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## Maximizing comfort for the person with dementia: Nursing care approaches that work across the continuum of care

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## Abstract

Dementia is a progressive terminal condition for which there is no cure. Alzheimer's disease is prevalent in 60–80% of all dementias. Those with Alzheimer's disease may suffer from well-intentioned, albeit uncomfortable treatments and nursing interventions, particularly as the person encounters increasing physical and mental decline and approaches the end-of-life. As the progression of dementia robs a person of their memory, ability to speak, and care for themselves, nursing professionals and family caregivers may not know the best practices in caring for these individuals. This paper incorporates a case study with an interdisciplinary team approach to illustrate the possibilities in providing positive caring interventions for the person with advanced dementia.

## Key words

palliative care, hospice, dementia, Alzheimer's disease, behavioral and psychological symptoms of dementia (BPSD), interdisciplinary team

## 1. Introduction

Dementia is not a specific disease but rather a progressive geriatric syndrome that is severe enough to impair memory, cognition and both instrumental and basic activities of daily living. To illustrate the effects of dementia, a fictitious case study illustrates the ravages of dementia.

Three years ago, Mrs. Emi Aida, age 84, was diagnosed with one of the many types of dementia; Alzheimer's disease. She has been a resident at Bene Vida nursing home for the past year, with multiple readmissions back to the hospital every 3 to 4 months due to ongoing and unresolved urinary tract and respiratory infections accompanied by a low-grade fever. As in the past, she is experiencing a superimposed delirium on dementia as evidenced by an acute onset, a fluctuating course of inattention, disorganized thinking and altered consciousness using the Confusion Assessment Method (CAM; Inouye et al 1990). Her score on the Mini-Mental State Examination (MMSE) is 4, out of a potential score of 30, 3 on the Clinical Dementia Rating (CDR) scale, and 7A on the

Functional Assessment Staging Tool (FAST), all of which are indicative of advanced dementia (Folstein et al 1975, Morris 1993, Reisberg 1988).

Mrs. Aida utters just a few understandable words and she is no longer able to execute both her instrumental and the usual activities of daily living (ADLs). She has co-morbid conditions of well-controlled hypertension, crippling osteoarthritis and progressive chronic obstructive pulmonary disease. Mrs. Aida takes an array of medications including antihypertensives, bronchodilator inhalers, which she can no longer self-administer, and anti-dementia medications. Each time she is admitted to the hospital, her condition continues to deteriorate with evidence of increasing cognitive decline, progressive loss of independence, weight loss, and behaviors suggestive of discomfort. Bene Vida nursing staff report that Mrs. Aida's behavioral and psychological symptoms of dementia (BPSD), or behaviors typically attributable to her dementia diagnosis, have become more frequent and pronounced. For example, she often will strike out and hit the direct

care nursing home staff and she groans and pounds on the table continuously when sitting for long hours in a chair. She also thrashes and screams in the shower, resisting all bathing efforts. Her only child, a son who is also her durable and medical power of attorney and manages her medical and financial affairs, lives close by and accompanies her to the hospital by ambulance.

He is very distraught, having witnessed years of deterioration and laments to the paramedic "...she is no longer the mother that I once knew. I know that she would not want to be this way."

## 2. What is dementia?

Dementia is not a specific disease but rather a progressive syndrome that includes memory loss, confusion, impaired thinking, language, judgment and movement difficulties. Over time, the effects of dementia will lead to total reliance on family and other caregivers for all needs by the advanced stage (Alzheimer's Association [AA] 2016a). Dementia is an umbrella term that includes an array of neurodegenerative diagnoses of which 60–80% are Alzheimer's disease (AA 2017). Like Mrs. Aida, approximately two-thirds of people diagnosed with dementia are women. Alzheimer's disease is listed as the 4th leading cause of death in Japan (Institute for Health Metrics and Evaluation 2015), the 6th leading cause of death for people age 65 and older in the United States (AA 2016b), and the 7th worldwide (World Health Organization World Health Organization [WHO] 2017a).

Individuals in the late or advanced stage of dementia with Alzheimer's disease share similar characteristics (AA 2016b). Increasing resistiveness to caregiver interventions may emerge when the person 'calls out' or demonstrates physical or verbal behaviors, rejects care, or strikes a caregiver if the approach is not optimized to meet their person's needs. The person will have increasing eating difficulties; leading to dysphagia and the inability to chew. They may be able to hold a cup for drinking or a fork with food but they will

have to be cued to drink and eat or may need to be fed; thus, leading to weight loss if care staff are not attentive to dementia-friendly foods and fluids to prevent dehydration and the risk for infections. Over time, the person becomes oriented only to him or herself; thus, running the risk of isolation and depression since these individuals may look like they can no longer engage in any meaningful activities or connections when in fact they can. Motor impairment will become more severe with the person's inability to reposition themselves or participate in activities and the risk for pressure ulcers escalates, which is also related to bowel and bladder incontinence common in the moderate stage of dementia.

As ambulatory skills are lost, the person with advanced dementia is generally moving into the final or end-stage of dementia. This stage will be marked by the loss of purposeful body movement and the total reliance on caregivers (family or others) for dressing, grooming, bathing, feeding, and bladder/bowel care. Difficulty interacting and responding to surroundings may lead to increasing resistiveness to care, largely viewed as self-protection measures or in response to pain. The person will become dysphagic and mute and they will lose the ability to sit up, hold up their head and/or smile. They will no longer respond to their name. The person with end-stage dementia will encounter numerous intercurrent infections related to urinary tract or upper respiratory infections. Repeated infections and fevers or progressive weight loss may escalate. In the terminal stage, hospice care becomes a consideration for additional support and comfort-focused strategies during the last 6 months of life.

To date, there is no cure for dementia or Alzheimer's disease and it is considered a terminal condition. While there is no cure, individuals continue to undergo numerous uncomfortable and aggressive life-sustaining treatments, such as cardiopulmonary resuscitation and tube feedings (Mitchell 2016, Mitchell et al 2012, Volicer 2005). These medically futile procedures

often lead to poor outcomes and a diminished quality of life. Pain is commonplace and often goes undetected and untreated (Herr et al 2011). In addition, delirium is common for people with dementia as individuals often succumb to intercurrent infections related to dehydration, decreased mobility and aspiration pneumonia due to beginning dysphagia making the clinical picture more complex for nurses to decipher (Oligario et al 2015). Palliative care is necessary for these individuals.

### 3. What is palliative care?

The World Health Organization defines palliative care as follows:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO 2017b).

Palliative care attends to loss and grief and the need for psychosocial support for patients and families along the trajectory of serious illness. Furthermore, palliative care enhances quality of life and regards life, dying and death as a normal process as it incorporates an interdisciplinary team approach to the family-patient dyad. Palliative care in the United States is introduced early on in a disease trajectory for individuals with serious illness, such as Alzheimer's disease, and may include therapies to modify the disease with curative or restorative intent. Over time, these life-prolonging medical interventions will generally diminish in favor of increased attention to comfort measures to relieve pain and suffering and improve quality of life (Coyle 2015). In addition, hospice care is a part of the palliative care continuum and is focused on care of the patient and family in the last six months of life. To date, palliative care for conditions other than progressive cancer and Acquired Immune Deficiency Syndrome (AIDS)

are not part of the formal healthcare system in Japan however, continuing collaboration and research in palliative care for dementia is evolving (Nakanishi et al 2015a, Nakanishi et al 2015b, Takenouchi and Tamura 2015).

For persons with dementia, palliative care may not be initiated until late in the treatment plan, thus limiting the opportunity for aggressive attention to physical and psychological symptoms, social and family needs, and spiritual support for the person and family alike (van der Steen 2010). While dementia is considered a medical and psychiatric condition, care planning requires a person-directed palliative care approach that maximizes the person's capabilities while anticipating and meeting needs and minimizing interventions that are considered uncomfortable and often lead to distress and behaviors. Palliative care needs to be operational in all clinical settings and especially for persons with dementia who have complex care needs and are at risk for multiple transitions of care (AMDA 2016). Palliative care should be initiated upon the diagnosis of dementia; affording the opportunity for the patient, family and clinical team to plan person-directed care along the trajectory of the illness.

### 4. Theories: Caring for the person with dementia

Tom Kitwood's seminal work, *Dementia Reconsidered, the Person Comes First* (1997), provides a foundation for a person-directed care approach. By coming to know the person and their needs, respecting their choices, incorporating preferences, and enabling independence and self-efficacy even when the person can no longer actively participate in their self-care; the focus can shift to what can be done to support dignity and comfort rather than what is lost. As such, the anticipation of need, advocacy, positive interactions and maximum attention to what brings pleasure for this person becomes critical; especially as the disease erodes cognition, verbal communication and self-care.

Two theories help to explain discomfort and behaviors in people with dementia. The Progressively Lowered Stress Threshold (PLST) theory proposes that ongoing neurodegenerative changes compromise the person's ability to decode and respond to both internal and external stimuli which then leads to stress (Hall and Buckwalter 1987). With limited ability to cope, the person unknowingly becomes anxious and then dysfunctional behaviors emerge. The cycle continues until the stress is relieved. For the clinician, this is a conceptual shift in understanding that behaviors have meaning and that behaviors, which are often a reaction to clinician interventions, are communication of unmet need (Long 2009). Examples of behaviors may include, but are not limited to, calling out, hitting, continually crying, pacing, repetitive questioning and more. Thus, when behaviors occur, a search for the cause is critical, especially when the person can no longer verbally communicate.

The Consequences of Need-driven, Dementia-compromised Behaviors (C-NDB) theory suggests that when the person with dementia is unable to make their needs known due to communication deficits, behaviors evolve (Kovach et al 2005). When original or basic needs are not met, consequences emerge and the effects cascade with new needs and behaviors ensuing. Many behaviors may be instigated by meaningful family and care staff not realizing that the need to be safe, fed, stimulated and loved are primary needs that a person with advanced dementia may not be able to communicate other than through non-normative behaviors. Thus, the behavior is a reaction and not a consequence of the disease and appropriate person-directed palliative care interventions can break the cycle.

In this situation, Mrs. Aida is severely distressed and compromised. Nursing interventions need to focus on her delirium and other ongoing stress and resulting behaviors, promote physical and emotional comfort that aligns with her personal preferences, and anticipate needs, since Mrs. Aida

is not able to effectively and verbally communicate or do this herself anymore. Attention to caregiver grief is necessary through ongoing communication about the progression of dementia and positive caregiving approaches that engage family members in this final journey. Finally, evidence-based research and clinical practice guidelines continue to evolve and are interwoven into the remaining case scenario.

##### 5. Nursing care for the person with advanced dementia

Mrs. Aida is admitted to the medical nursing unit at Baywood Medical Center. Her blood pressure is elevated and pulse is rapid. She is agitated and combative, requiring physical restraints and antipsychotic medications. Intravenous (IV) antibiotics are ordered, but Mrs. Aida unknowingly jerks out the IV line even when restrained. After 4 hospitalizations in the past year and in consultation with the son, the hospitalist physician refers Mrs. Aida to the palliative care team (PCT), which includes a social worker, physician, nurse, pastoral care and an array of therapists, pharmacists and a dietician to plan ongoing care. The PCT, unit nurse manager, hospitalist and son review Mrs. Aida's current status, medications, comfort level, prognosis and documented advance directives in a family meeting to prioritize her care needs which include stabilizing her current condition but also planning for the future with consideration of her advance directives. A comprehensive plan of care is developed to plan for her return back to her home, *Bene Vida*.

Since Mrs. Aida is experiencing a hyperactive delirium related to a confirmed infection, safety is of utmost importance (Close and Long 2012). Although she is intermittently combative and resistive to care, the arm restraints and antipsychotic medications are weaned in favor of the son and other family members staying with Mrs. Aida around-the-clock until she stabilizes. Numerous interventions are instituted that protect her well-being including placement in a quiet

room away from the noisy nurse's station, applying her eyeglasses and hearing aide, and maintaining nutrition and hydration with food and fluids that she enjoys (Kolanowski 2016). Since Mrs. Aida is nonverbal and unable to reliability self-report pain, a behavioral observation pain tool specific for people with dementia is used (Herr et al 2011) and it is soon determined that she is experiencing moderate to severe pain. With a quiet room, minimal noise and distractions, soon Mrs. Aida becomes more alert and comfortable and is able to ingest liquid antibiotics and opioid analgesics. The team evaluates the rest of her medications to ascertain efficacy, burden and risk in sync with the updated Beer's criteria (American Geriatrics Society [AGS] 2015). As such, several medications are discontinued since they are considered potentially inappropriate and possibly harmful. The bronchodilators, that she no longer uses and causes her extreme anguish when she tries, are also discontinued.

Simultaneously, the hospital social worker confers with the son and the Bene Vida social worker to review Mrs. Aida's life story, a biosketch that details her background, desires, likes and dislikes (Dougherty et al 2006, Thompson 2012). A revised life story is placed above Mrs. Aida's bed and soon all nursing care staff are calling her by her preferred and given name "Emi". The life story captures essential information for nursing staff to use when Emi becomes distressed and to enhance meaningful connections. In this situation, nursing staff reminisce about the past with Emi while using numerous distractors and nonpharmacologic interventions to address pain and the unfamiliarity of being in a hospital (Gallagher and Long 2011, Gitlin et al 2012). Soon, she is able to sit up in a chair for short intervals since staff realize that her arthritis and inability to sit for long causes pain. Acetaminophen around-the-clock is now all that she needs in addition to frequent rest intervals and intermittent back massages. As a result, she no longer bangs her hands on the overhead table, which was commonplace at Bene Vida. In

addition, family and staff engage in prayer and spiritual song when anxiety emerges and to bring enjoyment as a normal occurrence. The hospital dietician and PCT gleans dietary preferences from Emi's life story and modifies her diet, eliminating the low-salt food which she dislikes and does not eat (American Dietetic Association 2010). With a liberalized diet, soon Emi is eating soft and sweet foods which she enjoys and her weight is expected to improve. Thus, her care plan is truly customized, attending to her needs, deficits and personal preferences.

Within days, Emi stabilizes and another family conference is held to review her current status and plan for her transition. While Emi's medical condition continues to improve, she lacks the cognitive capacity to make medical decisions. Additional comfort measures are identified and advance directives are again reviewed in light of her current progression along the Alzheimer's disease trajectory. The PCT, unit nursing staff, hospitalist and son recommend a feeding tube to administer medications and food in the future when she is no longer able to swallow. However, it is noted that Emi does not want intravenous hydration of antibiotics or artificial nutrition "to prolong misery and suffering" according to her son. This is specified in her advance directives and the care team honors these advance care planning decisions (AGS 2014). While Emi is currently not a candidate for hospice, the eligibility criteria (Table 1) is reviewed with her son for future

Table 1. Hospice eligibility in the United States

All of the following, or 7C on the Functional Assessment Staging Tool (FAST), which includes:
<ul style="list-style-type: none"> <li>• Unable to ambulate, bathe and dress without assistance</li> <li>• Constant or intermittent urinary or fecal incontinence</li> <li>• No meaningful or intelligible verbal communication limited to six words or less</li> </ul>
One of the following in the past 12 months:
<ul style="list-style-type: none"> <li>• Aspiration pneumonia</li> <li>• Septicemia</li> <li>• Decubitus ulcers, multiple, stage 3-4</li> <li>• Fever, recurrent after antibiotics</li> <li>• Inability maintain sufficient fluids and caloric intake with 10% weight loss during the previous month or serum albumin &lt; 2.5 g/dl</li> </ul>

(Reference: CMS 2015)

consideration in keeping with her advance directives that specify the provision of comfort measure to alleviate pain, physical symptoms, social and spiritual distress.

#### 6. Palliative care coordination

The PCT and hospital care team transition Emi back to the nursing home. With the Bene Vida staff, they review at length the revised and updated approaches to her care and jointly examine other opportunities to create comfort. Both teams discuss the need to continue to assess and address Emi's pain, largely becoming more intense with her lack of mobility, her inability to sit in a chair for long intervals, and the need for rest in bed. Her incapacity to self-report pain will require Bene Vida to institute procedures and a behavioral observation pain tool to assess pain and provide the appropriate analgesic and nonpharmacological interventions around-the-clock (Herr et al 2011).

Additionally, Bene Vide nursing facility staff ponder other evidence-based comfort measures that could reduce stress and dementia-related behaviors. Since showers and the use of a shower chair emerged as a threatening, intrusive and unwelcoming event for Emi in the past, the nursing facility team start using the towel bath method; preserving personal bathing preferences first, promoting privacy and warmth and thereby minimizing self-protective behaviors (Hall et al 2013). With this change, Emi is receiving impeccable personal hygiene in the comfort of her own bed, often sleeping right through the spa-like bed-bath experience while enjoying individualized music from her iPod (Music and Memory 2017, Zhang et al 2017).

Her family doctor orders a general diet and dietary personnel customize her meal preferences to foods she can eat and enjoy or "dementia-friendly comfort foods". Emi is now eating 75% of her meals, most of which are natural but soft foods. In addition, she is offered, and ingests, numerous fluids including juices and chocolate drinks. Nursing staff realize that Emi is no longer

able to request a drink or food and must have regular offerings throughout the day. Staff also place the food item or drink in her hand so that Emi can use muscle memory to feed herself while she is still able. Additionally, while Emi will likely encounter dysphagia in the final stages of her life, her advance directives will guide treatment and careful hand-feeding will allow her to eat her food until she is no longer able to do so (AGS 2014).

Correspondingly, after her evening meal, Emi enjoys oral hygiene when care staff use techniques from Mouth Care without a Battle© and other support oral hygiene approaches (University of Iowa 2011, The Cecil G. Sheps Center for Health Services Research 2017). Much like other personal hygiene tasks, staff personalize her oral care experience with tooth-brushing techniques and practices that foster engagement and reduce self-protective behaviors. Similarly, the activity/recreational therapy professional incorporates additional sensory stimulation into her normal ADLs such as staff reading engaging picture books and taking Emi outdoors for short intervals. With the addition of back massages, individualized music, and comfort food, Emi's plan of care is indeed holistic and person-directed.

Finally, Emi's son and the Bene Vide interdisciplinary team affirm that no future hospitalizations nor burdensome IV antibiotics will be considered in lieu of Emi receiving supportive care at Bene Vida nursing facility and hospice services in the future (Mitchell 2015). Thus, palliative care is an approach that honors an individual's choice, focuses on evidence-based practice that maximizes comfort while reducing pain and other symptoms that cause distress, and promotes respect and dignity until the end-of-life.

#### 7. Conclusion

The entire nursing home team assembled to review the new plan of care and certified nursing assistants received extra training to execute the bathing procedures, pain protocol, and engagement plan of care that includes music and prayer. Her

weight loss has stabilized and pain is minimal. The life story was updated and the son continues to receive supportive care from community resources and the Bene Vida social work team to manage ongoing loss and grief. Emi's preferences and advance directives continue to be honored, the delirium has resolved, her behaviors have radically diminished, and hospice is making a visit soon to discuss care options while never giving up hope for a cure.

This exemplar case study magnifies the importance of the interdisciplinary team in transitions of care, communication, and collaboration that is specific to palliative care for people with dementia who have complex care needs in the advanced stage. In conclusion, Alzheimer's disease and other dementias are terminal conditions. Person-directed palliative care for dementia is necessary and this can be accomplished by integrating current theories and evidence-based practice that are comfort-focused into the plan of care across all clinical health settings. With no cure for AD and related dementias on the horizon, palliative care needs to become the "new normal" in the care of and for people with dementia with nursing care approaches that work.

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