alzheimer's association

**End–of–life Care for People with Dementia in
Residential Care Settings**

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EXECUTIVE SUMMARY

The Alzheimer's Association commissioned this literature review on end-of-life-care for nursing home residents with advanced dementia as part of its ongoing Campaign for Quality Residential Care. Our concern is driven by evidence that indicates the following:

- 67% of dementia-related deaths occur in nursing homes.
- 71% of residents with advanced dementia died within 6 months of admission, yet only 11% were referred to hospice.
- Non-palliative care is quite common in residents with dementia. This includes tube feeding, laboratory tests, restraints, and intravenous therapy.

Our intent is to provide the evidence base for practice and policy recommendations to improve that care, as well as to stimulate additional research on the topic.

Methods – The author initially reviewed 300 articles in the literature from 1994 to 2004, and then narrowed his discussion to 158 studies that contain new information obtained by experimental or quasi-experimental methods. Many studies were observational. The review identified relatively few evaluations of new interventions or randomized clinical trials. There was almost no research on management of advanced dementia in assisted living facilities.

Results – End-of-life care for residents with advanced dementia involves a number of key issues: appropriate management of symptoms including pain and behaviors, involvement in programs such as hospice, and decisions about medical interventions. The body of evidence presented indicates the following:

1. Aggressive medical treatment for residents with advanced dementia is often inappropriate for medical reasons, has a low rate of success, and can have negative outcomes that hasten functional decline and death.

- Cardiopulmonary resuscitation (CPR) is three times less likely to be successful in a person with dementia than in one who is cognitively intact. Those who initially survive are taken to an intensive care unit where most die within 24 hours.

- Individuals with advanced dementia are more often hospitalized than those who are cognitively intact or have milder dementia. Transfer from nursing home to

hospital results in functional decline that does not improve significantly at discharge. Patients often develop confusion, anorexia, incontinence and falls. These symptoms are often managed by aggressive medical interventions.

- The most common cause of hospitalization is infection, most often pneumonia, even though hospitalization is not necessary for optimal treatment. Immediate survival and mortality rates are similar whether treatment is provided in a long term care facility or a hospital: long-term outcomes are better in residents treated in a nursing home.

- Intercurrent infections are a common and almost inevitable consequence of advanced dementia for several reasons: reduced immune response, incontinence, swallowing difficulties, immobility, and inability to report symptoms. Antibiotic therapy does not seem to prolong survival and is not necessary for symptom control. When antibiotics are used, they may cause significant adverse effects, and the diagnostic procedures associated with use of antibiotics add to the resident's confusion and discomfort.

- Tube feeding in residents with advanced dementia does not increase survival. It does not prevent aspiration pneumonia, malnutrition or pressure ulcers. It does not reduce the risk of infections or improve functional status or comfort of the patient.

2. **Quality palliative care is an effective alternative to aggressive treatment and is closely related to staffing and training in nursing homes.**

- Nursing homes with dementia special care units, greater physician-to-patient ratios, and physician extenders, and those that provide intravenous therapy and nurse aide training programs are far less likely to hospitalize their residents.

- Simple strategies involving hands-on care by well-trained staff – such as massage, oral hygiene, changes in diet, and hand-feeding -- can prevent infection and manage feeding problems without resort to tube-feeding.

- Model programs that provide on-site treatment of medical complications show fewer preventable hospitalizations and lower hazard rates of mortality.

- A palliative care unit for hospitalized residents with advanced dementia decreased hospital and intensive care unit length of stay and use of other non–beneficial resources.

- Hospice is a valuable service for persons with advanced dementia, particularly in management of pain, continuous involvement of the primary physician, and avoidance of hospitalization. Social support provided to caregivers is also important given their high levels of depressive symptoms and anxiety.

- Guidelines for palliative care in dementia are available for clinicians and family members and, when applied, have been shown to improve end-of-life care.

3. While there is an expanding body of knowledge about the risk and benefits of treatments for persons with advanced dementia, there are significant barriers to translating that knowledge to practice.

- Physicians overestimate prognosis in persons with advanced dementia and have unrealistic expectations about the effectiveness of feeding tubes. A minority discusses end-of-life care with families and even fewer provide any advance care planning. When end-of-life care is discussed, it does not often include issues about treatment of infection and tube-feeding.

- Caregivers of persons with dementia generally select more life-sustaining interventions than healthy older adults say they want. Family members are not well prepared for their role as surrogate decision-makers, have limited understanding of dementia progression, and are uncomfortable and ambivalent in their role. They do not receive sufficient support from health care professionals, although this is improved if the patient is receiving hospice.

- Medicaid reimbursement has a direct impact on end-of-life care. In 26 states, Medicaid pays nursing homes a higher rate for residents who are tube-fed, even though the cost of care for a resident without a feeding tube is higher.

- State Medicaid reimbursement also influences hospitalization rates. A 10 state study found that an increase in the rate of reimbursement to nursing homes of $10 would significantly reduce the risk of hospitalization and the odds of mortality.

- Current Medicare guidelines discourage optimal end-of-life care for people with advanced dementia. The guidelines are difficult to apply and have been shown to be invalid predictors of survival.

Recommendations

The Alzheimer's Association commissioned this study to encourage improved practice and policy affecting end-of-life care for persons with advanced dementia, and to stimulate additional research on the topic. The author begins that process with his own recommendations:

- His practice recommendations include limits on cardiopulmonary resuscitation, increased use of physician extenders in nursing homes, maintenance of oral health, avoidance of antibiotic use, and increased physician involvement in discussions related to end-of-life-care, particularly at the time of nursing home admission.

- His policy recommendations include elimination of fiscal incentives in Medicaid and Medicare for hospitalization and tube-feeding of nursing home residents, Medicare payment for palliative care for residents with dementia, and national criteria for designation of a surrogate decision-maker.

- He sets forth recommendations for research in a number of important areas.

- He calls for a broad discussion of optimal end-of-life care to correct common misconceptions about the effectiveness of aggressive medical interventions, and education for family and professional caregivers about the natural course of Alzheimer's disease and dying, symptoms of terminal dementia, and principles of appropriate end-of-life care.

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Introduction

End-of-life care for people with dementia in the United States is undergoing rapid change. There is a shift from dying in a hospital to dying in a nursing home or assisted living and the number of individuals dying at home is also increasing. A recent national study found that 67% of dementia-related deaths occurred in nursing homes. The proportion of dementia-related deaths occurring in hospitals varied from state to state from 5% to 37% and was higher in states with a greater number of hospital beds and fewer nursing home beds (1). These results indicate that non-medical factors are affecting the place of death. Hospices are increasingly involved in end-of-life care in nursing homes and are more willing to include individuals dying from other conditions than cancer although only 11% of residents with advanced dementia are referred to hospice (2). There is also some evidence that residents with dementia receive less aggressive medical care than cognitively intact residents. A study of residents in fifty-nine randomly selected nursing homes in Maryland from1992 to 1995 showed that residents with dementia had lower annual rates of physician visits and hospitalizations, and fewer physician visits subsequent to fevers and infections than cognitively-intact residents (3).

However, advanced dementia is often not perceived as a terminal illness and the prognosis is vastly overestimated. At nursing home admission, only 1% of residents with advanced dementia were perceived to have a life expectancy of less than 6 months while 71% died during that period (4). Therefore, it is often not recognized that a palliative approach is the optimal care for these residents and non-palliative interventions are quite common: tube feeding in 25%, laboratory tests in 49%, restraints in 11%, and intravenous therapy in 10% of the residents with advanced dementia. In part, because the palliative approach is not generally used, residents with dementia suffer from several distressing conditions, such as pressure ulcers (15%), constipation (13%), pain (12%) and shortness of breath (8%) (4). Of course, poor care is not limited to residents with dementia; another study found that in two nursing facilities 82% of the nursing home residents died with pressure ulcers (5).

This information indicates that there is a need for improvement of end-of-life care for residents with dementia. Quality indicators for management of medical conditions in nursing home residents were recently proposed but many of them would not apply to residents with advanced dementia (6;7). There is a need for research specifically targeted to residents with advanced dementia that would evaluate improvements in their care and palliative programs such as Palliative Excellence in Alzheimer Care Efforts (PEACE) (8). This literature review summarizes current research evidence relevant to end-of-life care

for residents with advanced dementia with the hope that it will be used as a basis for practice and policy recommendations and will stimulate further research in this area.

Methods

Potentially useful articles in literature from 1994 to 2004 were collected from a Medline search and additional sources. The Medline search used a combination of terms such as dementia, Alzheimer's disease, end-of-life care, hospice, and cardiopulmonary resuscitation/CPR. This search yielded 150 citations. Additional citations were identified by searches of identified articles' reference sections, searches of reference sections of practice guidelines ("Care at the End of Life" published by the American Medical Director's Association, "Guidelines for a Palliative Approach in Residential Care" published by the Edith Cowan University, Australia), search of "Hospice and Palliative Care in Alzheimer's Disease" resource list prepared by the Alzheimer's Association Green-Field Library, and by search of the author's private data base. These searches resulted in the collection of 300 articles. Some of these articles report studies in general nursing home populations, which include but are not limited to residents with dementia. However, since more than half of nursing home population has some cognitive impairment, these articles are relevant to the current topic.

All of these articles were reviewed for relevance to the current topic and for inclusion of research data. Articles were included for discussion in this review only if they contained new information obtained by experimental or quasi-experimental methods. Most relevant review articles were included if they contained information about research results obtained before 1994 that is still the state of the art. This selection process resulted in the inclusion of 158 studies and review articles. Most of these studies are observational studies and only a few include evaluations of new interventions. Almost none of the studies are randomized control trials. There is almost a complete lack of research results concerning management of advanced dementia in assisted living facilities. The only available study indicates that end-of-life care is similar in process and outcomes in residential care facilities, assisted living, and nursing homes except that family satisfaction with end-of-life care was significantly higher in residential facilities and assisted living than in nursing homes (8a). Therefore, most of the information in this review will apply to both assisted living and nursing homes.

Results

There are several issues that need to be addressed when providing care for residents with advanced dementia. These issues include appropriate management of symptoms such as pain and behaviors, involvement in programs such as hospice, and decisions regarding various medical interventions. A crucial component of this care is providing information about the benefits and burdens of these interventions to the resident's surrogate decision maker, supporting development of a care plan that takes into consideration previous wishes of the resident, if any, and his or her best interest as interpreted by the decision maker. The care plan should consider the goals of care and priority order of the three possible goals – survival, maintenance of function, and comfort (9). This section will

summarize the current research information concerning each of the issues that need to be addressed.

Cardiopulmonary resuscitation

Information from older literature regarding cardiopulmonary resuscitation (CPR) in nursing homes was summarized by Zweig (10). He reported that the survival to discharge from an acute care hospital after cardiac arrest in a nursing home ranged from 0 to 5% and was even lower when the arrest was unwitnessed. In a sample of 114 nursing home residents, 10% of residents were discharged from hospitals alive but no one with an unwitnessed cardiac arrest was successfully resuscitated (11). However, the sample excluded residents who died prior to the arrival of an EMS team resulting in an inflated survival rate. Even in a community sample, the survival rate after an unwitnessed arrest is much lower (0.8%) than after a witnessed arrest (5.3%) (12).

The impact of dementia on survival after cardiac arrest was investigated by Dull et al (13). These authors considered CPR in the presence of dementia "unwanted" because of poor survival rates. In their overall sample of out-of-hospital arrests, Alzheimer's disease or dementia was present in 5% of the patients and 13% of these individuals were discharged alive from the hospital. However, in the total nursing home population, only 3% of the residents survived to hospital discharge and only one of these survivors had an unspecified chronic disease. In other studies, the discharge rate of nursing home residents from the hospital after cardiac arrest ranged from 0 (14) to 3.4% (15).

Even in a hospital, CPR is three times less likely to be successful in patients with dementia than in patients who are cognitively intact, and the success rate is almost as low as in metastatic cancer (16). Age is another factor that decreases the success rate of CPR. A prospective cohort study was conducted from July 1989 to December 1993, in a suburban county emergency medical services system of community-dwelling adults who had an arrest from a presumed cardiac cause and who received out-of-hospital resuscitative efforts. The success rate decreased from 10% in 40-59 years old, to 8.1% in 60-69 years old, 7.1% in 70-79 years old, 3.9% in 80-89 years old and 1% in 90 and older (17). Survival is somewhat better when individuals experience cardiac arrest in the community (14) but a recent study reported that out of 235 cardiac arrests in shopping malls and apartment complexes, there were only 2 survivors in residential complexes despite the use of automatic external defibrilators (AED). Use of AED increased overall survival after out-of-hospital cardiac arrest from 28 to 40% (18) but the impact of AED use on CPR success in nursing homes is not known.

The benefits of successful resuscitation are further diminished by other factors. CPR is a stressful experience for those who survive, often associated with injuries such as broken ribs and necessitating mechanical respiration. Those who initially survive CPR are taken to an intensive care unit, where most die within 24 hours (10). The intensive care unit environment produces additional confusion and almost invariably, delirium. In samples from other populations, approximately one third of those who survive hospitalization will suffer increased dependence and some will have severe mental impairment (10). Furthermore, the CPR experience is often sufficiently traumatic for the

patient's families that they will request a Do Not Resuscitate (DNR) order to prevent repetition of CPR. Other residents of long-term care facilities who witness the CPR procedure are frequently upset as well.

Considering the balance of benefits and burdens, it has been suggested that CPR in a nursing home setting should be an optional procedure that should be specifically requested instead of depending on the presence of DNR orders (10). This would be a difference from the current status where CPR is considered a default option. However, even currently the CPR is used relatively rarely in residents dying in a nursing home, ranging from 2 to 5.6% of deaths (10). A survey of 36 nursing homes showed that less than 30% of them performed CPR in the past 6 months, and 23% had no written DNR policies. The majority of facilities (79%) required CPR in witnessed arrests of non–DNR residents while a minority (24%) required CPR even in unwitnessed arrests (19).

<u>Transfer to an Acute Care Setting</u>

Older literature reporting data regarding transfer of residents with dementia to an acute care setting was recently summarized (20). There is good evidence that transfer from nursing home to a hospital results in decline of psychophysiologic functioning including mobility, tranfer, toileting, feeding and grooming, and none of these functions improve significantly at discharge. Risk factors for this functional decline are cognitive impairment, previous functional impairment, low social activity level, and decubitus ulcers. Patients often develop confusion, anorexia, incontinence, and falls. These symptoms are often managed by aggressive medical interventions even in patients with advanced dementia (21).

Transfer from a long-term care facility to an acute care setting is most often due to an infection or breathing difficulties (22). Individuals with more advanced dementia (Clinical Dementia Rating scale +3) (22a) were more often hospitalized than cognitively intact individuals or individuals with milder dementia (23). The most common cause of hospitalization was an infection, while psychiatric symptoms did not differ between individuals who were hospitalized and those who were not hospitalized. Pneumonia is the most common cause of infection among residents of long-term care facilities with median reported incidence of 1 per 1,000 patient-days (24). Risk of pneumonia is increased in residents who are confined to bed, have a debilitating neurologic disease, and who are fed by a tube (20). Other risk factors include older age, male sex, swallowing difficulties and inability to take oral medications (25). Very often, the pneumonia recurs and patients discharged from a hospital after pneumonia have a 5 times higher risk for recurrence of pneumonia than patient admitted for other conditions (20). Actually, 43% of nursing home residents who survive an episode of pneumonia develop another episode within 12 months (24).

The mortality rate from pneumonia is increased by altered mental status (26) and cognitive impairment increases the risk of mortality almost 7 times (27). Pneumonia mortality is also increased by functional impairment even in individuals living in the community (28) and that probably would be true for residents of assisted living facilities. Mortality rates of least impaired nursing home residents at 12 and 24 months were 33%

and 48%, while mortality rates of most impaired residents were 65% and 77% (24). The mortality rate of hospitalized patients with end-stage dementia is significantly higher than mortality rates of cognitively intact individuals hospitalized for the same condition. Six-month mortalities for pneumonia are 53% in patients with dementia and 13% in cognitively intact patients and mortality rates for hip fracture are 55% in patients with dementia and 12% in cognitively intact patients (24a).

Transfer of residents to an acute care setting may not be optimal for management of infections and other conditions. A study found that 36% of emergency room transfers and 40% of hospital admissions were inappropriate for medical reasons and the inappropriate number increased to 44% of emergency room transfers and 45% of hospital admissions when advance directives were considered (29). The rate of hospitalization varies widely among long-term care facilities (30) and, if all hospitalizations are considered, cannot be predicted by any particular patient characteristics (31). Risk factors for hospitalization 6 months or later after admission are severe functional impairment, decubitus ulcers, feeding tubes, and primary diagnosis of congestive heart failure or respiratory disease (32).

Non-medical factors influence hospitalization rates. Nursing homes with special care units, greater physician-to-patient ratios and physician extenders are less likely to hospitalize their residents (33). These influences differ according to the nature of hospitalizations. Facilities with physician extenders were less likely to hospitalize for conditions that can be influenced by ambulatory care but not for other conditions, while facilities with more physicians were more likely to hospitalize for only conditions that can be influenced by ambulatory care. Facilities that provided intravenous therapy and operated nurses' aide training programs were less likely to hospitalize for all conditions (34). Hospitalization rates are also influenced by the level of state Medicaid reimbursement. Analysis of nursing homes in 10 states indicated that an increase in the reimbursement rate of $10 would result in 9% reduction in a resident's risk of hospitalization and also decrease the odds of mortality by 12% (35).

The data support the notion that hospitalization is not necessary for optimal treatment of pneumonia in nursing home residents. Immediate survival and mortality rates are similar whether treatment is provided in a long-term care facility or hospital (36;37) and long-term outcomes are better in residents treated in a nursing home. The six week mortality rate was 18.7% in non-hospitalized residents and 39.5% in hospitalized residents despite no significant differences between the hospitalized and non-hospitalized groups before diagnosis (38). Similarly, 2 months after the onset of pneumonia, a greater proportion of hospitalized residents had declined in their functional status or died. However, this improved outcome was seen only in residents with lower respiratory rate during infection and in those who were independent or mildly dependent at the baseline (39).

There is some evidence that this information is resulting in changes in management of residents who experience an additional (intercurrent) disease. A declining rate of acute care hospitalization for long-term care residents with dementia has been reported (40). In addition, acute care hospitals are developing strategies to promote appropriate care for residents who are admitted. A palliative care service that offered early assistance to the

intensive care unit staff about the treatment of patients with terminal dementia decreased hospital and intensive care unit length of stay, the time between identification of the poor prognosis and the establishment of palliative care goals, and the use of non-beneficial resources (41).

Intercurrent Infections

The most common infections in residents with dementia are urinary tract infection (UTI), upper respiratory infection, lower respiratory tract infection, cutaneous infection, gastrointestinal infection and eye infection (42). These infections are almost an inevitable consequence of advanced dementia for several reasons. There is evidence that immune responses are reduced in advanced dementia (43) decreasing the ability to resist development of an infection. Risk of development of urinary tract infections is increased by incontinence especially in women and by urinary retention in men (44). Swallowing difficulties with bronchoaspiration increase the risk of developing respiratory infections (45) and the inability to ambulate independently increases the risk of urinary and respiratory infections, deep vein thrombosis and infected pressure ulcers (46). It is also more difficult to diagnose infections in residents with dementia because of aphasia and because even individuals with mild dementia are less likely to report cough, rash, gastrointestinal symptoms, and joint pain than cognitively intact controls (47). Functional impairment is also an important factor because dependence in feeding and oral care is the most significant factor in predicting development of aspiration pneumonia in institutionalized elderly (48).

Some strategies are available for decreasing risk of development of intercurrent infections. Avoidance of internal urinary catheters is an important prevention strategy for UTIs because the bladder is colonized with bacteria soon after indwelling catheter insertion. Antimicrobial prophylaxis is effective in decreasing the recurrence of UTIs but is potentially toxic and leads to the development of antibiotic-resistant bacteria. Administration of estrogen for atrophic vaginitis decreases the frequency of symptomatic cystitis in elderly women prone to this recurrent disease (46). Estrogen deficiency causes lack of lactobacilli in vaginal flora but oral intake of yogurt was not found to increase vaginal colonization by lactobacilli (49). Administration of cranberry juice decreased the number of symptomatic UTIs in women but it is not clear what is the optimum dosage or method of administration (50). In contrast, attempts to acidify urine by administration of ascorbic acid did not change the urinary pH and did not decrease UTIs in patients with spinal cord injury (51).

Residual urine in the bladder after voiding, caused by bladder outlet obstruction, an underactive detrusor or detrusor hyperactivity with impaired contractility, promotes bacteriuria. The residual volume may be reduced by massaging the abdomen (Crede maneuver) and by straight catheterization on a regular basis. Discontinuation of anticholinergic medications that inhibit bladder contraction can decrease bladder volume. Administration of doxazosin or finasteride may improve bladder emptying in patients with outlet obstruction. In residents who are still surgical candidates, prostatectomy may resolve obstruction resulting in decreased residual volume (46).

Incidence of upper respiratory infections and pneumonia may be reduced by vaccinations. Evidence for effectiveness of pneumococcal vaccination is highly controversial (45) but a study in an institutionalized population showed that vaccinated residents had significantly lower risk of pneumonia, risk of death due to pneumonia, and risk of all deaths (52). This finding is important because pneumococcal disease is 4.4 times more common in residents of long-term care facilities than in community-living older adults and pneumococcal strains from long-term care residents were more likely to be resistant to antibiotics and strains from community-living adults (53). The current recommendation is to vaccinate with pneumococcal vaccine all individuals over the age of 65 and repeat the vaccine every $5 - 10$ years (45). Influenza vaccine is effective in community-living (54) and institutionalized elderly (55), even though it does not provide complete protection against influenza epidemics (56). It is recommended that influenza vaccination should be given annually not only to the residents but also to the staff.

Swallowing difficulty with resulting aspiration is a major risk for development of aspiration pneumonia. Aspiration of nasopharyngeal secretions occur during sleep in half of healthy adults but low burden of virulent bacteria in normal saliva together with normal cough reflex and ciliary transport, and normal immune mechanisms protect the airways from repeated infections (45). Silent aspiration is present in a large percentage of individuals who develop pneumonia in the community (57). With development of swallowing difficulties during progression of dementia, aspiration extends to food and liquids and results in choking during food intake. Choking during eating usually starts with thin liquids because swallowing of thin liquids requires the best coordination of muscles involved in swallowing. Choking sometimes can be prevented by switching from thin liquids to thick liquids, e.g. from milk to yogurt (58).

Other strategies to prevent aspiration pneumonia include oral hygiene, avoidance of smoking and endotracheal intubation, and potentiation of the cough reflex. Periodontal disease and dental plaques are risk factors for development of pneumonia in a nursing home. In dentate residents, risk factors for development of aspiration pneumonia included requiring help with feeding, chronic obstructive pulmonary disease, diabetes mellitus, number of decayed teeth, number of functional teeth, and presence of specific microbes in the saliva (59). Oral care was shown to decrease incidence of pneumonia, number of febrile days, and death from pneumonia (60). Decreased salivary production increases colonization of oral cavity by pathogens and is often caused by drugs with anticholinergic effects (61).

Cough reflex protects against aspiration and its enhancement decreases the risk of aspiration pneumonia. The cough reflex is enhanced by angiotensin converting enzyme inhibitors because they also inhibit metabolism of substance P, which is an important mediator of cough reflex (62). Another mechanism to increase cough reflex is potentiation of the dopaminergic system by administration of amantadine (63). Both of these strategies significantly decreased incidence of aspiration pneumonia. Tube feeding is not useful for prevention of aspiration pneumonia because it actually increases the rate of pneumonia development and pneumonia death rate in residents who had evidence of aspiration on videofluoroscopy (64). Tube feeding will be further discussed in the next section.

Antibiotic therapy is quite effective in treatment of single episodes of intercurrent infections in residents with dementia. However, its effectiveness is limited by the recurrent nature of infections in advanced dementia. Dementia severity increases the mortality after pneumonia because of aspiration and weight loss (65). Antibiotic therapy does not seem to prolong survival in residents with severe dementia who are unable to communicate and unable to ambulate alone or with assistance (46;66;67). Non-randomized studies also suggest that antibiotic therapy is not necessary for maintenance of symptom control during an infection episode because the observed comfort levels are similar in residents who receive antibiotic therapy and in residents who receive palliative care only (analgesics, antipyretics, oxygen) (46;68). In the Netherlands, antibiotic therapy was withheld in 23% of pneumonia patients with dementia and the patients who did not receive antibiotics had more severe dementia, more severe pneumonia, lower food and fluid intake, and were more often dehydrated (68a).

If antibiotics are administered they should be given orally because this route is as effective as parenteral administration (20) and results in less discomfort. Intravenous therapy is difficult in cognitively impaired residents who do not understand the need for this intervention and often try to remove the intravenous catheters. In patients with poor oral intake, intramuscular administration of cephalosporins offers a reasonable alternative (20). When antibiotics are used, they may cause significant adverse effects, such as diarrhea, gastrointestinal upset, allergic reaction, hyperkalemia and rarely agranulocytosis. Diagnostic procedures, such as blood drawing and sputum suctioning, which are necessary for the rational use of antibiotics, cause confusion and discomfort in a resident who does not understand their need and do not reveal the source of infection in 30% of cases (46).

Nutritional issues

Nutritional issues in progressive degenerative dementias include weight loss, apraxia that makes use of utensils difficult, chewing difficulties and food refusal. In the severe and terminal stages of dementia resident also develop swallowing difficulties and may be unable or unwilling to open their mouths (58). Weight loss may occur before Alzheimer's disease diagnosis (69) and may be caused by forgetting to eat and by olfactory dysfunction. Weight loss may be also caused by intensive pacing that can result in a significant increase of energy expenditure (58). It is always important to determine if the weight loss is not caused by poor feeding practices on the part of the staff. Poor professional supervision and inadequate staffing can result in decreased intake of food and liquids (70). In contrast, frontotemporal dementias are sometimes associated with hyperphagia. Patients often look for food constantly and sometimes try to eat even inedible objects (58). Target weight for residents with advanced dementia should take into consideration their functional impairment. If they are unable to ambulate even with assistance, the residents experience atrophy of their leg muscles from disuse. In that case, their ideal body weight may be much lower than the weight listed in tables that consider only height and frame and this lower weight is not an indication of malnutrition (71).

Apraxia results in inability to use utensils but the residents may be still able to feed themselves finger food. With the progression of dementia, the residents will be ultimately unable to feed themselves or drink without assistance. However, adequate nutrition can be

provided by hand feeding using a modified diet that is adapted to the ability of residents to chew and to their swallowing difficulties (58). Hand feeding can be provided until the beginning of the dying process when all physiological processes shut down. Reports from cognitively intact cancer patients indicate that dying residents do not feel hunger and thirst. Voluntary refusal of food and liquids is often initiated by hospice patients and does not result in discomfort. Hospice nurses reported that such individuals usually die within two weeks and rated their death experience as 8 on the scale from 0 (bad death) to 9 (a very good death) (72).

Unfortunately, quite often hand feeding is replaced by feeding initially through a nasogastric tube or through a percutaneous endoscopic gastrostomy (PEG) tube. The prevalence of feeding tubes in residents with advanced dementia varies from state to state, being lowest in Maine (7.5%) and highest in Mississippi (40.1%) (73). This geographic variation indicates that reasons other than medical need are responsible for large proportion of tube feeding in residents with dementia. Prevalence of feeding tubes also differs according to nursing home characteristics. Greater use of tube feeding in advanced cognitive impairment is associated with having a full-time speech therapist on staff, more licensed nurses and fewer nursing assistants on staff, larger facility size, higher proportion of Medicaid beds, absence of Alzheimer's disease unit, pressure ulcers in 10% or more of residents, and a higher proportion of residents lacking advance directives and with total functional dependency (74). Higher use of feeding tubes also occurs in facilities that are for profit and located in an urban area. Resident characteristics associated with greater likelihood of tube feeding include younger age, nonwhite race, male sex, divorced marital status, lack of advance directives, a recent decline in functional status, and no diagnosis of Alzheimer's disease (75). Residents characteristics associated with tube feeding differ between the U.S. and Canada. The tube-fed residents in the U.S. were more cognitively impaired, were more likely to have cardiopulmonary disease, diagnosis of dementia, female and older than 80 years, while they were less likely to have recurrent lung aspirations, a chewing or swallowing problem, do not resuscitate status, restraint use, weight loss, and stroke (76).

Two excellent reviews, which were published recently, summarize the medical and ethical issues connected with tube feeding in individuals with advanced dementia (77;78). Their findings together with information that was published more recently indicate that, although no randomized control trials investigating the effectiveness of tube feeding were performed, tube feeding does not prevent aspiration pneumonia and might actually increase its incidence, and does not prevent the consequences of malnutrition. Tube feeding also does not increase survival in most studies. Five more recent studies investigating the effect of tube feeding on survival were published. One study compared equally eligible patients where the only difference was that the surrogates either agreed to or refused tube placement. The median survival was 59 days in 23 patients who had PEG placement and 60 days in 18 patients who did not undergo PEG placement (79). Comparison of patients with advanced dementia who were discharged from a hospital with or without a feeding tube also did not show any measurable difference in survival (80). Two studies showed very high mortality after tube insertion. A British study found 54% mortality of patients with dementia at 1 month and 90% at one year (81), while an Israeli study found 39.5% 30-day mortality in patients who had tube inserted after

admission from a nursing home (87% of them underwent PEG insertion because of dementia) (82). There is only one study that suggests that tube feeding may be life prolonging in nursing home residents. This study used Minimum Data Set information for years 1993-1994 from 3 states and examined mortality after total dependency occurred. In this study, the survival at 1 year was 39% without feeding tubes and 50% with feeding tubes but the study did not specifically include residents with advanced dementia (83). The seminal reviews also concluded that tube feeding does not prevent or improve pressure ulcers, does not reduce the risk of infections, and does not improve functional status or comfort of the patient (77;78). No recent study challenged these conclusions.

Considering this evidence it is surprising that the use of feeding tubes is still widespread. Data from North Carolina hospitals indicate that the use of tube feeding in individuals with advanced dementia did not change from 1989 to 2000 (84). The widespread use of tube feeding could be due to two factors. The first one is misinformation about effectiveness of tube feeding among physicians, and the second one relates to economical incentives that promote tube feeding. A survey of random sample of 500 physicians asking about knowledge, beliefs, and self-reported practices of PEG tubes in advanced dementia found that physicians believed that PEG tubes have the following benefits in advanced dementia: reduced aspiration pneumonia (76%), improved pressure ulcer healing (75%), improved survival (61%), improved nutrition (94%) and functional (27%) status. The majority of these physicians underestimated 30-day mortality in patients who receive PEG tube and believed that PEG tube insertion is the standard of care. The majority of physicians also reported that they are influenced by recommendation from other nursing home staff members for tube insertion and almost half of the respondents had a nursing home request for PEG tube placement (85).

The request for PEG tube placement by a nursing home can be understood by comparing the cost and reimbursement of different feeding practices. The daily cost of nursing home care is higher for residents without feeding tubes ($4219) than for residents with tubes ($2379). Despite that, Medicaid reimbursement to nursing homes in at least 26 states is higher for demented residents who are tube-fed than for residents with similar deficits who are not tube-fed. At the same time, tube feeding also increases the costs paid by Medicare because of the expenses involved with the initial tube placement, and hospitalization or emergency room visit for the management of complications of tube-feeding (86).

Providing nutrition by a tube has many adverse consequences, including discomfort from the tube and restraints that are often necessary to prevent tube removal, lack of enjoyment of oral intake of food, lack of contact with care providers during the feeding process, and medical complications of tube placement. Practitioners often do not recognize that it is possible to convert tube feeding into hand feeding, and in some cases, residents may be able to feed themselves again (20). The strategies that can be used to prevent tube feeding in individuals with advanced dementia were described (87) and a recent program was developed to decrease the number of feeding tubes placed in patients with dementia in an acute care hospital. Formation of a palliative care team, which had to be consulted whenever a feeding tube was being considered, and an educational program resulted in a significant decrease in the number of all patients given feeding tubes as well as

in the number of patients with dementia given feeding tubes. However, there were still some patients who were actually given feeding tube despite having an advance directive refusing artificial nutrition (88). This indicates that there is a continuing concern with decisions regarding end-of-life care, which will be addressed in the next section.

<u>Decisions about end–of–life care</u>

Individuals with advanced dementia cannot make decisions about their end-of-life care and, therefore, these decisions have to be made by their surrogates. The decisions either can be made on the basis of the resident's previous wishes, or, when these wishes are not known, on the basis of the resident's best interest as perceived by the surrogate. The resident's wishes could be made formal by a living will that was completed before the resident acquired dementia or may be in the form of verbal communication expressing resident's philosophy regarding end-of-life care. The problem with living wills is that they are very often quite general and generally do not cover advanced dementia. It was reported that choices for other conditions predict poorly what the individual would want if he or she developed dementia (89). An opportunity for formulation of advance directives is mandated at the time of admission into a nursing home. However, this discussion is often focused primarily on CPR preference, and reviewed only after the crisis of acute illness and hospitalization. Advance directive forms often contain inconsistent language and vague conditions for implementation. Partially as a result of these factors, few nursing home residents receive hospice services, many die without family present and with little documented evidence of pain or symptom management (90).

Most individuals (93 – 95%) would not want cardiopulmonary resuscitation if they had severe dementia (91;92). However, the decision depends on the way the scenario is presented and depends very much on person's knowledge of or experience with Alzheimer's disease. Those who had this knowledge refused CPR more often, while knowledge of CPR did not make any difference (93). In a study of individuals admitted to a psychogeriatric ward of a general teaching hospital, DNR orders were related to diagnosis of dementia, use of antidepressants, age and morbidity (94). About two thirds of cognitively intact older adults would want additional treatment limitations; no hospitalization and no antibiotics, if they had severe dementia. There is a relationship between individuals' desire for life-sustaining treatments and having less education, greater independence, and a higher perceived quality of life (92).

White nursing home residents are more likely to have a living will, DNR order or surrogate decision-maker than other racial categories. There is also large variation in the prevalence of living wills in different states, with Ohio having almost a 10 times higher prevalence of living wills than California, Massachusetts and New York (95). There are some gender differences in end-of-life care preferences with men preferring more life-sustaining treatments and women preferring a more dignified death that included less life-sustaining treatments (96). The age at which the individuals are asked about their preferences also plays a role, with individuals 70 years old or older stating that the most important factor for their CPR decision is "I do not want to be a burden on my family" while younger individuals' most important factor is "I want to retain my capacity to think clearly" (97). The prevalence of advance directives in a nursing home is increased if the

proxies have advanced directives themselves, if the proxies are less religious, and if the residents are socially engaged (98).

The caregivers of individuals with dementia, who are most often their proxies, are generally selecting more life-sustaining interventions than healthy older adults quoted above would want for themselves. In the face of a critical illness, about half of spouses of Alzheimer patients with moderate to severe dementia would opt for CPR, respirator and feeding tube. Only 10% of them would forgo antibiotics. The spouses were more likely to forgo treatments in the face of a coma. Spouses of patients with more severe dementia were more likely to forgo CPR, and the care recipient having a poor quality of life was related to forgoing tube feeding (99). Similar results were obtained in a British study where 46% of family caregivers wanted CPR, 60% intravenous fluids, 52% intravenous antibiotics, and 60% oral antibiotics. In this study, the presence of severe dementia resulted in a reduced wish for intravenous antibiotics (100). Spouses consenting to treatment were more comfortable with their decision than those forgoing treatment (99), indicating need for caregiver support during the decision process. It was reported that family members are not well prepared for their decision-making roles and experience substantial burden, have limited understanding of dementia progression, are uncomfortable in setting the goals of care, had little experience with death and were ambivalent about the anticipated death of their relative considering the death both a tragedy and a blessing (101;102). Unfortunately, caregivers often do not receive sufficient emotional support from health care professionals, although this support is improved if the patient is receiving home hospice services (103).

Eighty-one percent of physicians reported in a survey that they counseled their patients regarding advance planning issues but only half of those discussed end-of-life care. Less than 20% of surveyed physicians provided advance care planning for their patients' caregivers and again only less than half of them discussed end-of-life care (104). Physicians themselves are in favor of palliative care if they develop advanced dementia. Only 2% wanted CPR, 87% of them indicated they would want all treatment withdrawn if the death is imminent, and 95% would want treatment withdrawn should they be in a persistent vegetative state. Only 1% believed that health care providers should never remove or withhold life-sustaining therapy and significant number favored active euthanasia (105). Physician attitudes are influenced by their race. Tube feeding in terminally ill patients was considered heroic by 58% of white physicians but only by 28% of black physicians. White physicians were more likely to find physician-assisted suicide an acceptable treatment alternative than black physicians. If they were in a persistent vegetative state, black physicians were more than six times more likely to request aggressive treatment while white physicians were three times more likely to want physician-assisted suicide. In a state of brain damage without terminal illness, 23% of black and 5% of white physicians wanted aggressive treatment (106). A survey of nephrologists showed that they considered medical benefits in dementia patients in decisions to discontinue renal dialysis, but 25% admitted difficulty with advance directives if the directives clashed with their beliefs (107). Nursing home physicians considered consensus of the treatment team as the most important factor in determining prognosis and developing a palliative care plan (108).

The end–of–life care decision that is most often discussed and made is a "do not resuscitate" (DNR) status. Characteristics of nursing home residents associated with a DNR order were reviewed by Zweig, 1997 (10). DNR orders in nursing populations are associated with advanced age, cognitive dysfunction, physical dependency, presence of advance directives or durable power of attorney for health care, absence of Medicaid, and daily visitors. The presence of a DNR order is also influenced by nursing home characteristics and ethnicity of nursing home residents. DNR decisions are affected by the language used to describe the CPR procedure and the probability of success presented to the resident. In a study of desire for CPR in a retirement village, 41% of residents opted for CPR if they had an acute illness before learning about survival statistics. When 10–17% success rate was presented, only 22% desired CPR. The preference decreased to 5% when they were told that with a chronic illness present the success rate of CPR is only $0-5\%$ (109). A DNR order is sometimes used by the care providers as a proxy for palliative care and results in more care limitations than just CPR (110). Residents with DNR orders are also less likely to be hospitalized during an acute illness episode than residents with full code (111).

Decisions about tube feeding are highly emotional and sometimes elicit court involvement. However, there is broad legal consensus that tube feeding is a medical procedure, which may be discontinued if the patient/proxy so desires, both in the United States and Australia (112). Discontinuation of tube feeding is also supported by most religious ethicists (78). The Orthodox Jewish position is that tube feeding should be given as long as it does not constitute undue danger, arouse serious opposition or cause suffering to the patient (113). A recent papal statement, supporting the use of tube feeding, was primarily targeted at maintaining tube feeding in individuals in a persistent vegetative state, who cannot perceive any suffering from tube feeding (114). Since individuals with Alzheimer's disease very rarely if ever progress into the persistent vegetative state (115), this statement may not affect their care, although there could be differing opinions (116).

The process of decision making regarding tube feeding is different in other countries. A Netherlands study showed that advanced care planning has taken place only in 68% of residents with dementia in whom the decision was made to forgo artificial nutrition and hydration and in two thirds of all residents the primary aim of foregoing artificial nutrition and hydration was to avoid unnecessary prolongation of life (117). In this study, almost all physicians, nurses and family members rated decision-making process as "good" or "adequate" and the only dissatisfaction was with having to make the decision under the pressure of time constraint. In contrast, a Canadian study showed that only half of the decision makers felt that they had received adequate support from the health care team in making the decision, and often a physician spoke with them for only 15 minutes or less (37%), or not at all (28%) (118). Fewer than half of the proxies who agree to institute long-term tube feeding were confident that the patient would want to have a tube feeding. The majority of proxies felt that they understood the benefits of tube feeding but believed that tube feeding prolongs life (84%) or prevents aspiration (67%). Fewer than half of the proxies felt that they understood the risks of tube feeding or felt that the feeding tube had improved the patient's quality of life. A minority (38%) of proxies who agreed to institute long-term tube feeding would want a feeding tube for

themselves (119).

Decisions about the end–of–life care may be made easier by use of guidelines for clinicians and family members. Guidelines for palliative care in dementia resulted in a decrease in prescribing antibiotics and increased use of analgesics, including opiates (120). A checklist of considerations for decisions regarding treatment of pneumonia was recently developed (121). There are also two guidelines that specifically address the issue of tube feeding (122;123). Professional societies also developed guidelines, (124) or published illustrative cases (125). Existing guidelines were recently reviewed and their end–of–life care content evaluated (126). In the area of dementia, out of 56 possible guidelines, 24 were reviewed and 7 accepted for the study. The best four guidelines were issued by the American Medical Association (127), American Psychiatric Association (128), California Workgroup on Guidelines for Alzheimer's Disease Management (129), and American Medical Directors Association (130). Most of these guidelines support the use of palliative care in advanced dementia.

Hospice Care

Hospice organizations are able to provide palliative care for individuals with advanced dementia living in assisted living or nursing home facilities. The use of hospice for individuals with a primary diagnosis of dementia increased from1% of hospice patients in 1995 (131) to 9.6% of patients in 2003 (132). This percentage is now similar to the percentage of deaths from Alzheimer's estimated from epidemiological data in 1999 (7.1%) (133) and percentage of reported deaths from Alzheimer's and cerebrovascular diseases (9%) (134). Despite that, there is evidence that only 11% of residents with advanced dementia are referred to hospice (2).

 The main barrier to more widespread use of hospice care for residents with advanced dementia is the Medicare requirement that a patient have a prognosis of death within 6 months. The current Medicare guidelines are difficult to apply (66;67) and are not valid predictors of survival in hospice patients with dementia (135). Other criteria for hospice eligibility were proposed (136-138) but were not accepted by Medicare. Most recently, estimation of prognosis based on the Minimum Data Set evaluations, was developed (139). A risk score derived by this method is directly proportional to the number of residents who die within six months, ranging from 2.7% at a score of 0 to 75% at a score of 12 or more. The problem is that the mortality increase is gradual with no clear cut–off point that could be used to eliminate hospice services for residents with advanced dementia who will live longer than six months without excluding many residents who die within 6 months. For instance, if the cut–off score is 9 or larger, 63% of residents will die within 6 months but 26% or residents with lower scores will also die within 6 months. Thus, a significant number of residents would be deprived of hospice services even though they die within the 6 months period. However, some residents with high scores will live for years.

Applying strict criteria for hospice eligibility may be counterproductive because most studies showed that Medicare costs are lower for residents enrolled in hospice care than for non–hospice residents (140;141). Although one study reported that expenditures for

hospice enrollees with dementia were higher than for non-enrollees (142). This discrepancy could be due to unclear eligibility criteria and longer survival of some residents (143). Suggestion was also made, that gender differences in mortality risks should be taken into consideration because the most important factors in men are severity of dementia and occurrence of delirium, while in women mortality is associated with impairment in ADLs, presence of pressure sores, malnutrition and comorbidity (144).

Hospices provide important services to both the resident and his or her family. Involvement in hospice improves management of pain. Hospice residents are twice as likely as non-hospice residents to receive regular treatment for daily pain, although the pain management was not optimal even in hospice residents (145). Hospice involvement improves documentation of pain assessment and hospice residents are more likely to receive opioid treatment than non-hospice residents (146). Management of pain in residents with advanced dementia is complicated by the difficulty in assessment of pain presence and intensity because of the patient's language and comprehension deficits. These residents are unable to complete any pain assessment tools (147) and pain assessment relies on observation of pain signs by a caregiver. Two observational scales were recently proposed (148;149) but a study comparing them is not yet available.

Hospice services are also important for the family members and caregivers of individuals with dementia. Caregivers more often say that the hospice involvement benefits them than they would say that it benefits the patient. Caregivers value the continuous involvement of the patient's primary physician in his or her care, and an emphasis on avoiding hospitalization (150). Hospices also provide social support and bereavement services that are not available in nursing homes (151). Social support for caregivers of institutionalized individuals with dementia is very important because depressive symptoms and anxiety is as high in caregivers after they institutionalized their relative as when they were in-home caregivers. The use of antidepressants does not change and the use of anxiolytics increases in caregivers after placement (152). Caregivers of individuals with dementia involved in a hospice program continue being at risk for depression, and having lower life satisfaction and physical health than non-caregivers (153). The depression and low life satisfaction is not related to the patient impairment or amount of care but is associated with female gender, caregiver health problems, and negative social interactions (154).

Discussion

The search of literature presented in this review showed lack of definitive information in several areas. Most of the studies included in this review are observational and some studied a general nursing home population without distinguishing between cognitively intact residents and those with dementia. Research in this area is hampered by ethical concerns (155) and it is very likely, for example, that a randomized control study on tube feeding will never be done. Despite these limitations, there are several recommendations that can be made on the basis of this review.

1. Cardiopulmonary resuscitation should be an optional strategy in advanced dementia.

The probability of success of CPR is very low but the probability of great burden being inflicted on individuals who do survive initially is very great. Injuries caused by CPR, and exposure to an ICU environment and aggressive medical interventions cause great discomfort and suffering in an individual who does not understand the need for these interventions. Those who die during or soon after the CPR, and their families, are deprived of a comfortable and dignified death. Therefore, CPR should be performed only if it is specifically requested by the surrogate or by the patient who is well informed about the success rates and medical consequences of CPR (10).

2. Distinction should be made between witnessed and unwitnessed cardiac arrest.

The probability of successful CPR in an elderly person with disabling dementia after unwitnessed arrest in an institution is zero (11). The distinction between these two situations should be explained to the surrogate, or the institution could have a general policy that specifies that no resuscitation attempt after an unwitnessed arrest. Actually, the majority of nursing homes already do not require CPR in unwitnessed cardiac arrest (19). However, there is a need for further research into the effectiveness of automatic external defibrillators in the nursing homes.

3. Physician extenders should be present in nursing homes to prevent unnecessary hospitalization and tranfer to an emergency room.

Transfer to an acute care setting is very traumatic for a resident with advanced dementia and actually increases the mortality rate. Some excellent programs, such as Evercare and the Program for All-Inclusive Care for the Elderly (PACE) decrease significantly the rate of hospitalizations of nursing home residents. Evercare is a program that provides care by teams of physicians and nurse practitioners who promote on-site treatment of medical complications using Medicare capitation. When residents enrolled in Evercare were compared with un-enrolled residents, Evercare residents had fewer preventable hospitalizations and a lower hazard rate of mortality (156). PACE is a program that provides care for frail elderly who meet states' criteria for nursing home care in an appropriate setting using capitated payments from both Medicaid and Medicare. The hospitalization rate of PACE participants is similar to the hospitalization rate of the general Medicare population despite the greater morbidity and disability of PACE participants and only 8% of PACE participants died in a hospital (157).

4. Eliminate fiscal incentives for hospitalization of nursing home residents.

Currently the nursing home does not have any incentive to prevent hospitalization by providing more services because hospitalization costs are covered by Medicare. In addition, after the resident is readmitted from a hospital to a nursing home, his or her expenses may be covered by Medicare, which results in a higher nursing home reimbursement then Medicaid provides. A combination of Medicare and Medicaid funding or increased Medicaid funding for nursing homes could facilitate nurse aide training programs that have been shown to decrease the risk of hospitalization (34). It was shown that a modest increase in reimbursement rate would decrease not only

hospitalization but also mortality rate (35). Treatment of infections in nursing homes not only causes less discomfort to the resident but also decreases the mortality rate (38).

5. Maintain oral health of nursing home residents with dementia

Incidence of aspiration pneumonia is greatly increased in the presence of periodontal disease, plaques, number of decayed teeth and presence of specific microbes in saliva (59) and oral care has been shown to decrease incidence and mortality of pneumonia (60). It is also important to prevent decreased salivary production caused by anticholinergic medications because decreased salivary production increases colonization of oral cavity by pathogens (61).

6. Avoid use of antibiotics for treatment of generalized infection in residents with terminal dementia when comfort is the primary goal of care.

Antibiotic therapy does not prolong survival in individuals who are unable to communicate and unable to ambulate alone or with assistance (46;66;67). Non-randomized studies indicate that antibiotic therapy is also not necessary for maintaining comfort of residents because the comfort may be maintained equally well without antibiotics by administration of antipyretics, analgesics and oxygen if necessary (46;68). Avoidance of antibiotics eliminates the need for aggressive diagnostic procedures and prevents possible adverse effects cause by antibiotic administration.

7. Eliminate fiscal incentives for tube feeding in nursing homes.

Currently, nursing homes are reimbursed more for residents with tube feeding than for residents who are fed by hand, although it is more expensive for the nursing homes to provide hand feeding (86). Feeding tubes are also more expensive to the health care system because of the cost of insertion and treatment of complications that is paid for by Medicare. It has to be recognized that tube feeding does not provide any benefits to most residents with advanced dementia while it is decreasing their quality of life.

8. Increase physicians' involvement in discussions related to end–of–life care decisions.

Physicians should be present when end–of–life issues are discussed. This discussion should be happening shortly after the admission to a nursing home because the time of admission is too stressful for caregivers to be able to make these decisions. The physician role is crucial because good end–of–life care requires an interdisciplinary approach where all team members understand the goals of care and agree with them.

9. Discuss issues other than CPR shortly after admission

Good discussion about end–of–life care options includes setting general goals for care (9) and an explanation of the advantages and disadvantages of specific treatment strategies that include hospitalization, tube feeding and use of antibiotics for treatment of generalized infections. It is easier to discuss these issues before a crisis situation and come to a consensus that can be formalized as an Advance Proxy Plan (158). Discussing strategies

other than CPR decreases the risk that the CPR order will be considered also to be an order for limiting other interventions (111).

10. <u>Provide national criteria for designation of a surrogate decision maker</u>

Criteria for designation of a surrogate decision maker differ from state to state. Some states require involvement and agreement of all relatives belonging to a specific category (e.g., siblings). This requirement makes timely decision very difficult because some of the individuals may be difficult to reach or not be involved with the patient for many years. The model could be criteria used by the U.S. Department of Veterans Affairs that specifies clearly the hierarchy of next-of-kin individuals, if no health proxy was designated.

11. <u>Provide palliative care for residents with advanced dementia before they are eligible for hospice services by the current eligibility criteria</u>

It is very difficult to predict six-month mortality in residents with dementia because death is most often caused by unpredictable intercurrent infections. Current Medicare criteria are not based on any clinical data and do not predict 6 month survival (135). The Medicare eligibility criteria should be modified and based on empirically derived risk scores (139). An alternative would be to make hospice care part of long-term care instead of being a separate program.

If the goal of care for residents with advanced dementia is primarily maintenance of function, such a resident should not be transferred to an acute care setting because hospitalization results in decline of functional abilities that do not recover after discharge back into nursing home (20). If the primary goal of care is comfort, most of the aggressive medical interventions, including use of antibiotics for treatment of generalized infections, should be avoided. The team should concentrate on palliative care measures and "high touch" interventions.

These recommendations are necessarily limited by the lack of pertinent research information in several important areas. The areas that need more research attention in the future include determination of optimal environment and activities level, development of nutritional guidelines for end-of-life, and prevention and management of contractures. New important programs for end-of-life care are being developed but they need careful evaluation before they are generally accepted. However, it is hoped that these recommendations will generate discussion related to optimal end-of-life care for residents with advanced dementia. Such a discussion is needed to correct common misconceptions about the effectiveness of aggressive medical interventions in this patient population. It is also important to provide correct information about the natural course of Alzheimer's disease and dying from Alzheimer's disease because knowledge about the disease was found to be more important than information about medical interventions (93). The Alzheimer's Association could play a crucial role in educating both family and professional caregivers about symptoms of terminal dementia and principles of appropriate end-of-life care.

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