

Impact of Palliative Interventions and Mortality Rate in Hospitalized Patients with Advanced Dementia

Abstract

By the year 2040 the prevalence of dementia in the United States alone is estimated to rise to over nine million affected individuals, with an age-specific prevalence that is similar in virtually all nations in which it has been studied. Costs of care increase with severity of dementia, with an annual United States estimate of over 200 billion dollars by the year 2040. Dementia causes a myriad of suffering, for the patients themselves as well as for their family and paid caregivers. Despite the inevitably progressive, incurable, and terminal nature of dementing illnesses, programs providing palliative approaches focused on relief of suffering, maximizing comfort and quality of life, and support for family caregivers are remarkably sparse. This evolves in part from the highly variable survival time of patients with advanced dementia, making accurate prognostication impossible and leading to uncertainty about the proper goals of medical care: is the purpose of health care to maximize the length of life or is the primary focus the promotion of best possible quality of life?

A series of studies aimed at characterizing the care of persons with advanced dementia in the hospital setting found: (1) a substantial proportion on persons with advanced dementia are lacking functional surrogate decision-makers; (2) painful and uncomfortable hospital procedures are commonly employed in this patient population; and (3) palliative care consultation had little impact on the type of care received. These findings have implications for establishing new models of medical care for this growing patient population.

Alzheimer disease and related dementing illnesses are incurable, progressive disorders leading gradually to complete loss of cognitive function and subsequent death. There are presently over four million Americans with diagnosed dementia, approximately half of whom are in the late stages of disease: bed- or chair-bound, unable to comprehend or recognize their surroundings or caregivers, incontinent, and completely dependent on others for all activities of daily living. The prevalence of dementia increases exponentially between ages 65 and 85, doubling with every five years of age, and has risen ten-fold since 1900 in association with the increase in life expectancy occurring in the last century. The age-specific prevalence is similar in virtually all nations in which it has been studied, including France, Italy, Great Britain, Japan, China, and the United

States.¹ By the year 2040 the prevalence of dementia in the United States is estimated to rise to over nine million affected individuals.² Costs of care increase with severity of the dementing illness with an annual United States estimate of over 100 billion dollars in 1993 alone, a figure that is expected to double by 2040.²

Site of care during the advanced stages of dementia has not been well studied, in part because of the unreliable nature of death certificate data in identifying dementia as a cause of death.³ In one study in an academic teaching nursing home, 25% of long-term nursing home residents were hospitalized at least once during the second six months of their nursing home stay, a group characterized by a higher risk of severe functional decline, recent deterioration, heart or respiratory failure, feeding tubes, and decubitus ulcers.⁴ Another study of dementia patients with involved family caregivers found that the majority of care in the last six years of life was provided at home, with death occurring at home in 42%, in a nursing home in 32%, and in the hospital for 26%.⁵ For patients without closely involved family caregivers, as well as for those spending their last months to years in a nursing home, the frequency of hospitalization and of death in hospital is presumably higher.

Dementia as a disease in need of palliation

Dementing illness causes a myriad of suffering, for the patients themselves as well as for their family and paid caregivers. In the early stages, awareness of loss of memory and capacity is commonly associated with severe depression, anxiety, and a progressive sense of helplessness, existential dread, and loss of meaning in life. In later stages, dementia patients frequently suffer from agitation, paranoia, hallucinations, fear, and anxiety. The inability to recognize or remember caregivers who are attempting to help with dressing or bathing or feeding is often terrifying and may lead to hostile physical or verbal outbursts. Restlessness and wandering with associated risk of getting lost are common. Standard forms of medical care such as a physical examination, routine wound care, or a blood test may be experienced as incomprehensible and frightening bodily assaults. The inability to articulate or ask for relief from common causes of pain, such as arthritis, headache, or skin breakdown may also be contributors to agitation and restlessness, and are often unrecognized.

Serious and life-threatening medical illnesses common among the elderly population are also major contributors to suffering in the dementia patient. For instance, pneumonia is associated with dyspnea, tachypnea, cough, and pain, causing symptom distress that is typically undetected and untreated in the cognitively impaired. The leading causes of death for persons with end-stage dementing illness are infectious diseases, primarily pneumonia, urosepsis, and infectious complications of pressure ulcers and skin breakdown. Suffering results both from the endogenous effects of the acute illness itself, as well as the distress associated with its treatments (for instance, venipuncture, blood gas determinations, and other needle sticks, restraints, nasogastric tubes, and endotracheal suctioning).^{6,7}

Because of the progressive dependency predictably associated with even the earlier stages of dementing illnesses, the burden on family caregivers is enormous. The vast

majority of the personal care as well as the financial resources needed for paid assistance required by dementia patients, comes not from the health care system but primarily from family members, with an associated toll in terms of fiscal, emotional, physical, and existential and spiritual suffering.^{8,9} The SUPPORT study, focusing on hospitalized adults with a broad range of life-threatening illnesses found that over half of the families suffered one or more serious adverse effects (for instance, loss of most of the family's savings) during the course of the patient's terminal illness.¹⁰ Long-term family caregivers of patients with chronic illnesses such as dementia typically face much longer periods, often a decade or more, of intensive responsibility for the needs of their loved one. Family caregivers perform tasks ranging from negotiating the intricacies of the health care system, to the provision of skilled (injections, tube feedings) and so-called unskilled (bathing, toileting, diaper changing) care to their demented relatives whose needs progressively increase just as their ability to interact or express affection continues to decline.¹¹ The suffering and needs of families of dementia patients is therefore a major focus of palliative care for this population.

Barriers to palliative care in dementia

Despite the inevitably progressive, incurable, and terminal nature of dementing illnesses, programs providing palliative approaches focused on relief of suffering, maximizing comfort and quality of life, and support for family caregivers are remarkably scarce. Even the Medicare Hospice program, whose sole focus is the palliation of terminal illness, serves almost no patients with a primary diagnosis of dementia. In a national survey of over 1000 United States hospices in 1995, fewer than 1% of hospice patients had a primary diagnosis of dementia and only 7% had dementia as a secondary diagnosis with another terminal illness.¹² Reasons reported by these hospices to account for low enrollment of dementia patients include the difficulty of accurately prognosticating survival time and the high (and costly) respite needs of dementia family caregivers.¹² The basis for these concerns lies in the Medicare hospice reimbursement system, originally developed to be responsive to the short-term and more predictable needs of cancer patients and their family caregivers: United States' hospices are reimbursed under a capitated per-diem rate, and are subject to retroactive denials of payment for patients who survive longer than the six month prognosis eligibility criterion required for admission to hospice. Thus, patients who live longer than six months, as well as those with costly custodial care and respite service needs, pose unacceptable financial risks to most hospice programs in the United States. Other studies have reported that hospice staff are unaccustomed to and uncomfortable with patients who cannot express their own wishes and with whom they cannot establish any kind of a relationship.¹³ Furthermore, the long-term and experienced family care giver is sometimes perceived by hospice staff as overly controlling of the patient's care and not as accepting of the skilled services and advice provided by hospice professionals, in contrast to patients and families with shorter illness experience and more traditional hospice diagnoses, such as cancer.

In part because of the variable survival time of patients with advanced dementia, uncertainty about the proper goals of medical care is common: is the purpose of health care to maximize length of life or is the primary focus the promotion of best possible quality of life? Family and professional caregivers vary in their endorsement of palliation and comfort measures as the primary goal of medical care for persons with advanced dementia. In a study of active family caregivers and MD and non-MD members of the Gerontological Society of America, a majority of all groups chose palliation as the most appropriate level of care for end-stage dementia patients.¹⁴ Such a choice was associated with increasing age of the respondent and prior experience with a terminal care situation. In contrast, another study of family members (mostly adult daughters) of severely demented nursing home residents found that a majority favored hospitalization and intensive care under hypothetical scenarios of pneumonia and worsening sepsis, although most rejected tube feeding and cardiopulmonary resuscitation under the same circumstances.¹⁵ Ambiguity about the goals of medical care typically surfaces when decisions about treatment of acute or intercurrent illnesses, such as infections, arise: should the pneumonia patient be treated with antibiotics, transferred to the hospital, or intubated, or should they be treated symptomatically with analgesics, antipyretics and oxygen? Should a dementia patient who is refusing food or having difficulty swallowing be nourished via a feeding tube? The answers to these questions depend critically upon the goals of care and since each of these medical interventions may prolong life, a family member's decision to forego any one of them becomes an active decision to let the patient die of their underlying disease. Particularly when the patient has not previously articulated his wishes for care under such circumstances (through the process of advance care planning), family decision-makers typically find such decisions wrenching, and often feel as if they are holding the power of life and death for their loved one in their own hands, a responsibility they are neither prepared for nor anxious to assume. Even the process of balancing the burden of suffering against the value of continued life is difficult for surrogate decision-makers since dementia patients can neither express their preferences nor describe what they are feeling to their professional and family caregivers. In the absence of reliable evidence of the patient's wishes and degree of physical suffering necessary to assess what would constitute the patient's best interests, the family decision-maker must base their decision on what seems to manifest the proper expression of a loving fiduciary role, that is, 'what would a good wife do for her husband under these circumstances?' rather than 'would my husband want this quality of life if he were able to communicate?' or 'is my husband suffering as a result of his disease and its' treatment?'.¹⁶

More accurate prognostication of survival time in advanced dementia would help both professional and family decision-makers to negotiate these choices. If it were possible to predict with reliability which dementia patients were likely to die within a six-month period regardless of medical treatment, the focus on palliation as the most appropriate goal of medical care would be clearer. Several investigators have attempted to define measurable clinical characteristics that place persons with advanced dementia at predictably high risk of death. Though Volicer and colleagues found that following a fever episode older age, more advanced dementia, a palliative

care plan, and recent (within six months) nursing home admission were predictive of six month mortality, a substantial fraction of patients meeting these criteria survived for longer periods.¹⁷ Another study of mildly demented subjects followed over seven years found that male sex, shorter duration of illness, presence of extrapyramidal signs, and a lower mental status score were associated with a higher risk of mortality, but again the time ranges were broad and the individual variability high, limiting the utility of such algorithms for individual decisions about use of life-sustaining treatments.¹⁸ Multiple descriptive studies of mortality rates after percutaneous endoscopic gastrostomy tube placement in cognitively impaired individuals found a median of survival of only six to seven months.¹⁹⁻²¹ Although these high mortality rates suggest that need for a feeding tube is a marker of serious underlying illness, precise estimates of survival time for individual patients are impossible. Thus, to a degree typical of other chronic illnesses such as heart or respiratory failure, substantial prognostic uncertainty is probably an irreducible feature of Alzheimer's dementia.²² This suggests that other bases for decision-making, involving knowledge of patient's prior wishes and values, surrogate assessments of patient quality of life, and forging a consensus based on shared narratives about the patient as a person will continue to be key variables in the process of determining the goals of medical care for persons suffering from advanced stages of dementing illness.^{23,24}

Research in hospitalized dementia patients

In a series of studies aimed at characterizing the care of persons hospitalized with advanced dementia, Mount Sinai researchers have evaluated the capability of surrogates of patients with advanced dementia to participate in medical decision-making on their behalf; the burden of suffering associated with common hospital procedures and experiences for acutely ill adult in-patients; and the impact of hospital-based palliative care consultation on the care received by older persons with acute medical illness superimposed on advanced dementia.

*Barriers to obtaining consent in dementia research: implications for surrogate decision-making.*²⁵

As part of a randomized controlled clinical trial of palliative care consultation in acutely ill hospitalized persons with advanced dementia, nearly 50% (68/145) of otherwise eligible subjects could not be randomized because they either had no functional surrogate to make decisions on their behalf, or their surrogate was incapable of participating in the decision-making process. The absence of a functional surrogate appears to be more common among hospitalized dementia patients than among similar patients in long-term care or home settings, and may explain in part how the patient came to be transferred to a hospital (that is, there was no functional surrogate to make the decision to keep the patient at home or in the nursing home in the context of an acute illness). The prevalence of dementia patients without functional surrogates is unknown, although several other studies also suggest that the problem is not rare, and is likely to increase with the growth in the population at risk.²⁶⁻²⁸ These

data suggest that mechanisms of decision-making for advanced dementia patients will require attention to those without functional surrogates, and studies of how best to protect the interests of this uniquely vulnerable population of patients are badly needed.²⁹

*Suffering associated with routine hospital procedures and experiences*³⁰

Hospitalized patients are routinely subjected to multiple needle sticks, difficult invasive procedures, and so-called 'transfer trauma' associated with change in physical environment and caregivers. Dread of hospitalization is common among older or seriously ill patient populations familiar with what the experience is like. For cognitively impaired populations who can neither consent to nor understand the reasons for such experiences, iatrogenic suffering associated with hospitalization is likely to be at least as great as it is for the cognitively intact patient. If family members and other surrogates are to balance the potential benefits of hospitalization in terms of longer life and relief of acute illness against the burden of suffering imposed by hospitalization, some quantitative measure of these burdens would be helpful. To this end, Mount Sinai researchers interviewed 130 cognitively intact hospitalized patients for their ranking of the pain and discomfort associated with sixteen common procedures (for instance, arterial blood gas determination) and experiences (for instance, waiting for a procedure in radiology).³⁰ Subjects rated arterial blood gas determinations, nasogastric tube placement, central line placement, peripheral intravenous catheter insertion, and mechanical ventilation as the top five most painful procedures (in descending order). The five procedures associated with highest discomfort were nasogastric tube placement, mechanical ventilation, mechanical restraints, central line placement, and indwelling urethral catheters. The study showed that a five-point numeric rating scale was able to produce valid and reliable rankings of pain and discomfort. Subjects were able to accurately discriminate pain from discomfort, and although these measures were correlated, they differed across the procedures studied. These data should be used to help identify and reduce the iatrogenic suffering associated with hospitalization for acute illness, and, in patients unable to speak for themselves, can serve as surrogate measures of the pain and discomfort dementia patients may experience in the hospital.

*A randomized controlled clinical trial of palliative care consultation for hospitalized patients with advanced dementia*³⁵

Although exact numbers are not available, substantial numbers of advanced dementia patients spend time in acute care hospitals when they are nearing death. In a multi-institutional study, 30.6% of nursing home patients with pneumonia were transferred to hospitals, comparable to figures reported in several other studies (see cites below).³¹ One study of 3782 long-term care residents found that 25% were hospitalized at least once, with higher risk associated with heart or respiratory failure, recent functional decline, decubitus ulcer, and presence of a feeding tube.³² Another study of 312 long-term care patients who developed pneumonia found lower two-month mortality overall in the 79% of patients treated in the nursing home as com-

pared to the 21% transferred to hospital.³³ However, patients with only moderate dependency at baseline (that is, the least functionally impaired) and evidence of less severe pneumonia (normal respiratory rate) had the greatest risk of functional decline or death after hospitalization for pneumonia. Finally, in a Veterans Affairs long-term care setting, a study of 108 consecutive pneumonia patients found a 19% two week, 59% one year, and 75% two year mortality rate, with risk of death highest in the most functionally impaired.³⁴ In this study 29% of patients were transferred to an acute care hospital, a factor which had no influence on mortality.

Because of the frequency of and distress associated with hospitalization in persons with advanced dementia, a study of the impact of palliative care consultation focused on comfort-oriented goals of care was undertaken in a sample of acutely ill hospitalized dementia patients. Mount Sinai investigators conducted a prospective randomized controlled trial of palliative care consultation (intended to enhance comfort and reduce distressing interventions) versus usual care in 100 consecutive severely demented patients studied over a three-year period in a large New York City teaching hospital.³⁵ The intervention and control group were comparable on major baseline characteristics, including age, sex, dementia stage, ethnicity, existence of advance directives, site of residence, diagnosis at admission, and presence of a feeding tube at time of admission. There were no differences in number of re-hospitalizations, mean length of stay post-randomization, or mortality. Few patients in either group received invasive or complex diagnostic tests but overall 40% received daily phlebotomy, 74% intravenous therapy, 75% systemic antibiotics, 44% new feeding tubes, and 69% of the subjects received long-term enteral feeding. There were no differences between intervention and control groups with respect to any of these outcomes. Intervention patients were more likely than control patients to be discharged with an explicit palliative care plan but otherwise there were no other outcome differences between control and intervention groups. Mortality rates were high and were similar in both intervention and control groups. Median survival was 175 days (50% of the subjects were dead within six months of study entry).

The palliative care consultation failed to effect the care of hospitalized patients with advanced dementia. Patients hospitalized with end-stage dementia have a high mortality rate equivalent to that seen in metastatic solid tumor malignancies and end-stage congestive heart failure. Awareness of the terminal nature of the illness should guide establishment of appropriate goals of care for this population including measures directed at maximizing comfort and avoidance of unduly burdensome medical interventions.³⁵ For unclear reasons, the palliative care consultation had minimal impact upon the care received by the intervention patients, an observation with important implications for research priorities on palliative care in end-stage dementia. Reasons advanced by the investigators to account for the absence of effect of the intervention included:

1. Low numbers of subjects (as noted above, nearly half of eligible patients could not be entered in the study because they had no functional surrogate) may have resulted in a type 2 error.

2. The consultative and investigational nature of the intervention (that is, the primary doctor did not request the consult but instead agreed to have his or her patient entered into the study) may have been too weak to influence care decisions made by primary doctors and family decision-makers.
3. It is likely that selection bias plays an important role in that patients with advanced dementia who are hospitalized in the context of acute illness are probably predisposed to receive invasive acute care as opposed to comfort oriented measures that might have resulted in a decision not to transfer to hospital in the first place. This possibility gains support from the observation that surrogates of study subjects were often difficult to reach, rarely visited the hospital, and had variable levels of engagement with the day-to-day decision-making about their relative's care.
4. Most of the dementia patients were strangers to the attending physician responsible for their hospital care- this lack of primary care continuity may have encouraged the use of life-prolonging technologies since the responsible physician typically had no insight into the patient's values or prior stated preferences.
5. New York State requires a high evidentiary standard of clear and convincing evidence of a patient's wishes before a surrogate is empowered to decide to forego life-sustaining treatments. This legal context inhibits decisions to choose palliative care plans in the absence of formal advance directives (present in only 15 % of these subjects).
6. Finally, the primary physicians and family decision-makers may not have considered advanced dementia to be a terminal illness and may have assumed that comfort as the primary goal of medical care only becomes appropriate in the last weeks or months of life. In fact the variability in survival time even in the most severe dementing illnesses and the associated uncertainty about prognosis inhibits the application of palliative care plans as long as prolonging life remains the highest priority goal of medical care.

Important research questions

Clinical research in palliative care is difficult in virtually all patient and family groups because of the intensity of illness and the difficulties inherent in asking such vulnerable populations to give time and energy to the aims of clinical research. These challenges are magnified many times in the late stages of dementia, a group of patients who can neither understand nor consent to participation in research, and who cannot report or express their symptoms and other sources of distress. Reliance on surrogates for consent to participate depends both upon the availability of surrogates and upon their capacity to understand and give informed consent on behalf of their loved-one, both major barriers to the conduct of the study described above. Similarly the reliability of surrogate reports of patient symptoms is poor and surrogate responses have repeatedly been shown to demonstrate poor agreement with the reports of cognitively intact patients.³⁷ In view of these observations research is needed on means of enhancing patient participation in establishing their wishes about

the goals of medical care in early stages of illness, both by assessing capacity of early dementia patients to participate in such a decision-making process, and then by assessing the impact of such decisions on the care ultimately received. Thus the main research priorities in palliation of late stage dementing illness are:

1. Studies of the capacity of early stage dementia patients to articulate their wishes and goals for their future medical care.
2. Longitudinal studies of the long-term impact of such a decision-making process on actual care received years later.
3. Given that much, but not all, data suggests that advance care planning has minimal impact on ultimate care decisions, studies of the reasons for this failure and efforts to address them are also needed.³⁸⁻⁴⁰
4. Studies are needed to evaluate sources of suffering in dementia, their frequency and intensity, and how these vary by ethnicity, care setting, and dementia stage. Application of surrogate measures such as quantification of distress due to procedures and diseases in the cognitively intact can be used to estimate burden of suffering in dementia patients. Further study of observational measures of distress intensity in different settings and clinical circumstances is also needed.
5. Larger studies of palliative approaches to care of end-stage dementia are urgently needed. Though randomization is difficult because surrogates may have strong preferences for types of care, it should be attempted to diminish the chance that outcomes attributed to the palliative care intervention are in fact due to other variables. These studies of new models of care for advanced dementia must be conducted in diverse clinical settings, but especially in acute care hospitals, and in the nursing homes and home care settings where most dementia patients reside.
6. Randomized trials of care of acute illness superimposed on chronic dementia in different settings are needed to identify optimal approaches, both in terms of burden of illness, burden of diagnostic and treatment interventions, family and professional caregiver satisfaction, mortality, and costs.
7. Finally, studies of new models of care focusing on real support for family caregivers at home (personal care aides, housekeeping support, support groups, respite care), long-term care settings characterized by home-like as opposed to institutional settings with training support for the difficult work of aides and other paid caregivers, and models aimed at safety, reassurance, and patient centered activities (as opposed to the traditional institutional medical model) are also necessary.⁴¹⁻⁴³

The major methodological challenge in research on palliation in late stage dementing illness is the lack of direct evidence (by patient report) of what the patient is feeling. This lack of reliable patient-centered measures of suffering drives the use of surrogate measures based either upon the observations of others (family or other caregiving staff) or upon extrapolation from the reports of cognitively intact persons with similar clinical experiences. In a related manner, surrogate consent for participation in research, or even for the process of basic medical decision-making depends critically upon the ability of the surrogate to engage with and understand the issues as well as their willingness to take responsibility for decisions on their relatives behalf.

A substantial minority of persons suffering from advanced dementia has no functional surrogate, a major barrier both to research and to rational clinical decision-making.

The prognostic uncertainty inherent in chronic degenerative disorders such as dementia poses challenges to consensus on the goals of medical care, which also inhibit conduct of research and development of new models of palliation for dementia. While most, but not all, family members and health professionals endorse comfort care as the primary goal of medical care in end-stage dementia, these theoretical beliefs are severely challenged when immediate decisions about life-sustaining treatments are faced in the context of sudden or acute medical deterioration. Lack of valid predictors of mortality for individual patients will require that professionals and the public develop a moral and relational framework that will allow a shift in the priorities of medical care away from the current predominant focus on maximal possible life-prolongation, to an alternative focus on compassionate care and a maximal sense of security and comfort, given the progressive and hopeless nature of the disease. In combination with serious efforts to determine patient's wishes for care in earlier stages of disease, such public and professional education will improve awareness of the progressive and irreversible nature of dementia, creating expectation and demand for the excellent compassionate care that should become the standard for advanced disease.

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