

End of Life in Dementia Care: Research Evidence to Support the Provincial Dementia Service Framework

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Purpose of the Research

To identify research evidence to support the development of recommendations for End of Life (EOL) dementia care to be incorporated into the provincial Dementia Service Framework.

Method

A scan of the research literature for the period 1996 to present, guided by the following questions, was conducted.

1. What are the issues that differentiate end of life care for those with dementia from end of life care for the general population?
2. What are the emerging best practices to address these?
3. What is the strength of evidence that supports them?

Several data bases (i.e., AgeLine, CINAHL, PsychLit, Pubmed, Web of Science, Google Scholar), web sites (e.g., Canadian, Australian, New Zealand and British government sites; Alzheimer Societies; J.W. Crane Library; Canadian Study of Health and Aging) were searched using a combination of terms such as dementia, Alzheimer's Disease, end of life care, palliative care, hospice, best practices, caregiving, care provider, policy, cardiopulmonary/CPR, antibiotics, interventions, tube feeding, hospital transfer, advanced directives, prognosis, environments, and experience. These searches resulted in 285 publications (see attached bibliography), which were examined for relevance to the topic and inclusion of research data. Most of the studies are observational studies and only a few included evaluation of interventions. Almost none of the studies are randomized control trials. Some expert opinion publications (Canadian Consensus on Dementia Care, Best Practices in Long Term Care and Guide to End of Life Care for Seniors) and reference sections of pertinent unpublished papers were also searched.

Analysis

The Strength of Recommendation Taxonomy (Ebell, Siwek, Weiss, Woolf, Susman et al., 2004) SORT, was used to rate (1) the quality of individual studies, and then (2) the strength of the resulting body of evidence that could support potential recommendations in a given area.

The quality of individual quantitative studies is assessed on two criteria: quality of patient oriented outcomes and study design.

- Patient oriented outcomes (i.e., outcomes that matter to patients such as reduction in morbidity and mortality, symptom improvement, quality of life and lower cost); are rated as good quality, limited, or none.
- The design of each study is rated using Levels of Evidence 1, 2 or 3.
 - A rating of 1 is given to SR/meta-analysis of high quality studies with consistent findings; high quality randomized control trials (RCT); high quality cohort studies for prognosis; validated clinical decision rule in a relevant population and high quality diagnostic cohort studies.

- A rating of 2 is given to lower quality SR/meta-analysis, clinical trials or cohort studies; and to retrospective cohort studies, case control studies, and case series.
- A rating of 3 is given to: consensus guidelines; extrapolations from bench research; usual practice; opinion; disease-oriented evidence or case series for studies of diagnosis, treatment, prevention or screening.

The SORT tool does not have a schema for assessing qualitative studies and nothing similar could be found. In keeping with the practice of Interior Health Phased Pathway the criteria of credibility, applicability (or fittingness), auditability and confirmability are used to assess the quality of individual qualitative studies. If all four criteria are met the study is included in the body of knowledge and given a Level of Evidence rating of 2.

The strength of evidence for recommendations (based on the SORT methodology) is determined by assessing groups of related studies (i.e. the bodies of evidence for particular topics) in terms of consistency of conclusions between studies and the degree to which they have patient oriented outcomes.

A = recommendations are based on consistent good quality patient oriented evidence.

B = recommendations are based on inconsistent or limited patient oriented evidence.

C = recommendations are based on consensus, usual practice, opinion, disease oriented evidence or case series for studies of diagnosis, treatment, prevention, or screening.

Results

The results from literature reviewed were combined into statements to describe the body of evidence, as follows, and then developed into potential recommendations for the Dementia Service Framework.

- **Sensory stimulation activity** in advanced dementia can increase psychological well being (Witucki & Twibell,1997).
- **Intercurrent infections** are a highly likely consequence of advanced stage dementia (Volicer, 2005).
 - Risk of intercurrent infections can be reduced by annually vaccinating individuals with dementia, care givers and care providers for influenza (Brandels et al 1998).
 - Oral care program reduces occurrence of pneumonia at EOL in LTC facility settings (Yoneyama et al).
- **Aggressive medical treatment** for individuals with advanced dementia is often inappropriate for medical reasons, has low rates of success and can have negative outcomes that hasten functional decline and health (Volicer, 2005).
 - **CPR** is unlikely to be successful (Dull et al,1994; Benkendorf et al, 1997; Ebell et al 1998) and where it is most survivors go to intensive care but die within 24 hours (Zweig 1997).
 - **Antibiotic therapy** does not seem to prolong survival in advanced dementia and is not necessary for comfort which can be maintained through other means without antibiotics (Volicer et al, 1998). Where used the diagnostic procedures may be uncomfortable and the treatment cause adverse side

effects. (Fabiszewski et al, 1990; Volicer et al 1998; Luchins et al 1997; Hanrahan et al 1999). Irregardless of whether or not pneumonia is treated with antibiotics it cause suffering and symptomatic treatment is required (van der Steen et al, 2002).

- **Tube feeding** at EOL should be discouraged on clinical grounds (Finucane et al, 1999). Tube feeding does not increase survival of those with advanced dementia (Murphy & Lipman, 2003; Meier et al, 2001; Finucane et al, 1999), reduce the risk of infection (Gillick, 2000) prevent aspiration or improve functional status or comfort of the individual with dementia (Gillick, 2004; Sanders et al 2000; Abuksis et al 2000). There is considerable discord between physician opinion, reported practice and literature in regard to tube feeding at end of life (Shega et al, 2003).
 - Incidence of tube feeding can be reduced through protocol to consult palliative care team prior to doing so, and through educational program (Monteleoni & Clark 2004).
 - Education for physicians and other health care professionals needed about PEG placement for those with dementia at EOL.
- **Pain** in advanced dementia is difficult to assess and requires a combination of patient report, caregiver report and direct observations (AGS Panel on Persistent in Older Adults, 2002). Pain is often undetected (Cook et al, 1999) and under treated for those with dementia compared to those without, (Morrison et al, 2000; Kaasalainen et al, 1998).
- **Hospitalization** at EOL frequently results in functional decline that does not improve significantly at discharge (Volicer et al 2001). Aggressive medical treatment (with its' own risks) is often used to manage confusion, anorexia, incontinence and falls that often follow hospital transfer (Ahronheim et al 1996). Pneumonia can be equally well managed in facility, with better outcomes, compared to hospital treatment. (Fried et al, 1997; Mylotte et al 1998).
 - Transfer from facility to hospital is influenced by non-medical factors: nursing homes with special care units, greater physician to patient ratios and physician extenders (Evercare and PACE programs in US: Kane et al 2005; Wieland et al 2000) are less likely to hospitalize their residents (Intrator et al, 1998, 2004); Fried et al, 1997; Barker et al; Thompson et al, 1999).
 - Hospital and intensive care unit stay can be decreased by early assistance to unit staff by a palliative care team (Campbell et al 2004).
 - EOL experience for caregivers in Assisted Living (or similar) settings compared to Nursing Home settings is similar in process and outcome (Sloane et al, 2003).
- **Caregivers at EOL experience burden**, have limited understanding of disease progression, and are ambivalent about anticipated death of family member (Forbes et al, 2000; Gessert et al, 2000). The negative impact of caregiving on those caring for someone with dementia vs those caring for a cognitively intact person, is greater,

(Ory et al, 1999). Caregivers who are strained have increased mortality rate in comparison to their non caregiving relatives (Shulz & Beach, 1999). Caregivers experience high levels of depression prior to death of family member (Schulz et al, 2003).

- Caregivers require support through the grief process (Canadian Study of Health and Aging Work Group, 2002; Meuser & Marwit, 2001).
 - Respite and psychoeducational support groups have demonstrated efficacy in supporting caregivers' psychological well being; (Brodaty & Green, 2001).
 - Caregivers report satisfaction for family members with AD where the PEACE (Palliative Excellence in Alzheimer Care Effort) program is in place (Shega et al, 2003)
- **Caregivers are not well prepared for decision making roles** (Mitchell & Lawson, 1999). Spouses of individuals with advanced dementia generally select CPR, respirator, antibiotics and feeding tubes in face of critical illness(Potkins et al 2000).
 - Where education about pros and cons CPR (O'Brien et al, 1995) use of antibiotics and other treatment options in advanced dementia is provided, cognitively intact individuals would limit their treatment (Schonwetter et al, 1996; Gjerdingen et al 1999).
 - Positive relationship with health care professional is vital to support caregivers who must make treatment decisions for end of life care (Caron et al, 2005)
 - Those caregivers who forgo treatment require most emotional support (Mezey et al 1996).
- **Discussion about EOL care** should be guided by patient's prior wishes, agreed upon goals of therapy, and knowledge of potential benefits and burdens of treatment options (Sachs, 2004).
 - What matters most in EOL care from perception of seriously ill persons and caregivers is: trust in treating physician; avoidance of unwanted life support; effective communication; continuity of care; life completion (life review, resolving conflict, saying goodbye). Individualized approach to EOL care needed as priority given to each factor differs (Heyland et al 2006).
- Scenario based evidence suggests that surrogates can not accurately predict their elderly family members preference for life-sustaining treatments, even when the family member had completed a **health care directive or a valued activities directive** and discussed it with the surrogate (Coppola, Ditto, Danks and Smucker (2001) and Ditto, Danks, Smucker, Bookwala, Coppola et al (2001). A **protocol for proxy decision making** re EOL in dementia care, but has not been evaluated (Volicer, Cantor, Derse, Edwards, Prudhomme, et al. (2002: R3).
- Individuals dying with dementia have **symptoms and health care needs comparable to those dying of cancer** (McCarthy et al, 1997).
- **Good palliative care** calls for interdisciplinary care, attendance to advance care planning, psychosocial issues and management of symptoms (Gillick, 2005).

- **Multidisciplinary guidelines for EOL care**, collaboratively developed, can have positive impact on palliative care for EOL dementia (e.g., decreased antibiotic use, improved pain management (Lloyd-Williams & Payne, 2000/1).
- **Prognostic markers of advanced dementia incorporated into National Hospice Organization (USA) do not accurately predict 6 month life expectancy** except when at 7C or greater (Hanrahan et al, 1999; Schonwetter et al 2003).
- **Access to hospice care supports caregivers** and provides bereavement services (Murphy et al, 1997).
- Provider education, provider feedback and reminders are associated with significant improvements to **providers' adherence to disease management programmes** for patients with wide variety of chronic diseases (Weingarten et al 2002).

Expert Consultations

The bodies of evidence derived from the research literature (above) were shared in a telephone discussion with Dr Ladislav Volicer at the School of Aging Studies, University of Florida, a researcher and expert in the field of EOL dementia care. He validated the results and confirmed that there is a lack of research evidence to guide practice in the following areas:

- How to make an accurate prognosis about when individuals with dementia will die.
- Whether or not hospice care is a "better" place than nursing homes for individuals with dementia who have palliative care needs.
- Prevention and management of contractures.
- Development of nutritional guidelines for end of life.

Dr. Volicer made the point that lack of research evidence does not mean that current approaches are either adequate or inadequate, only that they have not been evaluated. He stated that expert opinion derived from patients, care givers and care providers should guide practice until such research occurs.

Dr. Kiran Rabheru, a Geriatric Psychiatrist in Vancouver Coastal Health Authority and associated with the Alzheimer Society of B.C., was also interviewed. He did not see any gaps in the results of the literature review and felt that this underlines a pressing need for research about EOL dementia care. He suggested that the recommendations for which there are supporting evidence should be very strongly worded in order that they lead practice. Dr. Rabheru felt that the gaps revealed should drive future research, e.g.:

- How should families be involved in decision making?
- How should conflict amongst family members regarding EOL decisions, be managed?
- How should information about EOL and treatment (e.g., antibiotics, CPR) be communicated to families?
- When should treatment be ended?

Dr. Jean Kozak, a psychologist and epidemiologist in Vancouver Coastal Health Authority, also validated the research recommendations in an interview. He too highlighted gaps in research to date, for example:

- Are advanced care plans effective (for the client, for the care providers)?.

- No reliable appropriate pain assessment when the individual can not communicate verbally.
- What is “best practice” in palliative care for those with dementia?
- Need to understand what we do that supports caregivers.
- What are the needs of caregivers at EOL?
- Would providing appropriate support during the EOL and following bereavement have positive impacts on caregivers’ health and mortality?
- Lack of research into role of spirituality at EOL for those with dementia and their caregivers.
- What kind of policy changes would facilitate access to palliative care in the home? To hospice care?

Louise Stern, a Doctoral candidate at the School of Social Work at the University of British Columbia was consulted about her work related to EOL dementia care and culture. No research studies that could support specific recommendations were identified. She suggested that attention to cultural values at EOL is however an important principle that could be incorporated into the Dementia Service Framework as expert opinion. Areas for research that she identified are:

- How do individuals and their families experience dementia and dying?
- What is the role of cultural values in how individuals and their families experience dementia and dying?
- What are the implications of cultural values for EOL decision making?

A meeting was held to review all of the EOL Recommendations in the Dementia Service Framework with members of the Provincial End of Life Working Group (Laurianne Jodouin, Manager, Home and Community Care, Ministry of Health; Donna Lommer, Executive Director, OHSR Residential and Palliative Services, IHA; Marianne McLennan, Director, Seniors’ Health, Spiritual Care and End of Life Care, VIHA; Judy Lett, Palliative Care Coordinator, NH); Dr. Romaine Gallagher, Division of Palliative Care Department of Family Practice, UBC; and, Dr. Brian Plain, Medical Consultant, VIHA. In regard to the research recommendations made in this document, participants did not identify additional research literature. They did however reiterate a need for research in areas identified by other consultants, as follows:

- There is an urgent need for research into advance care planning (e.g., how and when should it should be discussed with clients; family members role; communicating advanced care directives to care providers; are they followed?)
- How can sensitivity and adaptation of EOL services for ethnic and cultural differences be assured?
- Could a system for ethics reviews and consults support clients and care providers in making EOL decisions.
- How can clients and caregivers be informed (sensitively, accurately and effectively) of the physical and functional realities of the end stages of dementia, to support decision making.

Additional areas of research identified by participants are:

- How can pain be managed effectively for those with dementia at EOL when there are existing co-morbid conditions?
- How can care providers elicit clients’ values regarding EOL?
- What are the spiritual needs of individuals with dementia at EOL and how can these be met?

Recommendations for Dementia Service Framework

The bodies of evidence were “translated” into potential recommendations for incorporation into the Dementia Service Framework. The strength of the potential recommendations is noted, along with key supporting evidence. See Table 1.

TABLE I

POTENTIAL RECOMMENDATIONS FOR THE DEMENTIA SERVICE FRAMEWORK

• RECOMMENDATION	SUPPORTING EVIDENCE	STRENGTH
• Individual		
• Individuals with dementia should expect and receive appropriate pain assessment and adequate pain management	Pain in advanced dementia is difficult to assess and requires a combination of patient report, caregiver report and direct observations (AGS Panel on Persistent in Older Adults, 2002: R2)..Pain is often undetected (Cook et al, 1999: R3) and under treated for those with dementia compared to those without, (Morrison et al, 2000: R1; Kaasalainen et al, 1998: R2). There are a variety of pain assessment tools but none that are definitive for non communicative individuals with dementia (Stollee et al 2005: R1) Irregardless of whether or not pneumonia is treated with antibiotics it cause suffering and symptomatic treatment is required (van der Steen et al, 2002: R1).	A
• Individuals with dementia should expect to receive good oral care	Oral care program reduces occurrence of pneumonia at EOL in LTC facility settings Yoneyama et al ; R1)	A
• Individuals with dementia should expect to receive an annual vaccination for influenza	Intercurrent infections are highly likely consequence of advanced stage dementia (Volicer, 2005) Risk of intercurrent infections can be reduced by annually	B

	vaccinating individuals with dementia, care givers and care providers for influenza (Brandels et al 1998: R2).	
<ul style="list-style-type: none"> Individuals with dementia can expect to have their psychosocial needs met. 	Sensory stimulation activity in advanced dementia can increase psychological well being (Witucki & Twibell, 1997: R2).	B
<ul style="list-style-type: none"> Caregivers should expect to be informed about risks and benefits of interventions at end of life prior to their being considered for their family member. 	<p>Spouses of individuals with advanced dementia generally select CPR, respirator, antibiotics and feeding tubes in face of critical illness(Potkins et al 2000; R2)</p> <p>Caregivers are not well prepared for decision making roles (Mitchell & Lawson, 1999); and experience burden, have limited understanding of disease progression, ambivalent about anticipated death of family member (Forbes et al, 2000: R2; Gessert et al, 2000: R2).</p>	B
<ul style="list-style-type: none"> Caregivers should expect to receive emotional support from health care providers when needing to make decisions about levels of care to be provided at end of life. 	<ul style="list-style-type: none"> Positive relationship with health care professional is vital support to caregiver decision making (Caron et al, 2005: R2) Those caregiver who forgo treatment require emotional support (Mezey et al 1996: R2). 	B
<ul style="list-style-type: none"> Family members of those with dementia should expect emotional support from health care providers through their family members' dying and after their death, to be available. 	<ul style="list-style-type: none"> The negative impact of caregiving on those caring for someone with dementia vs those caring for a cognitively intact person, is greater, (Ory et al, 1999: R1) Caregivers require support through the grief process (Canadian Study of Health and Aging Work Group, 2002: R3; Meuser & Marwit, 2001). High levels of depression prior to death of family member—need support (Schulz et al, 2003: R1). Caregivers who are strained 	A

	<p>have increased mortality rate in comparison to their non caregiving relatives (Shulz & Beach, 1999: R1).</p> <ul style="list-style-type: none"> • Respite and psychoeducational support groups have demonstrated efficacy in supporting caregivers' psychological well being (Brodaty & Green, 2001: R2). 	
	Care Provider	
<ul style="list-style-type: none"> • Physicians and other healthcare providers are expected to increase their knowledge around advance care planning, including skills in providing end-of-life discussions and information about interventions, by participating in continuing education. 		C
<ul style="list-style-type: none"> • Healthcare providers should inform individuals with dementia and their caregivers that advance care planning for end-of-life care may improve their quality of life, and encourage and support this process. 	<ul style="list-style-type: none"> • Where education about pros and cons CPR (O'Brien et al, 1995: R2) use of antibiotics and other treatment options in advanced dementia is provided, cognitively intact individuals would limit their treatment (Schonwetter et al, 1996; Gjerdingen et al 1999: R2). 	B
<ul style="list-style-type: none"> • All physicians who care for individuals with dementia should be expected to possess the required skills to conduct end-of-life discussions with their patients and their significant others. This would include a skill set to: <ul style="list-style-type: none"> • Be able to convey difficult news. ▪ Possess interpersonal skills to facilitate engaging and listening to patients, their families and other healthcare providers. ▪ Encourage shared decision-making around planning and 	<ul style="list-style-type: none"> • Primary physician should guide discussion about EOL care in light of patient's prior wishes, agreed upon goals of therapy, and potential benefits and burdens of treatment options (Sachs, 2004: R3). 	C

<p>choosing appropriate interventions.</p> <ul style="list-style-type: none"> ▪ Knowledge of best practice palliative care interventions for dementia (von Gunten et al, 2000, R3) 		
<ul style="list-style-type: none"> • Healthcare providers should engage individuals with dementia and their family members in advance care planning by providing information: <ul style="list-style-type: none"> • about the disease course in advanced stage/end of life such as, <ul style="list-style-type: none"> • Likelihood of recurrent and intercurrent infections • Co-morbidities such as depression ▪ about risks vs benefits of various treatments/medical practices related to advanced dementia/end of life such as, <ul style="list-style-type: none"> • Antibiotic therapy • Enteral tube feeding. • CPR • Artificial hydration • Transfer to hospital 	<ul style="list-style-type: none"> • Aggressive medical treatment for individuals with advanced dementia is often inappropriate for medical reasons, has low rates of success and can have negative outcomes that hasten functional decline and health (Volicer, 2005) • Antibiotic therapy does not seem to prolong survival in advanced dementia and is not necessary for comfort which can be maintained through other means without antibiotics. Where used the diagnostic procedures may be uncomfortable and the treatment cause adverse side effects. (Fabiszewski et al, 1990; Volicer et al 1998; Luchins et al 1997; Hanrahan et al 1999) • Tube feeding does not increase survival of those with advanced dementia (Murphy & Lipman, 2003: R1; Meijer et al, 2001: R1; Finucane et al, 1999; R1) reduce the risk of infection (Gillick, 2000) prevent aspiration or improve functional status or comfort of the individual with dementia (Gillick, 2004; Sanders et al 2000, R1; Abuksis et al 2000). Tube feeding at EOL should be discouraged on clinical grounds (Finucane et al, 1999: R1). • CPR is unlikely to be successful (Dull et al, 1994; Benkendorf et al, 1997; Ebell et al 1998:R1) and where it is most survivors go to intensive care but die within 24 	<p>A</p> <p>A</p> <p>B</p> <p>B</p>

	<p>hours (Zweig 1997).</p> <ul style="list-style-type: none"> • Transfer from facility to acute care frequently results in functional decline that does not improve significantly at discharge (Volicer et al 2001). Aggressive medical treatment (with its' own risks) is often used to manage confusion, anorexia, incontinence and falls that often follow hospital transfer (Ahronheim et al1996). 	
<p>Support Systems</p>		
<ul style="list-style-type: none"> • Individuals with advanced dementia and their caregivers may expect access to palliative care expertise and staff at all times, across care settings. 	<ul style="list-style-type: none"> • Caregivers report satisfaction for family members with AD where PEACE (Palliative Excellence in Alzheimer Care Effort) program in place (Shega et al, 2003: R3) • Individuals dying with dementia have symptoms and health care needs comparable to those dying of cancer (McCarthy et al, 1997: R2). • EOL experience for caregivers in Assisted Living (or similar) compared to Nursing Home settings is similar in process and outcome (Sloane et al, 2003: R2). • Good palliative care calls for interdisciplinary care, attendance to advance care planning, psychosocial issues and management of symptoms (Gillick, 2005: R3). 	<p>B</p> <p>C</p> <p>B</p> <p>C</p>
<ul style="list-style-type: none"> • Individuals with dementia and their families should expect system change to better align what matters most to them at end-of-life to the care provided within the health authorities. 	<ul style="list-style-type: none"> • What matters most in EOL care from perception of seriously ill persons and caregivers is: trust in treating physician; avoidance of unwanted life support; effective communication; continuity of care; life completion (i.e., life review, resolving conflict, saying goodbye); support services for remaining at home; symptom relief). An Individualized 	<p>B</p>

	approach to EOL care needed as priority given to each factor differs (Heyland et al 2006: R2).	
Individuals with dementia can expect that care providers are vaccinated against influenza.	<ul style="list-style-type: none"> Risk of intercurrent infections can be reduced by annually vaccinating individuals with dementia, care givers and care providers for influenza (Brandels et al 1998). 	A
Health Care Environments		
<ul style="list-style-type: none"> Training/education related to provision of end of life care should be provided/supported across all care settings by the Health Authorities and partners for individuals with dementia, caregivers; care aids/home support workers; health professionals and physicians across settings 	<ul style="list-style-type: none"> Considerable discord between physician opinion, reported practice and literature (Shega et al, 2003: R2). Incidence of tube feeding can be reduced through protocol to consult palliative care team prior to doing so, and through educational program (Monteleoni & Clark 2004: R2). Provider education, provider feedback and reminders are associated with significant improvements to providers' adherence to disease management programmes for patients with wide variety of chronic diseases (Weingarten et al 2002: R1-<i>not specific to dementia</i>). 	B B
<ul style="list-style-type: none"> Each Health Authority should develop a protocol for making end of life treatment decisions/care where the individual lacks decisional capacity, and that involves significant others when available 	<ul style="list-style-type: none"> Primary physician should guide discussion about EOL care in light of patient's prior wishes, agreed upon goals of therapy, and potential benefits and burdens of treatment options (Sachs, 2004: R3). Multidisciplinary guidelines, collaboratively developed, can have positive impact on palliative care for EOL dementia (decreased antibiotic, improved pain management (Lloyd-Williams & Payne, 2000/1: R2). 	C B

•	<ul style="list-style-type: none"> • Government policy should ensure equitable access to appropriate services and supports in the home for those who plan to die there at equivalent cost to those individuals who are institutionalized (e.g., for incontinence and similar care products; home support; respite; palliative care consultation/team). 	<ul style="list-style-type: none"> • Access to hospice care supports caregivers and provides bereavement services (Murphy et al, 1997) 	C
•	<ul style="list-style-type: none"> • Criteria for designating end of life to enable designation as “palliative” and therefore access to appropriate services/supports needs to be established and should consider longer time frame than 6 months. 	<ul style="list-style-type: none"> • Prognostic markers of advanced dementia incorporated into National Hospice Organization do not accurately predict 6 month life expectancy except when at 7C or greater (Hanrahan et al, 1999: R1; Schonwetter et al 2003). 	B

Bibliography

- Abuksis G, Mor M, Segal N, Shemesh I, Plout S, Sulkes J et al. Percutaneous endoscopic gastrostomy: high mortality rates in hospitalized patients. *Am J Gastroent* 2000; 95(1):128-132.
- Ahronheim JC, Morrison RS, Baskin SA, Morris J, Meier DE. Treatment of the dying in the acute care hospital - Advanced dementia and metastatic cancer. *Arch Intern Med* 1996; 56:2094-2100.
- Ahronheim JC, Mulvihill M, Sieger C, Park P, Fries BE. State practice variations in the use of tube feeding for nursing home residents with severe cognitive impairment. *JAGS* 2001; 49:148-152.
- Ahluwalia N, Vellas B. Immunologic and inflammatory mediators and cognitive decline in Alzheimer's disease. *Immunology and Allergy Clinics of North America* 2003; 23(1):103.
- Albert SM, Costa R, Merchant C, Small S, Jenders RA, Stern Y. Hospitalization and Alzheimer's disease: Results from a community-based study. *J Gerontol [A]* 1999; 54(5):M267-M271.
- Albinsson L, Strang P. A palliative approach to existential issues and death in end-stage dementia care. *Journal Of Palliative Care* 18 (3): 168-174 Fal 2002.
- Allen RS, DeLaine SR, Chaplin WF, Marson DC, Bourgeois MS, Dijkstra K, Burgio LD. Advance care planning in nursing homes: correlates of capacity and possession of advance directives. *Gerontologist*. 2003 Jun;43(3):309-17.
- Alspaugh MEL, Zarit SH, Greene R. Longitudinal patterns of risk for depression in dementia caregivers: Objective and subjective primary stress as predictors. *Psychology And Aging* 14 (1): 34-43 Mar 1999.
- American Psychiatric Association. Practice guideline for the treatment of patients with Alzheimer's disease and other dementias of late life. *Am J Psychiatry* 1997; 154(5) supplement): 1-39.
- Aminoff, B. Measuring the suffering of end-stage dementia: reliability and validity of the Mini-Suffering State Examination. *Archives of Gerontology and Geriatrics*, Volume 38, Issue 2, Pages 123-130.
- Aminoff and Adunsky. Their last 6 months: suffering and survival of end-stage dementia patients. *Age Ageing* 2006;35:597-601.
- Ashby MA, Mendelson D. Gardner; re BWV: Victorian Supreme Court makes landmark Australian ruling on tube feeding. *Medical Journal of Australia* 2004; 181(8):442-445.

Ballard C, Fossey J, Chithramohan R, Howard R, Burns A, Thompson P, Tadros G, Fairbairn

A. Quality of care in private sector and NHS facilities for people with dementia: cross sectional survey. *British Medical Journal* 323 (7310): 426-427 Aug 25 2001.

Barker WH, Zimmer JG, Hall WJ, Ruff BC, Freundlich CB, Eggert GM. Rates, patterns, causes, and costs of hospitalization of nursing home residents: a population-based study. *Am J Publ Health* 1994; 84(10):1615-1620.

Bayer. Death with dementia--the need for better care. *Age Ageing* 2006 Volume 35:101-102.

Benkendorf R, Swor RA, Jackson R, Rivera-Rivera EJ, Demrick A. Outcomes of cardiac arrest in the nursing home: destiny or futility? *Prehospital Emergency Care* 1997; 1:68-72.

Bern-Klug M, Gessert CE, Crenner CW, Buenaver M, Skirchak D. "Getting everyone on the same page": nursing home physician's perspectives on end-of-life care. *Journal of Palliative Medicine* 2004; 7(4):533-544.

Blasi, ZV, Hurley AC, Volicer L. End-of-life care in dementia: a review of problems, prospects, and solutions in practice. *Journal of the American Medical Directors Association* 2002 Mar-Apr;3(2):57-65.

Bookwala J, Coppola KM, Fagerlin A, Ditto PH, Danks JH, Smucker WD. Gender differences in older adults' preferences for life-sustaining medical treatments and end-of-life values. *Death Studies* 2001; 25(2):127-149.

Boult L, Dentler B, Volicer L, Mead S, Evans JM. Ethics and research in long-term care: a position statement from the American Medical Directors Association. *JAMDA* 2003; 4:171-174.

Brandeis GH, Berlowitz DR, Coughlin N. Mortality associated with an influenza outbreak on a dementia care unit. *Alzheimer Dis Assoc Disord* 1998; 12(3):140-145.

Brandt, Hella, Luc Deliens, Jenny T van der Steen, and Marcel Ooms. E The last days of life of nursing home patients with and without dementia assessed with the Palliative care Outcome Scale. *Palliative Medicine*, Vol. 19, No. 4, 334-342 (2005).

Brechtl JR, Murshed S, Homel P, Bookbinder M. Monitoring symptoms in patients with advanced illness in long-term care: A pilot study. *Journal Of Pain And Symptom Management* 32 (2): 168-174 Aug 2006.

Brody H, Green A, Koschera A. Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal Of The American Geriatrics Society* 51 (5): 657-664 May 2003.

Brooker, D. Dementia care mapping: A review of the research literature
GERONTOLOGIST 45: 11-18 Sp. Iss. 1, OCT 2005.

Brown S. Systematic review of nursing management of urinary tract infections in the cognitively impaired elderly client in residential care: is there a hole in holistic care? International Journal of Nursing Practice 2002; 8:2-7.

Bunch TJ, White RD, Khan AH, Packer DL. Impact of age on long-term survival and quality of life following out-of-hospital cardiac arrest. Critical Care Medicine 2004; 32(4):963-967.

Burton LC, German PS, Gruber-Baldini AL, Hebel JR, Zimmerman S, Magaziner J. Medical care for nursing home residents: differences by dementia status. JAGS 2001; 49:142-147.

Byszewski AM, Graham ID, Amos S, Man-Son-Hing M, Dalziel WB, Marshall S, Hunt L, Bush C, Guzman D. A continuing medical education initiative for Canadian primary care physicians: The driving and dementia toolkit: A pre- and post evaluation of knowledge, confidence gained, and satisfaction. Journal Of The American Geriatrics Society 51 (10): 1484-1489 Oct 2003.

Campbell DE, Lynn J, Louis TA, Shugarman LR. Medicare program expenditures associated with hospice use. Ann Intern Med 2005; 140(4):269-277.

Campbell ML, Guzman JA. A proactive approach to improve end-of-life care in a medical intensive care unit for patients with terminal dementia. CRITICAL CARE MEDICINE 32 (9): 1839-1843 SEP 2004.

Canadian Coalition for Seniors Mental Health. National Guidelines for Seniors Mental Health: The assessment and treatment of mental health issues in long term care homes. Retrieved October 26, 2006 from www.ccsmh.ca

Canadian Study of Health and Aging Working Group. Patterns and health effects of caring for people with dementia: the impact of changing cognitive and residential status. Gerontologist. Volume: 42:643-652. (2002).

Canadian Study of Health and Aging Working Group. Patterns of caring for people with dementia in Canada. Can J Aging Volume: 13: 470-487. Campbell ML, Guzman JA. A proactive approach to improve end-of-life care in a medical intensive care unit for patients with terminal dementia. C Care Med 2004; 32(9):1839-1843.

Care for patients in a "permanent vegetative state". Origins 2004; 33:737-740.

Caron CD, Griffith J, Arcand M. Decision making at the end of life in dementia: How family caregivers perceive their interactions with health care providers in long-term-care settings. *Journal Of Applied Gerontology* 24 (3): 231-247 Jun 2005.

Caron, Chantal D. Decision Making at the End of Life in Dementia: How Family Caregivers Perceive Their Interactions With Health Care Providers in Long-Term-Care Settings. *Journal of Applied Gerontology*, Vol. 24, No. 3, 231-247 (2005).

Casarett D, Takesaka J, Karlawish J, Hirschman KB, Clark CM. How should clinicians discuss hospice for patients with dementia? Anticipating caregivers' preconceptions and meeting their information needs. *Alzheimer Dis Assoc Disord* 2002; 16(2):116-122.

Castello T, Girona L, Gomez MR, Mena Mur A., Garcia L. The possible value of ascorbic acid as a prophylactic agent for urinary tract infection. *Spinal Cord* 1996; 34(10):592-593.

Cavalieri TA, Latif W, Cieselski J, Ciervo CAJr, Forman LJ. How physicians approach advance care planning in patients with mild to moderate Alzheimer's disease. *Journal of the American Osteopathic Association* 2002; 102(10):541-544.

Chappell N, Penning M. Behavioural problems and distress among caregivers of people with dementia. *Ageing Soc. Volume:16: 57-73. (1996).*

Christakis NA, Escarce JJ. Survival of Medicare patients after enrollment in hospice programs. *N Engl J Med* 1996; 335:172-178.

Clyburn LD, Stones MJ, Hadjistavropoulos T, Tuokko H. Predicting caregiver burden and depression in Alzheimer's disease. *Journal of Gerontology: Social Sciences*. 2000. Vol. 55B: pages S2-S13.

Cohen CA, Pringle D, LeDuc L. Dementia caregiving: The role of the primary care physician. *Canadian Journal Of Neurological Sciences* 28: S72-S76 Suppl. 1, Feb 2001.

Colantonio A, Kositsky A, Cohen C, Vernich L. What support do caregivers of elderly want? Results from the Canadian Study of Health and Aging. *Can J Public Health. Volume: 92: 376-379. (2001).*

Colodner R, Edelstein H, Chasan B, Raz R. Vaginal colonization by orally administered *Lactobacillus rhamnosus* GG. *Israel Medical Association Journal* 2003; 5(11):812-813.

Coppola, K., Ditto, P., Danke, J., Smucker, W. Accuracy of primary care and hospital-based physicians' predictions of elderly outpatients' treatment preferences with or without advance directives. *Archives of Internal Medicine*, 16, 205-212 (2001).

Covinsky KE, Palmer RM, Counsell SR, Pine ZM, Walter LC, Chren MM. Functional status before hospitalization in acutely ill older adults: validity and clinical importance of retrospective reports. *JAGS* 2000; 48(2):164-169.

Croghan JE, Burke EM, Caplan S, Denman S. Pilot study of 12-month outcomes of nursing home patients with aspiration on videofluoroscopy. *Dysphagia* 1994; 9(3):141-146.

Dautzenberg PL, Hooyer C, Schonwetter RS, Dermout KM, vd Veer JK, Duursma SA. Dementia in resuscitation policy: a prospective study of a psychogeriatric ward in a Dutch general teaching hospital. *Age Ageing* 1996; 25(3):234-238.

de la Cuesta C. The craft of care: Family care of relatives with advanced dementia. *Qualitative Health Research* 15 (7): 881-896 Sep 2005.

Ditto, P., Danke, J., Smucker, W., Coppola, K., Dresser, R. et al. Advance care directives as acts of communication: A randomized controlled trial. *Archives of Internal Medicine*, 161, 421-430 (2001).

Dull SM, Graves JR, Larsen MP, Cummins RO. Expected death and unwanted resuscitation in the prehospital setting. *Annals of Emergency Medicine* 1994; 23(5):997-1002.

Ebell MH, Becker LA, Barry HC, Hagen M. Survival after in-hospital cardiopulmonary resuscitation. A meta-analysis. *J Gen Int Med* 1998; 13(12):805-816.

Ebell, M., Siwek, J., Weiss, B., Woolf, S., Susman, J., Ewigman, B., Bowman, M.(2004) Strength of recommendation taxonomy (SORT): A patient-centred approach to grading evidence in the medical literature, 53, No. 2, 111-120

Ewbank DC. Deaths attributable to Alzheimer's disease in the United States. *Am J Publ Health* 1999; 89(1):90-92.

Finucane TE, Christmas C, Travis K. Tube feeding in patients with advanced dementia: A review of the evidence. *JAMA* 1999; 282(14):1365-1370.

Finucane TE, Harper GM. Attempting resuscitation in nursing homes: policy considerations. *JAGS* 1999; 47(10):1261-1264.

Fisk JD, Sadovnick AD, Cohen CA, Gauthier S, Dossetor J, Eberhart A et al. Ethical guidelines of the Alzheimer society of Canada. *Can J Neurol Sci* 1998; 25:242-248.

Fried TR, Gillick MR, Lipsitz LA. Short-term functional outcomes of long-term care residents with pneumonia treated with and without hospital transfer. *JAGS* 1997; 45(3):302-306.

Fried TR, Gillick MR, Lipsitz LA. Whether to transfer? Factors associated with hospitalization and outcome of elderly long-term care patients with pneumonia. *J Gen Int Med* 1995; 10(5):246-250.

Fried TR, Mor V. Frailty and hospitalization of long-term stay nursing home residents. *JAGS* 1997; 45(3):265-269.

Forbat, Liz and Kathryn Pekala Service. Who cares? Contextual layers in end-of-life care for people with intellectual disability and dementia. *Dementia*, Vol. 4, No. 3, 413-431 (2005).

Forbes S, Bern-Klug M, Gessert C. End-of-life decision making for nursing home residents with dementia. *Journal of Nursing Scholarship* 2000; 32(3):251-258.

Forbes, Sarah and Mercedes Bern-Klug, Charles Gessert. End-of-Life Decision Making for Nursing Home Residents with Dementia. *Journal of Nursing Scholarship*. Vol. 32 Issue 3 Page 251 September 2000.

Froggatt K, Payne S. A survey of end-of-life care in care homes: issues of definition and practice. *HEALTH & SOCIAL CARE IN THE COMMUNITY* 14 (4): 341-348 JUL 2006.

Fulton BR, Edelman P, Kuhn D. Streamlined models of dementia care mapping. *AGING & MENTAL HEALTH* 10 (4): 343-351 JUL 2006.

Gallicchio L, Siddiqi N, Langenberg P, Baumgarten M. Gender differences in burden and depression among informal caregivers of demented elders in the community. *International Journal of Geriatric Psychiatry*. Volume: 17:154-163. (2002).

Ganzini L, Goy ER, Miller LL, Harvath TA, Jackson A, Delorit MA. Nurses' experiences with hospice patients who refuse food and fluids to hasten death. *N Engl J Med* 2003; 349:359-365.

Gessert CE, Forbes S, Bern-Klug M. Planning end-of-life care for patients with dementia: roles of families and health professionals. *Omega* 2000; 42(4):273-291.

Gessert, Charles E., Sarah Forbes, and Mercedes Bern-Klug. Planning End-of-Life Care for Patients with Dementia: Roles of Families and Health Professionals. *OMEGA: The Journal of Death and Dying*. Volume 42, Number 4 / 2000-2001. 273 – 291.

Gessert CE, Haller IV, Kane RL, Degenholtz H. Rural-urban differences in medical care for nursing home residents with severe dementia at the end of life. *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* 54 (8): 1199-1205 AUG 2006.

Ghusn HF, Teasdale TA, Pepe PE, Ginger VF. Older nursing home residents have a cardiac arrest survival rate similar to that of older persons living in the community. *J Am Geriatr Soc* 1995; 43(5):520-527.

Gilliam CM, Steffen AM. The relationship between caregiving self-efficacy and depressive symptoms in dementia family caregivers. *AGING & MENTAL HEALTH* 10 (2): 79-86 MAR 2006.

Gillick M, Berkman S, Cullen L. A patient-centered approach to advance medical planning in the nursing home. *JAGS* 1999; 47:227-230.

Gillick MR. Sounding board - Rethinking the role of tube feeding in patients with advanced dementia. *N Engl J Med* 2000; 342(3):206-210.

Gjerdengen DK, Neff JA, Wang M, Chanoler K. Older persons' opinions about life-sustaining procedures in the face of death. *Arch Fam Med* 1999; 8(5):421-425.

Glueckauf RL, Ketterson TU, Loomis JS, Dages P. Online support and education for dementia caregivers: Overview, utilization, and initial program evaluation. *TELEMEDICINE JOURNAL AND E-HEALTH* 10 (2): 223-232 SUM 2004.

Griffith CH3, Wilson JF, Emmett KR, Ramsbottom-Lucier M, Rich EC. Knowledge and experience with Alzheimer's disease. Relationship to resuscitation preference. *Archives of Family Medicine* 1995; 4(9):780-784.

Haley WE, LaMonde LA, Han B, Burton AM, Schonwetter R. Predictors of depression and life satisfaction among spousal caregivers in hospice: application of a stress process model. *Journal of Palliative Medicine* 2003; 6(2):215-224.

Haley WE, LaMonde LA, Han B, Narramore S, Schonwetter R. Family caregiving in hospice: effects on psychological and health functioning among spousal caregivers of hospice patients with lung cancer or dementia. *Hospice Journal* 2001; 15(4):1-18.

Hanrahan P, Luchins DJ. Feasible criteria for enrolling end-stage dementia patients in home hospice care. *The Hospice Journal* 1995; 10(3):47-55.

Hanrahan P, Luchins DJ. Access to hospice programs in end-stage dementia: A national survey of hospice programs. *J Am Geriatr Soc* 1995; 43:56-59.

Hanrahan P, Raymond M, McGowan E, Luchins DJ. Criteria for enrolling dementia patients in hospice: a replication. *American Journal of Hospice and Palliative Care* 1999; 16(1):395-400.

Happ MB, Capezuti E, Strumpf NE, Wagner L, Cunningham S, Evans L et al. Advance care planning and end-of-life care for hospitalized nursing home residents. *J Am Geriatr Soc* 2002; 50(5):829-835.

Head B. End-stage dementia: hospice offers expert interdisciplinary care for end-stage dementia.

Health Canada (2000) A guide to life for end-of-life care for seniors.

Hebert RS, Dang QY, Schulz R. Preparedness for the death of a loved one and mental health in bereaved caregivers of patients with dementia: Findings from the REACH study. *Journal Of Palliative Medicine* 9 (3): 683-693 JUN 2006.

Helton MR, van der Steen JT, Daaleman TP, Gamble GR, Ribbe MW. A cross-cultural study of physician treatment decisions for demented nursing home patients who develop pneumonia. *Annals Of Family Medicine* 4 (3): 221-227 May-Jun 2006.

Heru AM, Ryan CE, Iqbal A. Family functioning in the caregivers of patients with dementia. *International Journal Of Geriatric Psychiatry* 19 (6): 533-537 Jun 2004.

Heru AM, Ryan CE. Family functioning in the caregivers of patients with dementia: One-year follow-up. *Bulletin Of The Menninger Clinic* 70 (3): 222-231 Sum 2006.

Hirakawa Y, Masuda Y, Uemura K, Kuzuya M, Kimata T, Iguchi A. End-of-life care at group homes for patients with dementia in Japan - Findings from an analysis of policy-related differences. *ARCHIVES OF GERONTOLOGY AND GERIATRICS* 42 (3): 233-245 MAY-JUN 2006.

Home Healthc Nurse. 2003 Mar;21(3):150-1. Holtzman J, Pheley AM, Lurie N. Changes in orders limiting care and the use of less aggressive care in a nursing home population. *J Am Geriatr Soc* 1994; 42(3):275-279.

Hoyert DL, Kung H-C, Smith BL. Deaths: preliminary data for 2003. *National Vital Statistics Reports* 2005; 53(15):1-48.

Huang CY, Musil CM, Zauszniewski JA, Wykle ML. Effects of social support and coping of family caregivers of older adults with dementia in Taiwan. *INTERNATIONAL JOURNAL OF AGING & HUMAN DEVELOPMENT* 63 (1): 1-25 2006.

Hughes JC, Robinson L, Volicer L. Specialist palliative care in dementia - Specialised units with outreach and liaison are needed. *BRITISH MEDICAL JOURNAL* 330 (7482): 57-58B JAN 8 2005.

Intrator O, Castle NG, Mor V. Facility characteristics associated with hospitalization of nursing home residents: results of a national study. *Med Care* 1999; 37(3):228-237.

Intrator O, Zinn J, Mor V. Nursing home characteristics and potentially preventable hospitalizations of long-stay residents. *J Am Geriatr Soc* 2004; 52(10):1730-1736.

Intrator O, Mor V. Effect of state Medicaid reimbursement rates on hospitalizations from nursing homes. *J Am Geriatr Soc* 2004; 52(3):393-398.

Janssens JP, Krause KH. Pneumonia in the very old. *Lancet Infectious Diseases* 2004; (2):112-124.

Jepson RG, Mihaljevic L, Craig J. Cranberries for preventing urinary tract infections. *Cochrane Database Syst Rev* 2004;(2):CD001321.

Karlawish J, Quill T, Meier DE. A consensus-based approach to providing palliative care to patients who lack decision-making capacity. ACP-ASIM End-of-Life Care Consensus Panel. *Ann Intern Med* 1999; 130(10):835-840.

Kane RL, Flood S, Bershadsky B, Keckhafer G. Effect of an innovative medicare managed care program on the quality of care for nursing home residents. *Gerontologist* 2005; 44(1):95-103.

Kayser-Jones J, Schell E, Lyons W, Kris AE, Chan J, Beard RL. Factors that influence end-of-life care in nursing homes: the physical environment, inadequate staffing, and lack of supervision. *Gerontologist* 2003; 43, Spec. No 2:76-84.

Kayser-Jones J, Schell ES, Porter C, Barbaccia JC, Shaw H. Factors contributing to dehydration in nursing homes: inadequate staffing and lack of professional supervision. *JAGS* 1999; 47(10):1187-1194.

Khodeir M, Conte EE, Morris JJ, Frisoni GB, Volicer L. Effect of decreased mobility on body composition in patients with Alzheimer's disease. *Journal of Nutrition, Health & Aging* 2000; 4(1):19-24.

Kiely DK, Mitchell SL, Marlow A, Murphy KM, Morris JN. Racial and state differences in the designation of advance directives in nursing home residents. *J Am Geriatr Soc* 2001; 9(10): 1346-1352.

Kiely DK, Volicer L, Teno J, Jones RN, Prigerson HG, Mitchell SL. The validity and reliability of scales for the evaluation of end-of-life care in advanced dementia. *ALZHEIMER DISEASE & ASSOCIATED DISORDERS* 20 (3): 176-181 JUL-SEP 2006.

Kikuchi R, Watabe N, Konno T, Mishina N, Sekizawa K, Sasaki H. High incidence of silent aspiration in elderly patients with community-acquired pneumonia. *American Journal of Respiratory and Critical Care Medicine* 1994; 150(1):251-253.

Krullewitch H, London MR, Skakel VJ, Lundstedt GJ, Thomason H, Brummel-Smith K. Assessment of pain in cognitively impaired older adults: a comparison of pain assessment tools and their use by nonprofessional caregivers. *JAGS* 2000; 48:1607-1611.

Kupronis BA, Richards CL, Whitney CG, Active Bacterial Core Surveillance Team. Invasive pneumococcal disease in older adults residing in long-term care facilities and in the community. *J Am Geriatr Soc* 2003; 51(11):1520-1525.

Lacey D. End-of-life decision making for nursing home residents with dementia: A survey of nursing home social services staff. *HEALTH & SOCIAL WORK* 31 (3): 189-199 AUG 2006.

Lamberg JL, Person CJ, Kiely DK, Mitchell SL. Decisions to hospitalize nursing home residents dying with advanced dementia. *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* 53 (8): 1396-1401 AUG 2005.

Langmore SE, Terpenning MS, Schork A, Chen Y, Murray JT, Lopatin D et al. Predictors of aspiration pneumonia: how important is dysphagia? *Dysphagia* 1998; 13:69-81.

Lapane KL, Gambassi G, Landi F, Sgadari A, Mor V, Bernabei R. Gender differences in predictors of mortality in nursing home residents with AD. *Neurology* 2001; 56(5):650-654.

Lee HS, Kim DK, Kim JH. Stress in caregivers of demented people in Korea - a modification of Pearlin and colleagues' stress model. *INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY* 21 (8): 784-791 AUG 2006.

Lewis CL, Cox CE, Garrett JM, Hanson L, Holmes GM, Howard A et al. Trends in the use of feeding tubes in North Carolina hospitals: 1989 to 2000. *Journal of General Internal Medicine* 2004; 19:1034-1038.

Lloyd-Williams M, Payne S. Can multidisciplinary guidelines improve the palliation of symptoms in the terminal phase of dementia? *International Journal of Palliative Care Nursing* 2002; 8(8): 370-375.

Loeb M, McGeer A, McArthur M, Walter S, Simor AE. Risk factors for pneumonia and other lower respiratory tract infections in elderly residents of long-term care facilities. *Arch Intern Med* 1999; 159(17):2058-2064.

Lombardi G, Gallagher J, Gennis P. Outcome of out-of-hospital cardiac arrest in New York City. The pre-hospital arrest survival evaluation (PHASE) study. *JAMA* 1994; 271(9):678-683.

Luchins DJ, Hanrahan P, Murphy K. Criteria for enrolling dementia patients in hospice. *J Am Geriatr Soc* 1997; 45(9):1054-1059.

Marik PE, Varon J, Lisbon A, Reich HS. Physicians' own preferences to the limitation and withdrawal of life-sustaining therapy. *Resuscitation* 1999; 42(3):197-201.

Marsh GW, Prochoda KP, Pritchett E, Vojir CP. Predicting hospice appropriateness for patients with dementia of the Alzheimer's type. *Applied Nursing Research* 2000; 13(4):187-196.

Marshall, M. The challenge of looking after people with dementia - Professional carers need higher expectations and better training and support. *BRITISH MEDICAL JOURNAL* 323 (7310): 410-411 AUG 25 2001.

Marziali E, Donahue P. Virtual support groups for family caregivers for persons with dementia. *GERONTOLOGIST* 44: 209-209 Sp. Iss.1, OCT 2004.

Mast KR, Salama M, Silverman GK, Arnold RM. End-of-life content in treatment guidelines for life-limiting diseases. *Journal of Palliative Medicine* 2004; 7(6):754-773.

Matthews FE, Dening T. Prevalence of dementia in institutional care. *LANCET* 360 (9328): 225-226 JUL 20 2002.

McCarthy M, AddingtonHall J, Altmann D The experience of dying with dementia: A retrospective study. *INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY* 12 (3): 404-409 MAR 1997.

McCormick WC, Kukull WA, Van Belle G, Bowen JD, Teri L, Larson EB. Symptom patterns and comorbidity in the early stages of Alzheimer's disease. *JAGS* 1994; 42:517-521.

Mead GE, O'Keefe ST, Jack CI, Maestri-Banks AM, Playfer JR, Lye M. What factors influence patient preferences regarding cardiopulmonary resuscitation? *Journal of the Royal College of Physicians London* 1995; 29(4):295-298.

Mebane EW, Oman RF, Kroonen LT, Goldstein MK. The influence of physician race, age, and gender on physician attitudes toward advance care directives and preferences for end-of-life decision-making. *J Am Geriatr Soc* 1999; 47(5):579-591.

Medina-Walpole AM, McCormick WC. Provider practice patterns in nursing home-acquired pneumonia. *JAGS* 1998; 46(2):187-192.

Meier DE, Ahronheim JC, Morris J, Baskin-Lyons S, Morrison RS. High short-term mortality in hospitalized patients with advanced dementia - Lack of benefit of tube feeding. *Arch Intern Med* 2001; 161(4):594-599.

Meuser TM, Marwit SJ. A comprehensive, stage-sensitive model of grief in dementia caregiving. *GERONTOLOGIST* 41 (5): 658-670 OCT 2001.

Mezey M, Kluger M, Maislin G, Mittelman M. Life-sustaining treatment decisions by spouses of patients with Alzheimer's disease. *J Am Geriatr Soc* 1996; 44:144-150.

Michel JP, Pautex S, Zekry D, Zulian G, Gold G. End-of-life care of persons with dementia. *JOURNALS OF GERONTOLOGY SERIES A-BIOLOGICAL SCIENCES AND MEDICAL SCIENCES* 57 (10): M640-M644 OCT 2002.

Miller SC, Intrator O, Gozalo P, Roy J, Barber J, Mor V. Government expenditures at the end of life for short- and long-stay nursing home residents: differences by hospice enrollment status. *J Am Geriatr Soc* 2004; 52(8):1284-1292.

Miller SC, Mor V, Wu N, Gozalo P, Lapane K. Does receipt of hospice care in nursing homes improve the management of pain at the end of life? *J Am Geriatr Soc* 2002; 50(3):507-515.

Miller SC, Mor V, Teno J. Hospice enrollment and pain assessment and management in nursing homes. *J Pain Sympt Manag* 2003; 26(3):791-799.

Mitchell SL, Berkowitz RE, Lawson FM, Lipsitz LA. A cross-national survey of tube-feeding decisions in cognitively impaired older persons. *J Am Geriatr Soc* 2000; 48(4):391-397.

Mitchell SL, Buchanan JL, Littlehale S, Hamel MB. Tube-feeding versus hand-feeding nursing home residents with advanced dementia: a cost comparison. *JAMDA* 2003; 4:27-33.

- Mitchell SL, Kiely DK. A cross-national comparison of institutionalized tube-fed older persons: the influence of contrasting healthcare systems. *Journal of the American Medical Directors Association* 2001; 2(1):10-14.
- Mitchell SL, Kiely DK, Hamel MB. Dying with advanced dementia in the nursing home. *Arch Intern Med* 2004; 164(3):321-326.
- Mitchell SL, Kiely DK, Hamel MB, Park PS, Morris JN, Fries BE. Estimating prognosis for nursing home residents with advanced dementia. *JAMA* 2004; 291(22):2734-2740.
- Mitchell SL, Kiely DK, Hamel MB. Dying with advanced dementia in the nursing home. *ARCHIVES OF INTERNAL MEDICINE* 164 (3): 321-326 FEB 9 2004.
- Mitchell SL, Kiely DK, Gillick MR. Nursing home characteristics associated with tube feeding in advanced cognitive impairment. *J Am Geriatr Soc* 2003; 51(1):75-79.
- Mitchell SL, Lawson FM. Decision-making for long-term tube-feeding in cognitively impaired elderly people. *Can Med Assoc J* 1999; 160(12):1705-1709.
- Mitchell SL, Morris JN, Park PS, Fries BE. Terminal care for persons with advanced dementia in the nursing home and home care settings. *Journal of Palliative Medicine* 2004; 7(6):808-816.
- Mitchell SL, Teno JM, Miller SC, Mor V. A national study of the location of death for older persons with dementia. *J Am Geriatr Soc* 2005; 53(2):299-305.
- Mitchell SL, Tetroe JM, O'Connor AM. A decision aid for long-term tube feeding in cognitively impaired older adults. *Journal of American Geriatrics Society* 2001; 49(3):313-316.
- Mitchell SL, Teno JM, Roy J, Kabumoto G, Mor V. Clinical and organizational factors associated with feeding tube use among nursing home residents with advanced cognitive impairment. *JAMA* 2003; 290(1):73-80.
- Mitrani VB, Feaster DJ, McCabe BE, Czaja SJ, Szapocznik J. Adapting the structural family systems rating to assess the patterns of interaction in families of dementia caregivers. *GERONTOLOGIST* 45 (4): 445-455 AUG 2005.
- Monteleoni C, Clark E. Using rapid-cycle quality improvement methodology to reduce feeding tubes in patients with advanced dementia: before and after study. *Br Med J* 2004; 329(7464): 491-494.
- Mor, V, Intrator O, Fries BE, Phillips C, Teno J, Hiris J et al. Changes in hospitalization associated with introducing the Resident Assessment Instrument. *JAGS* 1997; 45(8):1002-1010.
- Morris JC. The Clinical Dementia Rating (CDR): current version and scoring rules. *Neurology* 1993; 43:2412 -2414.

Morris J, Volicer L. Nutritional management of individuals with Alzheimer's disease and other progressive dementias. *Nutrition in Clinical Care* 2001; 4(3):148-155.

Morrison RS, Siu AL. Survival in end-stage dementia following acute illness. *JAMA* 2000; 284(1):47-52.

Muder RR, Brennen C, Swenson DL, Wagener M. Pneumonia in a long-term care facility. A prospective study of outcome. *Arch Intern Med* 1996; 156(20):2365-2370.

Munn JC, Hanson LC, Zimmerman S, Sloane PD, Mitchell CM. Is hospice associated with improved end-of-life care in nursing homes and assisted living facilities? *Journal Of The American Geriatrics Society* 54 (3): 490-495 Mar 2006.

Murphy DJ, Burrows D, Santilli S, et al. The influence of the probability of survival on patients' preferences regarding cardiopulmonary resuscitation. *N Engl J Med* 1994; 330:545-549.

Murphy K, Hanrahan P, Luchins D. A survey of grief and bereavement in nursing homes: The importance of hospice grief and bereavement for the end-stage Alzheimer's disease patient and family. *J Am Geriatr Soc* 1997; 45(9):1104-1107.

Murphy LM, Lipman TO. Percutaneous endoscopic gastrostomy does not prolong survival in patients with dementia. *Arch Intern Med* 2003;163(11):1351-1353.

Mylotte JP, Naughton B, Saludades C, Maszarovics Z. Validation and application of the Pneumonia prognosis index to nursing home residents with pneumonia. *JAGS* 46[12], 1538-1544. 1998.

Nakagawa T, Wada H, Sekizawa K, Arai H, Sasaki H. Amantadine and pneumonia. *Lancet* 1999; 353(9159):1157.

Naughton BJ, Mylotte JM, Tayara A. Outcome of nursing home-acquired pneumonia: derivation and application of a practical model to predict 30 day mortality. *JAGS* 2001; 48(10):1292-1299.

Neil S. Wenger, MD, and Kenneth Rosenfeld. Quality Indicators for End-of-Life Care in Vulnerable Elders. *Journal of the American College of Physicians*. 16 October 2001 | Volume 135 Issue 8 Part 2 | Pages 677-685.

O'Rourke N. Factor structure of the Center for Epidemiologic Studies-Depression (CES-D) Scale among older men and women who provide care to persons with dementia. *International Journal of Testing*. Volume: 5:265-277. (2005).

O'Rourke N, Haverkamp BE, Tuokko H, Hayden S, Beattie BL. Hopelessness depression among spousal caregivers of suspected dementia patients. *J Clin Geropsychol*. 1997. Volume: 3: 173-182.

O'Rourke N, Haverkamp BE, Tuokko H, Hayden S, Beattie BL. The relative contribution of subjective factors to expressed burden among spousal caregivers of suspected dementia patients. *Can J Aging*. Volume: 15:583-596. (1996).

O'Rourke N, Tuokko HA. Caregiver burden and depressive symptomatology: the association between constructs over time. *Clinical Gerontologist*. Volume: 27: 41-52. (2004).

Ory MG, Hoffman RR, Yee JL, Tennstedt S, Schulz R. Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. *GERONTOLOGIST* 39 (2): 177-185 APR 1999.

Ostbye T, Tyas S, McDowell I, Koval J. Reported activities of daily living: agreement between elderly subjects with and without dementia and their caregivers. *Age Ageing*. Volume: 26: 99-106 (1997).

Palmer LB, Albulak K, Fields S, Filkin AM, Simon S, Smaldone GC. Oral clearance and pathogenic oropharyngeal colonization in the elderly. *American Journal of Respiratory and Critical Care Medicine* 2001; 164(3):464-468.

Parks SM, Haines C, Foreman D, McKinstry E, Maxwell TL. Evaluation of an educational program for long-term care nursing assistants. *J Am Med Dir Assoc*. 2005 Jan-Feb;6(1):61-5.

Pasman HRW, Onwuteaka-Philipsen BD, Ooms ME, van Wigcheren PT, Van der Wal G, Ribbe MW. Forgoing artificial nutrition and hydration in nursing home patients with dementia – patients, decision making, and participants. *Alzheimer Dis Assoc Disord* 2004; 18(3):154-162.

Peisah C, Brodaty H, Quadrio C. Family conflict in dementia: prodigal sons and black sheep. *International Journal Of Geriatric Psychiatry* 21 (5): 485-492 May 2006.

Perls TT, Hergert M. Higher respiratory infection rates on an Alzheimer's special care unit and successful intervention. *JAGS* 1995; 43:1341-1344.

Phinney A Family strategies for supporting involvement in meaningful activity by persons with dementia. *Journal Of Family Nursing* 12 (1): 80-101 Feb 2006.

Port CL, Zimmerman S, Williams CS, Dobbs D, Preisser JS, Williams SW. Families filling the gap: Comparing family involvement for assisted living and nursing home residents with dementia. *Gerontologist* 45: 87-95 Sp. Iss. 1, Oct 2005.

Potkins D, Bradley S, Shrimanker J, O'Brien J, Swann A, Ballard C. End of life treatment decisions in people with dementia: carers' views and the factors which influence them. *Int J Ger Psychiat* 2000; 15(11):1005-1008.

Pregliasco F, Mensi C, Serpilli W, Speccher L, Masella P, Belloni A. Immunogenicity and safety of three commercial influenza vaccines in institutionalized elderly. *Aging* 2001; 13(1):38-43.

Pyenson B, Connor S, Fitch K, Kinzbrunner B. Medicare cost in matched hospice and non-hospice cohorts. *J Pain Sympt Manag* 2004; 28(3):200-210.

Rabeneck L, McCullough LB, Wray NP. Ethically justified, clinically comprehensive guidelines for percutaneous endoscopic gastrostomy tube placement. *Lancet* 1997; 349:496-498.

Raina P, McIntyre C, Zhu B, McDowell I, Santaguida L, Kristjansson B, Hendricks A, Chambers LW. Using Structural Equation Modeling to understand the role of informal & formal supports on the well-being of caregivers of persons with dementia. *Social and Economic Dimensions of an Aging Population* Volume: 95. (2003).

Raina P, McIntyre C, Zhu B, McDowell I, Santaguido L, Kristjansson B, Hendricks A, Massfeller H, Chambers LW. Understanding the influence of the complex relationships among informal and formal supports on the well-being of caregivers of persons with dementia. *Canadian Journal on Aging*. 2004. Volume: 23: S49-S59.

Reilly RB, Teasdale TA, McCullough LB. Projecting patients' preferences from living wills: an invalid strategy for management of dementia with life-threatening illness. *JAGS* 1994; 42:997-1003.

Rempusheski VF, and Hurley AC. Advance directives and dementia. *J Gerontol Nurs*. 2000 Oct;26(10):27-34.

Reyes-Ortega G, Guyonnet S, Ousset PJ, et al. Weight loss in Alzheimer's disease and resting energy expenditure (REE): a preliminary report. *JAGS* 1997; 45(11):1414-1415.

Roelands M, Van Oost P, Depoorter A, Verloo H. Knowing the diagnosis and counseling the relatives of a person with dementia: the perspective of home nurses and home care workers in Belgium. *Health & Social Care In The Community* 13 (2): 112-124 Mar 2005.

Rosin AJ, Sonnenblick M. Autonomy and paternalism in geriatric medicine. The Jewish ethical approach to issues of feeding terminally ill patients, and to cardiopulmonary resuscitation. *J Med Ethics* 1998; 24(1):44-48.

Rudberg MA, Egleston BL, Grant MD, Brody JA. Effectiveness of feeding tubes in nursing home residents with swallowing disorders. *J Parenter Enter Nutr* 2000; 24(2):97-102.

Rurup ML, Onwuteaka-Philipsen BD, Pasma HRW, Ribbe MW, van der Wal G. Attitudes of physicians, nurses and relatives towards end-of-life decisions concerning nursing home patients with dementia. *Patient Education And Counseling* 61 (3): 372-380 Jun 2006.

Rutecki GW, Cugino A, Jarjoura D, Kilner JF, Whittier FC. Nephrologists' subjective attitudes towards end-of-life issues and the conduct of terminal care. *Clinical Nephrology* 1997; 8(3):173-180.

Ryden MB, Brand K, Weber E, Oh HL, Gross C. Nursing home resuscitation policies and practices for residents without DNR orders. *Geriatr Nurs* 1998; 19(6):315-319.

Sachs, Greg A., MD, Joseph W. Shega, MD, Deon Cox-Hayley. Barriers to Excellent End-of-life Care for Patients with Dementia. *Journal of General Internal Medicine*. Volume 19, No. 10. Page 1057. (October 2004).

Saliba D, Solomon D, Rubenstein L, Young R, Schnelle J, Roth C, Wenger N. Feasibility of quality indicators for the management of geriatric syndromes in nursing home residents. *J Am Med Dir Assoc*. 2005 May-Jun;6(3 Suppl):S50-9.

Saliba D, Kington R, Buchanan J, Bell R, Wang M, Lee M et al. Appropriateness of the decision to transfer nursing facility residents to the hospital. *JAGS* 2000; 48(2):154-163.

Sampson EL, Ritchie CW, Lai R, Raven PW, Blanchard MR. A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia. *INTERNATIONAL PSYCHOGERIATRICS* 17 (1): 31-40 MAR 2005.

Sanders DS, Carter MJ, D'Silva J, James G, Bolton RP, Bardhan KD. Survival analysis in percutaneous endoscopic gastrostomy feeding: a worse outcome in patients with dementia. *Am J Gastroent* 2000; 95(6):1472-1475.

Schacke C, Zank SR. Measuring the effectiveness of adult day care as a facility to support family caregivers of dementia patients. *Journal Of Applied Gerontology* 25 (1): 65-81 Feb 2006.

Schonwetter RS, Han B, Small BJ, Martin B, Tope K, Haley WE. Predictors of six-month survival among patients with dementia: an evaluation of hospice Medicare guidelines. *American Journal of Hospice and Palliative Care* 2003; 20(2):105-113.

Schonwetter RS, Walker RM, Solomon M, Indurkha A, Robinson BE. Life values, resuscitation preferences, and the applicability of living wills in an older population. *J Am Geriatr Soc* 1996; 44(8):954-958.

Schulz R, Belle SH, Czaja SJ, McGinnis KA, Stevens A, Zhang S. Long-term care placement of dementia patients and caregiver health and well being. *JAMA* 2004; 292(8):961-967.

Schulz R, Boerner K, Shear K, Zhang S, Gitlin LN. Predictors of complicated grief among dementia caregivers: A prospective study of bereavement. *American Journal Of Geriatric Psychiatry* 14 (8): 650-658 Aug 2006.

Schulz R, Mendelsohn AB, Haley WE, Mahoney D, Allen RS, Zhang S, Thompson L, Belle SH.
End-of-life care and the effects of bereavement on family caregivers of persons with dementia.
NEW ENGLAND JOURNAL OF MEDICINE 349 (20): 1936-1942 NOV 13 2003.

Sekizawa K, Matsui T, Nakagawa T, Nakayama K, Sasaki H. ACE inhibitors and pneumonia. *Lancet* 1998; 352(9133):1069.

Shannon TA, Walter JJ. Implications of the papal allocution on feeding tubes. *Hastings Cent Rep* 2004; 34(4):18-20.

Shapiro D, Tate R. The use and cost of community care services by elders with unimpaired cognitive function, with cognitive impairment/no dementia and with dementia. *Journal: Cdn J Aging*. Volume: 16:665-681. (1997).

Shega JW, Hougham GW, Stocking CB, Cox-Hayley D, Sachs GA. Barriers to limiting the practice of feeding tube placement in advanced dementia. *Journal of Palliative Medicine* 2003; 6(6):885-893

Shega JW, Levin A, Hougham GW, Cox-Hayley D, Luchins D, Hanrahan P et al. Palliative Excellence in Alzheimer Care Efforts (PEACE): a program description. *Journal of Palliative Medicine* 2003; 6(2):315-320.

Shurgot GR, Knight BG. Influence of neuroticism, ethnicity, familism, and social support on perceived burden in dementia caregivers: Pilot test of the transactional stress and social support model. *Journals Of Gerontology Series B-Psychological Sciences And Social Sciences* 60 (6): P331-P334 Nov 2005.

Simard J, Volicer L. Barriers to providing hospice care for people with dementia. In: Volicer L, Hurley A, editors. *Hospice care for patients with advanced progressive dementia*. New York: Springer Publishing Company, 1998: 231-246.

Sloane PD, Zimmerman S, Hanson L, Mitchell CM, Riedel-Leo C, Custis-Buie V. End-of-life care in assisted living and related residential care setting: comparison with nursing homes. *J Am Geriatr Soc* 2003; 51(11):1587-1594.

Sloane PD, Zimmerman S, Williams CS, Reed PS, Gill KS, Preisser JS. Evaluating the quality of life of long-term care residents with dementia. *Gerontologist* 45: 37-49 Sp. Iss. 1, Oct 2005.

Sloss EM, Solomon DH, Shekelle PG, Young RT. Selecting target conditions for quality of care improvement in vulnerable older adults. *J Am Geriatr Soc.* 2000 Apr;48(4):363-9.

Smith M, Gerdner LA, Hall GR, Buckwalter KC. History, development, and future of the progressively lowered stress threshold: A conceptual model for dementia care. *Journal Of The American Geriatrics Society* 52 (10): 1755-1760 Oct 2004.

Solomon D, Rubenstein L, Young R, Schnelle J, Roth C et al. Feasibility of quality indicators for the management of geriatric syndromes in nursing home residents. *Journal of the American Medical Directors Association* 2004; 5(5):310-319.

Solomon DH, Wenger NS, Saliba D, Young RT, Adelman AM, Besdine RK et al. Appropriateness of quality indicators for older patients with advanced dementia and poor prognosis. *J Am Geriatr Soc* 2003; 51(7):902-907.

Spector A, Orrell M. Quality of life (QoL) in dementia: A comparison of the perceptions of people with dementia and care staff in residential homes Source: *Alzheimer Disease & Associated Disorders* 20 (3): 160-165 Jul-Sep 2006.

Spitznagel MB, Tremont G, Davis JD, Foster SM. Psychosocial predictors of dementia caregiver desire to institutionalize: Caregiver, care recipient, and family relationship factors. *Journal Of Geriatric Psychiatry And Neurology* 19 (1): 16-20 Mar 2006.

Stoltz P, Willman A, Uden G. The meaning of support as narrated by family carers who care for a senior relative at home. *QUALITATIVE HEALTH RESEARCH* 16 (5): 594-610 MAY 2006.

Swor RA, Jackson RE, Tintinalli JE, Pirrallo RG. Does advanced age matter in outcomes after out-of-hospital cardiac arrest in community-dwelling adults? *Academic Emergency Medicine* 2000; 7(7):762-768.

Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *JAMA* 2004; 291(1):88-93.

Terpenning MS, Taylor GW, Lopatin DE, Kerr CK, Dominguez BL, Loesche WJ. Aspiration pneumonia: dental and oral risk factors in an older veteran population. *J Am Geriatr Soc* 2001; 49(5):557-563.

Thomas RE, Wilson D, Sheps S. A literature review of randomized controlled trials of the organization of care at the end of life. *Canadian Journal On Aging-Revue Canadienne Du Vieillissement* 25 (3): 271-293 Fal 2006.

Thompson RS, Hall NK, Szpiech M. Hospitalization and mortality rates for nursing home-acquired pneumonia. *Journal of Family Practice* 1999; 48:291-293.

Thompson RS, Hall NK, Szpiech M, Reisenberg LA. Treatments and outcomes of nursing-home-acquired pneumonia. *J Am Board Fam Pract* 1997; 10(2):82-87.

Thornton, A, Hatton C, Tatham A. Dementia Care Mapping reconsidered: exploring the reliability and validity of the observational tool. *International Journal Of Geriatric Psychiatry* 19 (8): 718-726 Aug 2004.

Wagner C, Popp W, Posch M, Vlasich C, Rosenberger-Spitzky A. Impact of pneumococcal vaccination on morbidity and mortality of geriatric patients: a case-controlled study. *Gerontology* 2003; 49(4):246-250.

Warden V, Hurley AC, Volicer L. Development and psychometric evaluation of the PAINAD (Pain Assessment in Advanced Dementia) Scale. *JAMDA* 2003; 4:9-15. (149)
Villanueva MR, Smith TL, Erickson JS, Lee AC, Singer CM. Pain assessment for the dementing elderly (PADE): reliability and validity of a new measure. *JAMDA* 2003; 4(1):1-8.

Wieland D, Lamb VL, Sutton SR, Boland R, Clark M, Friedman S et al. Hospitalization in the Program of All-Inclusive Care for the Elderly (PACE): rates, concomitants, and predictors. *J Am Geriatr Soc* 2000; 48(11):1373-1380.

Williams J, Rees J. The use of 'dementia care mapping' as a method of evaluating care received by patients with dementia - An initiative to improve quality of life. *JOURNAL OF ADVANCED NURSING* 25 (2): 316-323 FEB 1997.

Van der Steen JT, Ooms ME, Ader HJ, Ribbe MW, van der Wal G. Withholding antibiotic treatment in pneumonia patients with dementia: a quantitative observational study. *Arch Intern Med* 2002; 162(15):1753-1760.

Van der Steen JT, Ooms ME, Mehr DR, Van der Wal G, Ribbe MW. Severe dementia and adverse outcomes of nursing home-acquired pneumonia: Evidence for mediation by functional and pathophysiological decline. *J Am Geriatr Soc* 2002; 50(3):439-448.

Van der Steen JT, Ooms ME, Ribbe MW, Van der Wal G. Decisions to treat or not to treat pneumonia in demented psychogeriatric nursing home patients: Evaluation of a guideline. *Alzheimer Dis Assoc Disord* 2001; 15(3):119-128.

Van der Steen JT, Ooms ME, Van der Wal G, Ribbe MW. Pneumonia: The demented patient's best friend? Discomfort after starting or withholding antibiotic treatment. *J Am Geriatr Soc* 2002; 50(10):1681-1688.

Volicer L. Strategies for prevention of tube feeding in advanced dementia. *AAHPM Bulletin* 2001; 1(4):1-18.

Volicer, L. End-of-life care for people with dementia in residential care settings. *Alzheimer's Association* (2005).

Volicer, L., AC Hurley, ZV Blasi. Scales for evaluation of end-of-life care in dementia. *Alzheimer Dis Assoc Disord*. 2001 Oct-Dec;15(4):194-200.

Volicer L, Berman SA, Cipolloni PB, Mandell A. Persistent vegetative state in Alzheimer disease - Does it exist? *Arch Neurol* 1997; 54(11):1382-1384.

Volicer L, Cantor MD, Derse AR, Edwards DM, Prudhomme AM, Gregory DCR et al. Advance care planning by proxy for residents of long-term care facilities who lack decision-making capacity. *J Am Geriatr Soc* 2002; 50(4):761-767.

Volicer L, Hurley AC, Blasi ZV. Characteristics of dementia end-of-life care across care settings. *American Journal of Hospice and Palliative Care* 2003; 20(3):191-20.

Volicer, Ladislav, Ann C. Hurley, and Zuzka V. Blasi. Characteristics of dementia end-of-life care across care settings. *American Journal of Hospice and Palliative Medicine* Vol. 20, No. 3, 191-200 (2003).

Volicer L, McKee A, Hewitt S. Dementia. *Neurologic Clinics of North America* 2001; 19(4):867-885.

Voordouw BC, van der Linden PD, Simonian S, vand der Lei J, Sturkenboom MC, Stricker BH. Influenza vaccination in community-dwelling elderly: impact on mortality and influenza-associated morbidity. *Arch Intern Med* 2003; 163(9):1089-1094.

Yoneyama T, Yoshida M, Ohru T, Mukaiyama Hea. Oral care reduces pneumonia in older patients in nursing homes. *J Am Geriatr Soc* 2002; 50(3):430-433.

Zimmerman S, Sloane PD, Williams CS, Reed PS, Preisser JS, Eckert JK, Boustani M, Dobbs D. Dementia care and quality of life in assisted living and nursing homes. *Gerontologist* 45: 133-146 Sp. Iss. 1, OCT 2005.

Zweig SC. Cardiopulmonary resuscitation and do-not-resuscitate orders in the nursing home. *Archives of Family Medicine* 1997; 6:424-429.

Zweig SC, Kruse RL, Binder EF, Szafara KL, Mehr DR. Effect of do-not-resuscitate orders on hospitalization of nursing home residents evaluated for lower respiratory infections. *J Am Geriatr Soc* 2004; 52(1):51-58.