to nursing home surveys, with some surveyors being very subjective in their work. Providers and other experts cited the nursing home quality indicators for weight loss and pressure sores as penalizing homes that have residents who lose weight due to dysphagia or develop pressure sores because of immobility, when they are dying. A few providers mentioned that facilities that document pain can be penalized in comparison to those who do not, when performance on quality indicators is compared. Finally, according to some experts, some surveyors do not realize that residents on long term pain medications can tolerate a higher dosage than others with less frequent use of the pain medications.

Experts familiar with assisted living residences raised several public policy issues. One is that some states limit the number of residents who can be on hospice or do not permit hospice in assisted living residences at all. Other states require residents to leave assisted living if they have serious pressure ulcers, which they can acquire after hospital stays. Individuals living in some residences are also required to leave if they cannot manage their own medications. Experts pointed out that these policies can force individuals to leave assisted living, even if they can obtain the care they need.

Many experts raised inadequate funding as an impediment to provision of good end of life care. This underlies the perception among many research experts that nursing homes cannot hire sufficient staff to provide quality end of life care. In addition, experts stated that Medicare and Medicaid payments do not cover the time needed to accurately determine what problem a resident with dementia is experiencing, bereavement calls, or practitioner time needed to educate or counsel families about their loved one with dementia. According to one researcher, some states' Medicaid nursing home payment

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policies exclude hospice residents from the calculation of reimbursement rates, thereby lowering the reimbursement to nursing homes that serve many end of life residents.

Federal and state policies are not designed to consider the needs of dying residents with dementia. Provider reimbursement incentives are incongruent with palliative care. For example, some nursing home payment systems pay more for tube feeding a resident, rather than hand feeding him or her. Hence, there is a “perverse” financial incentive to perhaps unnecessarily subject a resident to tube feeding, which generally has negative consequences for residents with advanced dementia, when the resident may instead be better off being hand fed.

The practice of inserting feeding tubes in residents who have ceased eating is a controversial topic in some parts of the country and among some providers. Several researchers mentioned that in New York State facilities must insert feeding tubes unless the resident has a properly executed advance directives that prohibits this. Other researchers mentioned that some facilities have corporate policies that require insertion of feeding tubes when residents can no longer eat, out of a fear of liability if they do not do so.

Conclusion

We interviewed physicians, researchers, social workers, nurses and other experts involved in provision of end of life care to residents with dementia in nursing homes and assisted living residences. These experts had a remarkable level of agreement about the key characteristics of good care for residents with dementia. The experts believe that communication and advance planning for care are central to delivering quality care because they permit residents to receive the care that they would want if they could speak for themselves and enable families to make the best possible decisions on behalf of their loved ones.

Another common theme is the affirmation of person-centered approaches to care and involvement of families as early as possible in decisions about care for their loved ones. To provide good care to the family units, providers must know about the residents and their lives before acquiring dementia, how to communicate with residents, and how to assess needs and manage symptoms at the end of life. Providers must also know how to educate families about dementia as a terminal condition and about what they should expect as their loved ones draw closer to death.

Experts discussed a number of public policy barriers to provision of quality end of life care to residents with dementia. The major barriers fell into two categories. First, Medicare’s benefits are not sensitive to the needs of people with advanced dementia – beneficiaries cannot have ready access to palliative care because of the structure of the Medicare skilled nursing facility and hospice benefits. Second, Medicaid provider payments are viewed by many experts as too low to permit providers to provide adequate palliative care. A thorough re-examination of Medicare and Medicaid benefit and payment policies is warranted.

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Appendix 1: List of Interviewed Experts

Rebecca Allen, PhD

Department of Psychology, University of
Alabama
Center for Mental Health and Aging,
University of Alabama
Alabama

Andrew Neal Dentino, MD, CMD

AGSF, FAPA
Chair, Ethics Committee,
American Medical Directors Association
Medical Director
The Glen Retirement System
Louisiana

Amos Bailey, MD

Center for Palliative Care, the University of
Alabama at Birmingham
Birmingham Veterans Affairs Medical
Center
Alabama

Anne Ellett, NP, MSN

Silverado Senior Living
California

David Brechtelsbauer, MD, CMD

American Medical Directors Association
Sanford School of Medicine of the
University of South Dakota
South Dakota

Mary Jean Flossie, LNHA, BA, LPN

Altercare of Ohio, Inc
Ohio

David Casarett, MD, MA

Division of Geriatric Medicine,
University of Pennsylvania
Philadelphia Veterans Affairs Medical
Center
Pennsylvania

Linda Ganzini, M.D., M.P.H

Department of Psychiatry, Department of
Medicine, Oregon Health & Science
University
Portland Veterans Affairs Medical Center
Oregon

Deborah Cavallo, MBA

Dementia Care
Senior Resource Group
California

Cindy Gensamer, LNHA

Absolute Rehabilitation & Consulting
Services, Inc.
Ohio

Laurel Coleman, MD, CMD, FACP

National Board Member
Alzheimers Association
Medical Director, Beacon Hospice
Maine

James Hallenbeck, MD

Stanford School of Medicine
Palo Alto Veterans Affairs Health Care
System
California

Kerry W. Cranmer, MD, CMD, FAAHPM

American Medical Directors Association
Crossroads Hospice & Geriatric Medical
Services, Cranmer & Associates

Mary Harrison

Life Care Services
Pennsylvania

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Oklahoma

Susan Hewitt, MA, NCC, LPC
Bedford Veteran Affairs Medical Center
Massachusetts

Mark Leenay, MS, MD
National Medical Director
Evercare Hospice and Palliative Care
Medical Director, Palliative Initiatives
UnitedHealth Group
Minnesota

Ruth Hovland, RN, BA, MA
Mount Carmel
Clement Manor
Wisconsin

Victoria Lessa
THI of Baltimore Management, LLC
Maryland

Susan Huber, RN, BSN
St. Joseph Mercy Health System/Huron
Woods Memory Care Facility
Ann Arbor, Michigan

S. Lawrence Librach, MD, CCFP, FCFP
Department of Family and Community
Medicine, University of Toronto
Temmy Latner Centre for Palliative Care
Ontario, Canada

Ann Hurley, RN, DNSc, FAAN
Brigham and Womens Hospital
Massachusetts

Rakell Maroney, RN, BSN
Mount Carmel
Wisconsin

Sister Joyce Joecken, CSJ
Altercare of Ohio, Inc.
Ohio

David R. Mehr, MD, MS
Department of Family and Community
Medicine, University of Missouri-
Columbia School of Medicine
Missouri

Christine R. Kovach, RN, PhD
University of Wisconsin- Milwaukee
School of Nursing
Wisconsin

Diane Meier, MD
Mount Sinai School of Medicine
New York

Patricia Lane, RN, BSN
Geriatric Research and Education Clinical
Center (GRECC), Edith Nourse Rogers
Veterans Affairs Hospital,
Massachusetts

Jill Mendlen, RN
President and CEO
LightBridge Hospice
California

Christina LaRiccia, CRRN, RNC
Altercare of Ohio, Inc.
Ohio

Susan C. Miller, PhD, MBA
Center for Gerontology and Health Care
Research, Community Health Department,
Brown Medical School
Rhode Island

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Joanne Lynn, MD, MA, MS

RAND Corporation
Virginia

Paulette Sansone, LMSW, PhD.

Schervier Center for Research in Geriatric
Care
Schervier Nursing Care Center
New York

Susan L. Mitchell, MD, MPH,

Hebrew SeniorLife Institute for Aging
Research
Harvard Medical School
Massachusetts
Beth Israel Deaconess Medical Center
Massachusetts

Scott Shreve, DO

Hospice and Palliative Care Program,
Department of Veterans Affairs
Lebanon Veterans Affairs Medical Center
Pennsylvania State University
Pennsylvania

Betsy Murphy, BSN, FNP, CHPN

Capital Hospice
Virginia

Joyce Simard, MSW

Joyce Simard Consulting
Florida

Christina Puchalski, MD, MS

Department of Medicine and Department
of Health Care Sciences, George
Washington University School of Medicine
George Washington Institute for
Spirituality and Health
District of Columbia

Lin Noyes Simon, PhD, RN, CHPN

National Hospice and Palliative Care
Organization
Alzheimer's Family Day Center
Virginia

Michelle Putz, RN, MBA, BSN

Mount Carmel
Wisconsin

William Smucker, MD

Summa Health System
The Family Medicine Center of Akron
Ohio

Judith Rabig, RN, MA

Judith Rabig Consulting, LLC
New York

Joel E. Streim, MD

Section on Geriatric Psychiatry
Hospital of the University of Pennsylvania
VISN 4 Mental Illness Research Education
and Clinical Center Philadelphia VA
Medical Center Pennsylvania

Scott Robinson, RN, MSN

Silverado Hospice
California

Greg A. Sachs, MD

Section of Geriatrics, Dept. of Medicine
Center for Comprehensive Care and
Research on Memory Disorders
University of Chicago

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Illinois

Jenny T. van der Steen, PhD

EMGO Institute
VU University Medical Center
Amsterdam, The Netherlands

Ladislav Volicer, MD

School of Aging Studies, University of
South Florida
3rd Medical Faculty, Charles University,
Prague, Czech Republic

Rhonda Wiering, RN, BC, LNHA

Director of Quality Initiatives
Avera Health
South Dakota

Ruste Wilke, RN, MSN

Angela Hospice Home Care, Inc.
University of Michigan
Michigan

Laure Zulkowski, RN, BSN

Mount Carmel
Wisconsin