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### Literature search results

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### Search details

End of life patient with dementia, CVA or is unconscious. NG, PEG or comfort feeding or intravenous or subcutaneous fluids.

### Resources searched

NHS Evidence; TRIP Database; Cochrane Library; BNI; CINAHL; EMBASE; MEDLINE; PsychINFO; Google Scholar

**Database search terms:** “end of life”; palliative* adj2 car*; TERMINAL CARE; HOSPICE CARE; PALLIATIVE CARE; terminal* adj2 car*; hospice* adj2 car*; dying adj2 patient*; dementia*; exp DEMENTIA; exp DEMENTIA, VASCULAR; Alzheimer*; exp ALZHEIMER’S DISEASE; “cerebrovascular accident*”; CVA; stroke*; TIA; “transient ischaemic attack*”; “transient ischemic attack*”; exp CEREBRAL ISCHEMIA, TRANSIENT; cerebral adj2 thrombosis; cerebral adj2 embolism*; subarachnoid adj2 haemorrhage*; subarachnoid adj2 hemorrhage*; intracerebral adj2 haemorrhage*; intracerebral adj2 hemorrhage*; apoplexy*; unconscious*; exp UNCONSCIOUSNESS; coma*; vegetative adj2 state* NG adj2 feed*; PEG adj2 feed*; nasogastric adj2 feed*; ENTERAL NUTRITION; “percutaneous endoscopic gastrostomy” adj2 feed*; “percutaneous endoscopic gastrostomy” nasogastric; feed; fed*; nutrition; comfort adj2 (feed OR fed*); (intravenous OR subcutaneous) adj2 fluid*; exp FLUID THERAPY; exp HYPODERMOCLYSIS; hypodermoclysis; “systematic review*”; metaanalyis*; meta-analyis*; META ANALYSIS; SYSTEMATIC REVIEW; RCT; (randomised OR randomized) adj2 “controlled study”; randomi* adj2 “controlled trial*”; exp CLINICAL TRIAL; “clinical trial”; “case stud*”; CASE RECORD REVIEW; CASE REPORT; CASE SERIES; CASE STUDIES; CASE STUDY; CASE-CONROL STUDIES; case adj2 report*; case adj2 series; case adj2 record*; case-control adj2 stud*; adult* ADULT; aged; exp AGED; elder*; senior*; “older people”; “older person*”; geriatric*; “later life”; “middle age”; “old* age*”; MIDDLE AGED

**Evidence search string(s):** (“end of life” OR “palliative care” OR “terminal care” OR “dying patient**” (stroke* OR TIA* OR CVA* OR “cerebrovascular accident**” OR “transient ischaemic attack**” OR unconscious*) (feeding OR fluids)
Summary

There is a great deal of research on this area, with studies looking at the ethics of feeding at end of life as well as the clinical benefit.

Guidelines

**American Stroke Association**

*Guidelines for the Early Management of Adults With Ischemic Stroke* 2007

**British Geriatrics Society**

*The provision of a percutaneously placed enteral tube feeding service* 2011

1. PEG insertion does not improve survival in end-stage dementia and should be avoided except in circumstances where it can be justified as a palliative intervention, genuinely in the patient's best interest.

2. In the terminal stages of a patient's life, the burden of PEG insertion usually outweighs any benefit. Loss of desire for food is a natural part of the dying process and there is no evidence that providing nutrition in this situation improves patients' well-being. Similarly, PEG tubes should not be placed for the purpose of administering fluid or medication to a patient in whom death is inevitable in the short term.

**Nutritional Advice in Common Clinical Situations** 2009

1. Some patients who receive PEG tubes are in the terminal phase of their illness, calling into question the appropriateness of the intervention. The physician's role is to provide best quality information [10] on the short and long-term consequences of a trial of NG or PEG feeding [14], having investigated the options, listened to all relevant parties [10] and considered the patient’s circumstances, quality of life and prognosis [15], before deciding on the appropriateness or otherwise of either procedure.

2. The best available evidence, in the absence of randomised controlled trials, suggests that PEG tube feeding does not improve overall prognosis in patients with advanced dementia [19].

   Despite the above evidence which questions the value of enteral tube feeding in general in dementia there remains a need for physicians to consider each clinical situation on its merits [14].

**Guidelines for enteral feeding in adult hospital patients** 2003

If an illness is regarded as being in a terminal phase and the plan is to provide only compassionate and palliative care, ethical considerations indicate that a tube supply of nutrients or fluid need only be given to relieve symptoms. This does not mean that it should necessarily be used to prolong survival. In cases where benefits are in doubt, a planned “time limited” trial of feeding may be useful. Consent of a competent adult patient must be sought for such treatment and a patient’s competent refusal is binding.

**General Medical Council**

*End of life care: Clinically assisted nutrition and hydration*

**Health Improvement Scotland**

*End of Life Care Following Acute Stroke Best Practice Statement* 2010
See section 2b on nutrition and hydration.

**National Health and Medical Research Council**

*Guidelines for a Palliative Approach in Residential Aged Care, 2006*

See section 6.4 on nutrition and hydration

**NHS Diabetes**

*End of Life Diabetes Care – Clinical Care Recommendations, 2012*

**NHS End of Life Care**

*Advance Decisions to Refuse Treatment: a Guide for Health and Social Care Professionals, 2008*

**NICE**

*Stroke, 2008*

The group agreed that NG tube feeding should be the intervention of choice for acute stroke (excluding those receiving palliative care) if it is practical to do so and that nasal bridle tubes or gastrostomy should be the intervention of choice if it is impractical to use a NG tube.

*Dementia, 2006*

Nutritional support, including artificial (tube) feeding, should be considered if dysphagia is thought to be a transient phenomenon, but artificial feeding should not generally be used in people with severe dementia for whom dysphagia or disinclination to eat is a manifestation of disease severity. Ethical and legal principles should be applied when making decisions about withholding or withdrawing nutritional support.

**Royal College of Physicians**

*Long-term neurological conditions: management at the interface between neurology, rehabilitation and palliative care, 2008*

**Royal College of Psychiatrists**

*Dementia and people with learning disabilities, 2009*

*Eating and drinking:* People should be supported and encouraged to eat and drink by mouth for as long as possible, with specialist advice being obtained concerning any feeding and swallowing difficulties from speech and language therapists, occupational therapists and/or dieticians. Weight loss is common in late-stage dementia. Nutritional support, including artificial (tube) feeding should be considered if dysphagia is thought to be a transient phenomenon. NICE do not recommend that such artificial means are used in those with severe dementia for whom dysphagia or disinclination to eat is a manifestation of dementia severity. Specific ethical and legal principles apply with respect to withholding or withdrawing nutritional support.

**Evidence-based reviews**

**NIHR Health Technology Assessment Programme**

*Evaluating feeding policies in patients admitted to hospital with a recent stroke, 2007*

In Trial 2, the data suggest that a policy of early tube feeding may substantially reduce the risk of dying after stroke and it is very unlikely that the alternative policy of avoiding early tube feeding would significantly improve survival.
**Published research**

1. **When surrogates collide.**

**Author(s)** Baumrucker, Steven J, Carter, Gregory T, Mingle, Paige, Stolick, Matt, Oertli, Karrie A, Schmidt, Leslie Stilin, Morris, Gerald M

**Citation:** American Journal of Hospice & Palliative Medicine, June 2012, vol./is. 29/4(321-324), 1049-9091;1938-2715 (Jun 2012)

**Publication Date:** June 2012

**Abstract:** Presents a case report of a 39 year old obese female with a history of poorly controlled diabetes mellitus who was diagnosed with a brain stem stroke and developed hydrocephalus. The medical team feels that RC will not recover and will need a tracheostomy and feeding tube placed. Although RC's boyfriend whom she lived for the last 12 years feels that RC would not want her life prolonged under these circumstances, RC's father (whom she saw 2-3 times a year and has a good relationship) does not want to "just give up." A conflict between the father and the boyfriend regarding future care and scope of treatment has resulted in an ethics consult. Who is the most appropriate surrogate? This case highlights the importance of improving the understanding of palliative care. What makes this case feel different is the emotional sympathy we feel for the both the father and the boyfriend of the patient. (PsycINFO Database Record (c) 2012 APA, all rights reserved)

**Source:** PsycINFO

Available in *print* at

2. **End-of-life care for people with dementia from ethnic minority groups: A systematic review**

**Author(s)** Connolly A., Sampson E.L., Purandare N.

**Citation:** Journal of the American Geriatrics Society, February 2012, vol./is. 60/2(351-360), 0002-8614;1532-5415 (February 2012)

**Publication Date:** February 2012

**Abstract:** A systematic review of the literature was conducted to examine the relationship between ethnic minority status and provision of end-of-life care for people with dementia. It included all empirical research on people with dementia or severe cognitive impairment or their caregivers and with ethnic minority people as a subgroup in examining an outcome involving end-of-life care processes or attitudes toward end-of-life care. Two authors independently rated quality of included studies; 20 studies met eligibility criteria and were included in the review: 19 quantitative and one qualitative. All articles were based in the United States, with African American, Hispanic, and Asian groups being the ethnic minorities. Artificial nutrition and other life-sustaining treatments were more frequent and decisions to withhold treatment less common in African American and Asian groups. The qualitative evidence, albeit limited, found that attitudes toward end-of-life care were more similar than different between different ethnic groups. Differences in hospice usage patterns were less consistent and potentially influenced by factors such as study setting and dementia severity. Caregivers' experiences differed between ethnic groups, whereas levels of strain experienced were similar. Disparities in end-of-life care for people with dementia from ethnic minority groups appear to exist and may be due to the double disadvantage of dementia and ethnic minority status. Further research is needed in other western multicultural countries, with a focus on prospective qualitative studies to understand the underlying reasons for these differences, not just their occurrence. 2012, The American Geriatrics Society.

**Source:** EMBASE

Available in *fulltext* from *Journal of the American Geriatrics Society* at the ULHT Library and Knowledge Services' eJournal collection

Available in *fulltext* at *Journal of the American Geriatrics Society*; Note: the ULHT Library and Knowledge Services' eJournal collection
3. The impact of a multidisciplinary educational intervention to reduce PEG tube placement in patients with terminal-stage dementia: A translation of research into practice

**Author(s)** Campbell M.L., Dove-Medows E., Walch J., Sanna-Gouin K., Colomba S.

**Citation:** Journal of Palliative Medicine, September 2011, vol./is. 14/9(1017-1021), 1096-6218;1557-7740 (01 Sep 2011)

**Publication Date:** September 2011

**Abstract:** The purpose of this translation of research into practice (TRIP) project was to determine the impact of a multidisciplinary education-consultation intervention to reduce percutaneous endoscopic gastrostomy (PEG) tube placement in patients with terminal-stage dementia at a single urban hospital in a city characterized by numerous health care transitions. We attempted a "just-in-time" approach to educate busy clinicians through explicit recommendations offered during routine and requested consultation. The project results showed that the intervention had a modest positive clinical impact. Copyright 2011, Mary Ann Liebert, Inc.

**Source:** EMBASE

Available in fulltext from Journal of Palliative Medicine at EBSCOhost

Available in print at

4. Decision-making and outcomes of feeding tube insertion: A five-state study

**Author(s)** Teno J.M., Mitchell S.L., Kuo S.K., Gozalo P.L., Rhodes R.L., Lima J.C., Mor V.

**Citation:** Journal of the American Geriatrics Society, May 2011, vol./is. 59/5(881-886), 0022-8614;1532-5415 (May 2011)

**Publication Date:** May 2011

**Abstract:** Objectives: To examine family member’s perceptions of decision-making and outcomes of feeding tubes. Design: Mortality follow-back survey. Sample weights were used to account for oversampling and survey design. A multivariate model examined the association between feeding tube use and overall quality of care rating regarding the last week of life. Setting: Nursing homes, hospitals, and assisted living facilities. Participants: Respondents whose relative had died from dementia in five states with varying feeding tube use. Measurements: Respondents were asked about discussions, decision-making, and outcomes related to their loved ones’ feeding problems. Results: Of 486 family members surveyed, representing 9,652 relatives dying from dementia, 10.8% reported that the decedent had a feeding tube, 17.6% made a decision not to use a feeding tube, and 71.6% reported that there was no decision about feeding tubes. Of respondents for decedents with a feeding tube, 13.7% stated that there was no discussion about feeding tube insertion, and 41.6% reported a discussion that was shorter than 15 minutes. The risks associated with feeding tube insertion were not discussed in one-third of the cases, 51.8% felt that the healthcare provider was strongly in favor of feeding tube insertion, and 12.6% felt pressured by the physician to insert a feeding tube. The decedent was often physically (25.9%) or pharmacologically restrained (29.2%). Respondents whose loved ones died with a feeding tube were less likely to report excellent end-of-life care (adjusted odds ratio=0.42, 95% confidence interval=0.18-0.97) than those who were not. Conclusion: Based on the perceptions of bereaved family members, important opportunities exist to improve decision-making in feeding tube insertion. 2011, The American Geriatrics Society.

**Source:** EMBASE

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Available in fulltext at Journal of the American Geriatrics Society; Note: the ULHT Library and Knowledge Services’ eJournal collection
5. Decision-making and outcomes of feeding tube insertion: a five-state study.

**Author(s)** Teno JM, Mitchell SL, Kuo SK, Gozalo PL, Rhodes RL, Lima JC, Mor V

**Citation:** Journal of the American Geriatrics Society, May 2011, vol./is. 59/5(881-6), 0002-8614;1532-5415 (2011 May)

**Publication Date:** May 2011

**Abstract:** OBJECTIVES: To examine family member’s perceptions of decision-making and outcomes of feeding tubes. DESIGN: Mortality follow-back survey. Sample weights were used to account for oversampling and survey design. A multivariate model examined the association between feeding tube use and overall quality of care rating regarding the last week of life. SETTING: Nursing homes, hospitals, and assisted living facilities. PARTICIPANTS: Respondents whose relative had died from dementia in five states with varying feeding tube use. MEASUREMENTS: Respondents were asked about discussions, decision-making, and outcomes related to their loved ones’ feeding problems. RESULTS: Of 486 family members surveyed, representing 9,652 relatives dying from dementia, 10.8% reported that the decedent had a feeding tube, 17.6% made a decision not to use a feeding tube, and 71.6% reported that there was no decision about feeding tubes. Of respondents for decedents with a feeding tube, 13.7% stated that there was no discussion about feeding tube insertion, and 41.6% reported a discussion that was shorter than 15 minutes. The risks associated with feeding tube insertion were not discussed in one-third of the cases, 51.8% felt that the healthcare provider was strongly in favor of feeding tube insertion, and 12.6% felt pressured by the physician to insert a feeding tube. The decedent was often physically (25.9%) or pharmacologically restrained (29.2%). Respondents whose loved ones died with a feeding tube were less likely to report excellent end-of-life care (adjusted odds ratio=0.42, 95% confidence interval=0.18-0.97) than those who were not. CONCLUSION: Based on the perceptions of bereaved family members, important opportunities exist to improve decision-making in feeding tube insertion. Copyright 2011, Copyright the Authors. Journal compilation Copyright 2011, The American Geriatrics Society.

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6. Palliative assessment and advance care planning in severe dementia: An exploratory randomized controlled trial of a complex intervention

**Author(s)** Sampson E.L., Jones L., Thune-Boyle I.C., Kukkastenvehmas R., King M., Leurent B., Tookman A., Blanchard M.R.

**Citation:** Palliative Medicine, April 2011, vol./is. 25/3(197-209), 0269-2163 (April 2011)

**Publication Date:** April 2011

**Abstract:** Patients with advanced dementia often receive poor end-of-life care. We aimed to design and pilot a palliative care and advance care plan (ACP) intervention. Patients had undergone emergency hospital admission and had severe dementia. The intervention consisted of a palliative care patient assessment which informed an ACP discussion with the carer, who was offered the opportunity to write an ACP for the person with dementia. Carer-patient dyads were randomized to ‘usual care’ or the intervention. Carer-related outcome measures included the Kessler Distress Scale, Decision Satisfaction Inventory, Client Satisfaction Questionnaire and the Euroqol-5D, measured at baseline, six weeks, six months and three months after bereavement. The Satisfaction with End of Life Care in Dementia Scale was completed if the patient died. The 32 patient participants were physically frail and in the advanced stages of dementia: 62% had pressure damage to the skin, all needed feeding assistance and 95% were in pain. Nearly 50% died during the six-month follow-up period. Carers were difficult to recruit during acute admission; 33 patients and carers entered the study (22 intervention arm; 11 control arm). Only seven carers made ACPs. The care planning discussion was well received, but few carers wrote an

**Author(s)** Sampson, Elizabeth L, Jones, Louise, Thune-Boyle, Ingela C. V, Kukkastenvehmas, Riitta, King, Michael, Leurent, Baptiste, Tookman, Adrian, Blanchard, Martin R

**Citation:** Palliative Medicine, April 2011, vol./is. 25/3(197-209), 0269-2163;1477-030X (Apr 2011)

**Publication Date:** April 2011

**Abstract:** Patients with advanced dementia often receive poor end-of-life care. We aimed to design and pilot a palliative care and advance care plan (ACP) intervention. Patients had undergone emergency hospital admission and had severe dementia. The intervention consisted of a palliative care patient assessment which informed an ACP discussion with the carer, who was offered the opportunity to write an ACP for the person with dementia. Carer-patient dyads were randomized to 'usual care' or the intervention. Carer-related outcome measures included the Kessler Distress Scale, Decision Satisfaction Inventory, Client Satisfaction Questionnaire and the Euroqol-5D, measured at baseline, six weeks, six months and three months after bereavement. The Satisfaction with End of Life Care in Dementia Scale was completed if the patient died. The 32 patient participants were physically frail and in the advanced stages of dementia: 62% had pressure damage to the skin, all needed feeding assistance and 95% were in pain. Nearly 50% died during the six-month follow-up period. Carers were difficult to recruit during acute admission; 33 patients and carers entered the study (22 intervention arm; 11 control arm). Only seven carers made ACPs. The care planning discussion was well received, but few carers wrote an ACP, despite intensive support from an experienced nurse specialist. Advance care planning is, in theory, a necessary intervention for people with severe dementia; the reluctance of carers to write plans needs to be explored further. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract)

**Source:** PsycINFO

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end of April 2010 were eligible. Study Selection: We included studies in English language and which dealt with provision of palliative care in hospital for adults who died following acute stroke (ischemic, intracerebral and subarachnoid hemorrhage). We did not restrict study type, but studies had to include provision of palliative care, including discontinuation of non-palliative medications and interventions and active management of pain, respiratory secretions, and restlessness. Studies were also included if family satisfaction with palliative care was examined by direct observation, chart review, or retrospective questionnaire.

Results: 1491 studies were screened. 10 studies ultimately met eligibility criteria, reflecting data from 905 patients. These data suggest that most patients receiving palliative care following acute stroke have similar care needs, with relatively consistent strategies for management of symptoms; however, the needs of families in these circumstances has been examined only in small studies, with family concerns regarding feeding and hydration, symptom management, and the nature of palliative care being common points of concern for family members. Satisfaction was most likely when families felt that symptoms were appropriately managed or when they were involved in decision-making regarding the palliative care process. Conclusions: A limited number of studies have examined patient needs and the needs of patients and determinants of family satisfaction in the palliative care of individuals with stroke. Death due to stroke is a frequent event and more work is required regarding to ensure appropriate guidelines are developed to reduce the burden of suffering in this process.

Source: EMBASE

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Available in fulltext from Stroke at the ULHT Library and Knowledge Services' eJournal collection
Available in fulltext from Stroke at Highwire Press

9. Acute surgical emergencies in patients at or near the end of life

Author(s) Townsend M.C.

Citation: Ochsner Journal, 2011, vol./is. 11/4(338-341), 1524-5012 (2011)

Publication Date: 2011

Abstract: Patients with advanced or incurable preexisting illnesses often develop acute surgical emergencies. The decision to proceed with aggressive surgical intervention or provide comfort measures and symptomatic relief is often difficult. This article provides an organized overview of the multiple considerations required to produce optimal patient outcome. Academic Division of Ochsner Clinic Foundation.

Source: EMBASE

Available in print at

10. Current negative mood encourages changes in end-of-life treatment decisions and is associated with false memories.

Author(s) Sharman, Stefanie J

Citation: Cognition and Emotion, January 2011, vol./is. 25/1(132-139), 0269-9931;1464-0600 (Jan 2011)

Publication Date: January 2011

Abstract: To investigate the effects of mood on people's end-of-life treatment decisions and their false memories of those decisions, participants took part in two sessions. At Time 1, participants were experimentally induced into positive or negative moods. They decided whether they would want to receive or refuse treatments in a range of hypothetical medical scenarios, such as tube feeding while in a coma. Four weeks later, at Time 2, participants were induced into the same or the opposite mood and made these decisions a second time. They also recalled their previous decisions. Participants in negative moods at Time 2...
changed more of their current decisions and falsely remembered more of their previous decisions than participants in positive moods. These findings suggest that people's current moods influence whether they change their treatment decisions; current decisions in turn bias recall of past decisions (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract)

Source: PsycINFO
Available in print at

11. Palliative geriatrics. What are the differences between oncologic and non-oncologic palliative geriatric inpatients?

Author(s) Genz, H, Jenetzky, E, Hauer, K, Oster, P, Pfisterer, M.H.-D

Citation: Zeitschrift fur Gerontologie und Geriatrie, December 2010, vol./is. 43/6(369-375), 0948-6704;1435-1269 (Dec 2010)

Publication Date: December 2010

Abstract: Aim of the study: Analysis of differences between oncologic and non-oncologic patients in the first German hospital-based special care unit for palliative geriatrics. Methods: Systematic analysis of patients' records according to a standardized protocol. Results: A total of 217 patients from a hospital-based special care unit for palliative geriatrics (56.7% women, 43.4% men) were included over a retrospective period of 1.5 years. Patients were categorized as non-oncologic (53.4%, n=116) or oncologic (46.5%, n=101). Non-oncologic patients were older than oncologic patients (84.0 vs. 76.8 years, p=0.02), and showed a higher degree of functional dependence (p<0.001) and mortality (87.1% vs. 53.3%, p<0.001). The two most common non-oncologic categories of primary diagnoses were pulmonary and neurologic diseases: 19% each. Certain secondary diagnoses had a higher incidence with non-oncologic than oncologic patients, such as pulmonary disease (39% vs. 24%, p=0.02) and dementia (38% vs. 8%, p<0.001). The Charlson comorbidity index was found to be higher for oncologic patients than for non-oncologic patients (6.6 vs. 4.1, p=0.001). Non-oncologic patients also experienced more dysphagia (57% vs. 17%, p<0.001), NPO (43% vs. 12%, p<0.001), and tube or parenteral feeding (31% vs. 9%, p=0.001). Oncologic patients experienced more often symptoms of pain, constipation, agitation, diarrhea, vomiting, and nausea. Conclusion: There are clinically relevant differences between oncologic and non-oncologic palliative geriatric inpatients regarding the constellation of symptoms, care, mortality, and the prevalence of concerns about hydration and feeding. These differences ought to be taken into account for further education, as well as further improvement of the healthcare system, to enable an appropriate standard of palliative care for geriatric patients. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract)

Source: PsycINFO

12. The case of Samuel Golubchuk and the right to live.

Author(s) Jotkowitz A, Glick S, Zivotofsky AZ

Citation: American Journal of Bioethics, March 2010, vol./is. 10/3(50-3), 1526-5161;1536-0075 (2010 Mar)

Publication Date: March 2010

Abstract: Samuel Golubchuk was unwittingly at the center of a medical controversy with important ethical ramifications. Mr. Golubchuk, an 84-year-old patient whose precise neurological level of function was open to debate, was being artificially ventilated and fed by a gastrostomy tube prior to his death. According to all reports he was neither brain dead nor in a vegetative state. The physicians directly responsible for his care had requested that they be allowed to remove the patient from life support against the wishes of the patient's family. Concurrently the Manitoba College of Physicians and Surgeons released a statement which states that the final decision to withdraw life support lies with the physician. In our opinion the statement is ethically problematic for a number of reasons. 1. It is an affront to the guiding principles of Western medical ethics; patient autonomy and human freedom. 2. The position of Samuel Golubchuk's physicians and the new statement
lack cultural sensitivity towards other traditions. 3. In modern society there exists an erosion of a basic attitude towards the value of life. 4. The ability of physicians to predict life expectancy in terminally ill patients has been shown repeatedly to be quite limited.

**Source:** Medline
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Available in *fulltext* from American Journal of Bioethics at EBSCOhost
Available in *fulltext* from American Journal of Bioethics at EBSCOhost

**13. Developing an education intervention for staff supporting persons with an intellectual disability and advanced dementia.**

**Author(s)** Fahey-McCarthy, Elizabeth, McCarron, Mary, Connaire, Kevin, McCallion, Philip

**Citation:** Journal of Policy and Practice in Intellectual Disabilities, December 2009, vol./is. 6/4(267-275), 1741-1122 (Dec 2009)

**Publication Date:** December 2009

**Abstract:** Generally, staff working in settings that provide care for adults with intellectual disabilities (ID) have not received specific education with respect to extended care for terminal illnesses or late-stage dementia. Equally, staff working in specialist palliative care often are not familiar with the unique issues of supporting persons with intellectual disabilities affected by dementia. To understand care concerns with respect to supporting persons with ID and advanced dementia, and to develop, deliver, and evaluate an educational intervention with staff in ID settings and specialist palliative care services, 14 focus group interviews were conducted with staff across six ID services and one specialist palliative care provider in the greater Dublin (Ireland) area. Qualitative descriptive analysis resulted in the emergence of key themes and formed the development of an educational intervention. Pre- and posttest questionnaires assessed responses to a pilot delivery of the educational intervention. Formal feedback from staff indicated that the educational intervention was highly valued and addressed key training concerns. They agreed that the training supported aging in place, and the preparation for a good death including support for staff, peers, and family in their grief and bereavement. An educational intervention in the form of a trainer manual was produced to support cross-service system-in-service training on issues of addressing advanced dementia in persons with ID. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract)

**Source:** PsycINFO
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**14. Evaluating an organized palliative care approach in patients with severe stroke.**

**Author(s)** Blacquiere, Dylan P. V, Gubitz, Gord J, Dupere, David, McLeod, Deborah, Phillips, Stephen

**Citation:** The Canadian Journal of Neurological Sciences/ Le Journal Canadien Des Sciences Neurologiques, November 2009, vol./is. 36/6(731-734), 0317-1671 (Nov 2009)

**Publication Date:** November 2009

**Abstract:** Background: A recent survey found few guidelines on the provision of palliative care following stroke; none examined the efficacy or results of any such process. The role of the patient's family in decision making and in conflicts with staff has not been evaluated. We sought to formally evaluate the use of locally-developed palliative care guidelines on our Acute Stroke Unit (ASU). Methods: We retrospectively examined records of 104 patients who died on our ASU over a two-year period to determine if our existing palliative guidelines were reflected in clinical practice, and to identify conflicts that arose. Data on medical and nursing care, palliative decisions, and medication use were compared to the ASU's existing palliative care guidelines. Family concerns about the palliative process were also reviewed. Results: Of patients admitted to the stroke unit, 104 (16% of total admissions) died. Ninety-four (90.4%) of these were palliated; all received routine nursing and comfort care prior to death. Median time from admission to palliation was 3.6 days; median time from admission to death was 8.5 days. Most had vital signs (98.9%).
investigations (100%) and non-palliative medications (95.7%) stopped, and had nasogastric feeding (96.8%) and intravenous fluids (87.2%) withdrawn or never begun. Most were treated with morphine (93.6%) and scopolamine (81.9%). Concerns raised by family members centered around hydration and feeding (45.7%), doubts about palliative care (27.8%) and patient comfort (18.2%). Conclusions: A formal approach to palliation results in timely decisions regarding end of life care with relatively few conflicts. Further work to address the specific concerns of families is needed. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract)

Source: PsycINFO

Available in fulltext from Canadian Journal of Neurological Sciences at EBSCOhost

15. Evaluating an organized palliative care approach in patients with severe stroke

Author(s) Blacquiere D.P.V., Gubitz G.J., Dupere D., McLeod D., Phillips S.

Citation: Canadian Journal of Neurological Sciences, November 2009, vol./is. 36/6(731-734), 0317-1671 (01 Nov 2009)

Publication Date: November 2009

Abstract: Background: A recent survey found few guidelines on the provision of palliative care following stroke; none examined the efficacy or results of any such process. The role of the patient's family in decision making and in conflicts with staff has not been evaluated. We sought to formally evaluate the use of locally-developed palliative care guidelines on our Acute Stroke Unit (ASU). Methods: We retrospectively examined records of 104 patients who died on our ASU over a two-year period to determine if our existing palliative guidelines were reflected in clinical practice, and to identify conflicts that arose. Data on medical and nursing care, palliative decisions, and medication use were compared to the ASU's existing palliative care guidelines. Family concerns about the palliative process were also reviewed. Results: Of patients admitted to the stroke unit, 104 (16% of total admissions) died. Ninety-four (90.4%) of these were palliated; all received routine nursing and comfort care prior to death. Median time from admission to palliation was 3.6 days; median time from admission to death was 8.5 days. Most had vital signs (98.9%), investigations (100%) and non-palliative medications (95.7%) stopped, and had nasogastric feeding (96.8%) and intravenous fluids (87.2%) withdrawn or never begun. Most were treated with morphine (93.6%) and scopolamine (81.9%). Concerns raised by family members centered around hydration and feeding (45.7%), doubts about palliative care (27.8%) and patient comfort (18.2%). Conclusions: A formal approach to palliation results in timely decisions regarding end of life care with relatively few conflicts. Further work to address the specific concerns of families is needed.

Source: EMBASE

Available in fulltext from Canadian Journal of Neurological Sciences at EBSCOhost

16. The clinical course of advanced dementia.

Author(s) Mitchell SL, Teno JM, Kiely DK, Shaffer ML, Jones RN, Prigerson HG, Volicer L, Givens JL, Hamel MB

Citation: New England Journal of Medicine, October 2009, vol./is. 361/16(1529-38), 0028-4793;1533-4406 (2009 Oct 15)

Publication Date: October 2009

Abstract: BACKGROUND: Dementia is a leading cause of death in the United States but is underrecognized as a terminal illness. The clinical course of nursing home residents with advanced dementia has not been well described.METHODS: We followed 323 nursing home residents with advanced dementia and their health care proxies for 18 months in 22 nursing homes. Data were collected to characterize the residents' survival, clinical complications, symptoms, and treatments and to determine the proxies' understanding of the residents' prognosis and the clinical complications expected in patients with advanced dementia.RESULTS: Over a period of 18 months, 54.8% of the residents died. The probability of pneumonia was 41.1%; a febrile episode, 52.6%; and an eating problem, 85.8%. After adjustment for age, sex, and disease duration, the 6-month mortality rate for
residents who had pneumonia was 46.7%; a febrile episode, 44.5%; and an eating problem, 38.6%. Distressing symptoms, including dyspnea (46.0%) and pain (39.1%), were common. In the last 3 months of life, 40.7% of residents underwent at least one burdensome intervention (hospitalization, emergency room visit, parenteral therapy, or tube feeding). Residents whose proxies had an understanding of the poor prognosis and clinical complications expected in advanced dementia were much less likely to have burdensome interventions in the last 3 months of life than were residents whose proxies did not have this understanding (adjusted odds ratio, 0.12; 95% confidence interval, 0.04 to 0.37). 

CONCLUSIONS: Pneumonia, febrile episodes, and eating problems are frequent complications in patients with advanced dementia, and these complications are associated with high 6-month mortality rates. Distressing symptoms and burdensome interventions are also common among such patients. Patients with health care proxies who have an understanding of the prognosis and clinical course are likely to receive less aggressive care near the end of life. 2009 Massachusetts Medical Society

Source: Medline

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Available in print at South County Hospital Medical Library

Available in print at Lincoln County Hospital Professional Library

Available in fulltext at New England Journal of Medicine; Note: the ULHT Library and Knowledge Services’ eJournal collection

17. The clinical course of advanced dementia.

Author(s) Mitchell, Susan L, Teno, Joan M, Kiely, Dan K, Shaffer, Michele L, Jones, Richard N, Prigerson, Holly G, Volcier, Ladislav, Givens, Jane L, Hamel, Mary Beth

Citation: The New England Journal of Medicine, October 2009, vol./is. 361/16(1529-1538), 0028-4793:1533-4406 (Oct 15, 2009)

Publication Date: October 2009

Abstract: Background: Dementia is a leading cause of death in the United States but is underrecognized as a terminal illness. The clinical course of nursing home residents with advanced dementia has not been well described. Methods: We followed 323 nursing home residents with advanced dementia and their health care proxies for 18 months in 22 nursing homes. Data were collected to characterize the residents' survival, clinical complications, symptoms, and treatments and to determine the proxies' understanding of the residents' prognosis and the clinical complications expected in patients with advanced dementia. Results: Over a period of 18 months, 54.8% of the residents died. The probability of pneumonia was 41.1%; a febrile episode, 52.6%; and an eating problem, 85.8%. After adjustment for age, sex, and disease duration, the 6-month mortality rate for residents who had pneumonia was 46.7%; a febrile episode, 44.5%; and an eating problem, 38.6%. Distressing symptoms, including dyspnea (46.0%) and pain (39.1%), were common. In the last 3 months of life, 40.7% of residents underwent at least one burdensome intervention (hospitalization, emergency room visit, parenteral therapy, or tube feeding). Residents whose proxies had an understanding of the poor prognosis and clinical complications expected in advanced dementia were much less likely to have burdensome interventions in the last 3 months of life than were residents whose proxies did not have this understanding (adjusted odds ratio, 0.12; 95% confidence interval, 0.04 to 0.37). Conclusions: Pneumonia, febrile episodes, and eating problems are frequent complications in patients with advanced dementia, and these complications are associated with high 6-month mortality rates. Distressing symptoms and burdensome interventions are also common among such patients. Patients with health care proxies who have an understanding of the prognosis and clinical course are likely to receive less aggressive care near the end of life. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract)

**Author(s)** Sharp, Helen M, Shega, Joseph W

**Citation:** American Journal of Speech-Language Pathology, August 2009, vol./is. 18/3(222-230), 1058-0360 (Aug 2009)

**Publication Date:** August 2009

**Abstract:** Purpose: To describe the beliefs and practices of speech-language pathologists (SLPs) about the use of percutaneous endoscopic gastrostomy (PEG) among patients with advanced dementia and dysphagia. Method: A survey was mailed to a geographically stratified random sample of 1,050 medical SLPs. Results: The response rate was 57%, and 326 surveys met inclusion criteria. Fifty-six percent of SLPs recommended PEG for a patient with advanced dementia and dysphagia. Contrary to the evidence, many respondents believed that PEG improves nutritional status and increases survival. Relatively few SLPs believed that PEG improved patients' functional status or quality of life. Patient factors (e.g., age or prognosis) were more often identified as influences on recommendations for PEG than were extrinsic factors (e.g., cost). Nearly 40% believed that PEG was the standard of care, while 15% believed it should be. Very few SLPs (11%) would want a PEG themselves. Perceived standard of care was significantly related to both geographic region and population density (p < .05), but self-reported practices were not. Conclusions: Discrepancies between SLPs' beliefs, the literature, and self-reported practices were observed. The findings suggest the need to connect the evidence base to clinical practice and to include SLPs in local and national discussions about end-of-life care protocols. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract)

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19. Unnecessary time pressure in refusal of life-sustaining therapies: fear of missing the opportunity to die.

**Author(s)** Cochrane TI

**Citation:** American Journal of Bioethics, April 2009, vol./is. 9/4(47-54), 1526-5161;1536-0075 (2009 Apr)

**Publication Date:** April 2009

**Abstract:** During an illness requiring brief use of life-sustaining therapy (LST), patients and surrogates sometimes feel that LST must be withdrawn before it becomes unnecessary to avoid later being stuck living in a debilitated condition that the patient considers worse than death. This fear depends on the belief that the patient can legitimately refuse only artificial LST, so that if such therapies are no longer required, he or she will have missed the 'opportunity to die.' This fear of being stuck with life can lead to premature decisions to terminate LST and is unfounded because adequate ethical and moral justification exists for refusal of not just artificial LST, but also for refusal of natural LST, including oral hydration.
20. Fluids and nutrition: perspectives from Jewish Law (Halachah).

**Author(s)** Rosner F, Abramson N

**Citation:** Southern Medical Journal, March 2009, vol./is. 102/3(248-50), 0038-4348;1541-8243 (2009 Mar)

**Publication Date:** March 2009

**Abstract:** PURPOSE: The use of nutrition and hydration in the terminally ill had been considered normal supportive measures until recently. Currently, many institutions, health care personnel and family members hold that nutrition and hydration are extraordinary measures that may be terminated. METHODS: A case is offered to discuss the ruling by traditional Jewish law (Halachah) on the issue of nutrition and hydration. RESULTS: Judaism upholds the supreme sanctity of human life. Fluids and nutrition are considered as ordinary supportive measures rather than heroic. CONCLUSION: Withholding of fluids and nutrition is inconsistent with Jewish law. These modalities are neither withheld nor withdrawn on the patient with the brain tumor, dementia, and previous wishes not to be kept alive with machines.

**Source:** Medline

Available in **print** at

Available in **fulltext from American Journal of Bioethics at EBSCOhost**


**Author(s)** Babiarczyk, Beata, Kolonko, Jolanta

**Citation:** Psychogeriatria Polska, 2009, vol./is. 6/2(71-80), 1732-2642 (2009)

**Publication Date:** 2009

**Abstract:** Older people often suffering from dementia are an increasingly large segment of the Polish society. Patients in advanced stages of dementia often develop eating and feeding difficulties, depending on the severity of their cognitive impairment. Deciding how to care a patient with dementia who has stopped eating is difficult and raise ethical dilemmas for caregivers. The decisions are often made under pressure of family and society or are conducted by religious principles. This review will offer an analysis of the ethical and moral aspects of artificial nutrition and hydration decisions, based on the actual literature in this field. There are many opinions, often contradictory, regarding artificial nutrition in patient with advanced dementia, but most of the authors agree that the primary issue must be the respect for individual's right to self-determination. Careful calculation of benefits and burdens of artificial nutrition and hydration in accordance with cultural principles of the patient it may be of a major importance. If burdens of the artificial nutrition overweight benefits it should be withheld or withdrawn and palliative care should be the alternative choice. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract)

**Source:** PsycINFO

Available in **print** at

22. Patient preferences in instructional advance directives.

**Author(s)** Abbo, Elmer D, Sobotka, Sarah, Meltzer, David O

**Citation:** Journal of Palliative Medicine, May 2008, vol./is. 11/4(555-562), 1096-6218;1557-7740 (May 2008)

**Publication Date:** May 2008
**Abstract:** Background: Instructional advance directives (ADs) are traditionally written to apply in terminal illness. As such, they do not readily capture patient preferences for care in acute and chronic illness. Objective: To test whether patients prefer a modified AD that includes preferences to limit life-sustaining therapy (LST) for critical illness and advanced dementia over a traditional AD. Methods: A convenience sample of medically stable, hospitalized general medical patients were presented a traditional AD (the recommended Illinois statutory living will that limits LST in terminal illness) and a modified AD. The modified AD presents four conditional options: (1) to limit LST in terminal illness, (2) to limit LST in critical illness to a reasonable trial, (3) to refuse LST in advanced dementia (described in lay language), and (4) to refuse artificial hydration and nutrition (AHN) in advanced dementia. The primary outcome was the preferred AD to present to patients. Secondary outcomes included the AD choice of those who executed an AD and the options chosen by those executing the modified AD. Results: Seventy-two patients completed the survey. Eighty-six percent (95% confidence interval [CI], 76%-93%), preferred that the modified AD be presented to patients over the traditional AD. Twenty-one patients chose to execute an AD. Eighteen (86%; 95% CI, 64%-97%), executed the modified AD. Twelve executed all four options. Conclusions: Traditional instructional ADs fail to capture important patient preferences. Future research should further validate these preferences and explore whether including these specific options in ADs can improve their efficacy. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract)

**Source:** PsycINFO
Available in fulltext from *Journal of Palliative Medicine* at EBSCOhost

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**23. Freedom to choose: How to make end-of-life decisions on your own terms.**

**Author(s)** Burnell, George M

**Citation:** Freedom to choose: How to make end-of-life decisions on your own terms., 2008 (2008)

**Publication Date:** 2008

**Abstract:** (from the foreword) I began writing this book after I saw the appalling ignorance about the issues surrounding the Terri Schiavo case by journalists, politicians, television and radio commentators, leaders in Congress, and the White House. I felt that they and the public at large should be better informed about end-of-life situations that can face any of us at any time: the loss of brain function following an acute illness or accident, which can lead to a condition known as a "persistent vegetative state," the prospect of a lingering terminal illness, accompanied by insupportable suffering; and the possibility of living on tube-feeding and life-support machines for years when brain dead. Despite the notoriety of previous cases in the 70s and 80s, such as Karen Ann Quinlan and Nancy Cruzan, both in their twenties, recent polls have shown that less than a third of the population has completed advance directives that would have prevented the dilemma faced by the Schiavo family. There are many reasons why we fail to complete advance directives. First, there is a natural tendency to procrastinate the completion of such documents, which we associate with a terminal illness and with old age. Second, our culture tends to deny death, and we face any matter related to dying as something that is far away in the future and that concerns other people, not us. Third, many people think that completing advance directives--if they have knowledge of them--is a costly and complex matter that requires legal consultation; and then there is the superstitious feeling that if you don't ask for it, it won't occur. Fourth, people believe that physicians and health care professionals will use their best judgment when it comes to making decisions about end-of-life care; therefore there is no need to predict or second-guess what treatments will be needed in a time of crisis. And finally, should we be unable to make a decision for our health care, our family will decide what is best for us. All of these reasons can lead to difficult and emotionally charged situations for the individual and the family, which could easily be avoided with proper knowledge, information, guidance, and preparation. It is my hope that this book will help resolve whatever doubts and concerns you may have about these critical end-of-life issues and help you make the right decisions for yourself and your loved ones. (PsycINFO Database Record (c) 2012 APA, all rights reserved)
### 24. Complications of and controversies associated with percutaneous endoscopic gastrostomy: Report of a case and literature review

**Author(s)** Potack J.Z., Chokhavatia S.

**Citation:** MedGenMed Medscape General Medicine, 2008, vol./is. 10/6, 1531-0132 (2008)

**Publication Date:** 2008

**Abstract:** Context: Percutaneous endoscopic gastrostomy (PEG) is one of the most commonly performed gastrointestinal procedures, despite absence of benefit in many patients and risks associated with the procedure. Increased education of primary care physicians about the shortcomings of PEG may allow for better selection of patients to be referred for PEG placement. Evidence acquisition: We performed a comprehensive literature review by searching PUBMED using the search headings percutaneous enteral gastrostomy, PEG, complications, dementia, stroke, dysphagia, malnutrition, and complications. We identified English language articles from 1980 onward. The highest quality data were considered to be randomized controlled trials although given the paucity of trials in this area, we used all of the various types of literature. Evidence synthesis: We based the major conclusions of this review, where possible, on the most robust literature, namely, controlled trials. However, the majority of the available literature in this field is based on case series. We attempted to maximize the use of larger case series with longer term follow-up. Case reports were used only to report on rare complications where no other literature was available. Conclusions: Despite more than 30 years of experience with PEG, numerous questions remain regarding the utility of nutrition support in many of the clinical scenarios in which PEG placement is contemplated. There is a multitude of evidence that artificial nutrition does not improve outcome or quality of life in patients with dementia who have decreased oral intake. It is likely that ethical, moral, religious, and legal considerations of family members and caregivers play a role in the decision to place a PEG in a patient with dementia despite the medical evidence demonstrating lack of benefit. 2008 Medscape.

**Source:** EMBASE

Available in print at

### 25. Jewish law and end-of-life decision making: A case report

**Author(s)** Blinderman C.D.

**Citation:** Journal of Clinical Ethics, December 2007, vol./is. 18/4(384-390), 1046-7890 (Winter 2007)

**Publication Date:** December 2007

**Source:** EMBASE

Available in print at

### 26. A 93-year-old man with advanced dementia and eating problems.

**Author(s)** Mitchell SL

**Citation:** JAMA, December 2007, vol./is. 298/21(2527-36), 0098-7484;1538-3598 (2007 Dec 5)

**Publication Date:** December 2007

**Abstract:** More than 5 million Americans have dementia, a leading cause of death among persons older than 65 years in the United States. Eating problems typically develop during the advanced stage of dementia, which requires decision making to direct care toward either palliation or more aggressive measures, such as tube feeding. The case of Mr P, a 93-year-old man with end-stage dementia and recent hip fracture, illustrates the issues involved in this challenging crossroads when his daughter is confronted with his failure to orally maintain adequate hydration and nutrition. The discussion reviews the epidemiology and natural history of advanced dementia, the barriers to providing palliative care to
patients with this condition, the role of pharmacotherapy, and the treatment options for feeding problems and the advantages and disadvantages of each option, and suggests an approach to help clinicians provide effective and compassionate decision support to patients with advanced dementia and their family members.

**Source:** Medline

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27. Forgoing artificial nutrition or hydration in patients nearing death in six European countries.

**Author(s)** Buiting, Hilde M, van Delden, Johannes J. M, Rietjens, Judith A. C, Onwuteaka-Philipsen, Bregje D, Bilsen, Johan, Fischer, Susanne, Lofmark, Rutik, Miccinesi, Guido, Norup, Michael, van der Heide, Agnes, EURELD-Consortium

**Citation:** Journal of Pain and Symptom Management, September 2007, vol./is. 34/3 (305-314), 0885-3924 (Sep 2007)

**Publication Date:** September 2007

**Abstract:** Whether or not artificial nutrition or hydration (ANH) may be forgone in terminally ill patients has been the subject of medical and ethical discussions. Information about the frequency and background characteristics of making decisions to forgo ANH is generally limited to specific clinical settings. The aim of this study was to compare the practice of forgoing ANH in six European countries: Belgium, Denmark, Italy, The Netherlands, Sweden, and Switzerland. In each country, random samples were drawn from death registries. Subsequently, the reporting physician received a questionnaire about the medical decisions that preceded the patient's death. The total number of deaths studied was 20,480. The percentage of all deaths that were preceded by a decision to forgo ANH varied from 2.6% in Italy to 10.9% in The Netherlands. In most countries, decisions to forgo ANH were more frequently made for female patients, patients aged 80 years or older, and for patients who died of a malignancy or disease of the nervous system (including dementia). Of patients in whom ANH was forgone, 67%-93% were incompetent. Patients in whom ANH was forgone did not receive more potentially life-shortening drugs to relieve symptoms than other patients for whom other end-of-life decisions had been made. Decisions to forgo ANH are made in a substantial percentage of terminally ill patients. Providing all patients who are in the terminal stage of a lethal disease with ANH does not seem to be a widely accepted standard among physicians in Western Europe.

**Source:** PsycINFO

Available in *print* at Lincoln County Hospital Professional Library

28. The attitudes of Chinese family caregivers of older people with dementia towards life sustaining treatments.

**Author(s)** Kwok, Timothy, Twinn, Sheila, Yan, Elsie

**Citation:** Journal of Advanced Nursing, May 2007, vol./is. 58/3 (256-262), 0309-2402;1365-2648 (May 2007)

**Publication Date:** May 2007

**Abstract:** Aim: This paper is a report of a study to examine attitudes towards life-sustaining treatment in family caregivers of older Chinese people with dementia. Background: Deferring decisions about life-sustaining treatments to surrogate decision-makers is common among older people with dementia. However, surrogate decision-makers frequently lack knowledge about disadvantages and benefits of treatments and do not understand the principles of surrogate decision-making. Method: A total of 51 Chinese
family caregivers were interviewed during 2003 and 2004. The interview included an assessment of their knowledge about cardiopulmonary resuscitation and tube feeding, a questionnaire to assess their anticipated decisions for four treatments (cardiopulmonary resuscitation, artificial ventilation, tube feeding and antibiotic administration) if the older relative suffered critical illness or irreversible coma, and their comfort and certainty in making such decisions. Findings: Family caregivers displayed poor knowledge about life-sustaining treatments, with 30 (59%) and 13 (26%) unable to name any feature of cardiopulmonary resuscitation and tube feeding, respectively. Most relied on their own views in decision-making rather than on what they thought their relative would have wanted. Most family caregivers were reluctant to forgo treatments. Nursing home residence predicted family caregivers’ willingness to forgo artificial ventilation for critical illness. Financial burden predicted inclination to forgo antibiotics for critical illness and irreversible coma, as well as tube feeding in irreversible coma. Conclusion: More dialogue and education are needed about end of life issues in the early phase of dementia. Nurses should be aware of the cultural implications of surrogate decision-making for Chinese family caregivers. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract)

Source: PsycINFO
Available in fulltext from *Journal of Advanced Nursing* at EBSCOhost

29. Satisfaction with End-of-Life Care for Nursing Home Residents with Advanced Dementia.

**Author(s)** Engel, Sharon E, Kiely, Dan K, Mitchell, Susan L

**Citation:** Journal of the American Geriatrics Society, October 2006, vol./is. 54/10(1567-1572), 0002-8614;1532-5415 (Oct 2006)

**Publication Date:** October 2006

**Abstract:** Objectives: To identify factors associated with satisfaction with care for healthcare proxies (HCPs) of nursing home (NH) residents with advanced dementia. Design: Cross-sectional study. Setting: Thirteen NHs in Boston. Participants: One hundred forty-eight NH residents aged 65 and older with advanced dementia and their formally designated HCPs. Measurements: The dependent variable was HCPs' score on the Satisfaction With Care at the End of Life in Dementia (SWC-EOLD) scale (range 10-40; higher scores indicate greater satisfaction). Resident characteristics analyzed as independent variables were demographic information, functional and cognitive status, comfort, tube feeding, and advance care planning, HCP characteristics were demographic information, health status, mood, advance care planning, and communication. Multivariate stepwise linear regression was used to identify factors independently associated with higher SWC-EOLD score. Results: The mean ages +/- standard deviation of the 148 residents and HCPs were 85.0 +/- 8.1 and 59.1 +/- 11.7, respectively. The mean SWC-EOLD score was 31.0 +/- 4.2. After multivariate adjustment, variables independently associated with greater satisfaction were more than 15 minutes discussing advance directives with a care provider at the time of NH admission (parameter estimate=-2.39, 95% confidence interval (CI)=1.16-3.61, P<.001), greater resident comfort (parameter estimate=0.10, 95% CI=0.02-0.17, P=.01), care in a specialized dementia unit (parameter estimate=1.48, 95% CI=0.25-2.71, P=.02), and no feeding tube (parameter estimate=-2.87, 95% CI=0.46-5.25, P=.02). Conclusion: Better communication, greater resident comfort, no tube feeding, and care in a specialized dementia unit are modifiable factors that may improve satisfaction with care in advanced dementia. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract)

**Source:** PsycINFO
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Available in print at *Pilgrim Hospital Staff Library*
30. A patient with dementia and cancer: to feed via percutaneous endoscopic gastrostomy tube or not?.

**Author(s)** Shah SH

**Citation:** Palliative Medicine, October 2006, vol./is. 20/7(711-4), 0269-2163:0269-2163 (2006 Oct)

**Publication Date:** October 2006

**Abstract:** Despite the lack of clear benefits of feeding via gastrostomy tube in dementia patients, its use has been increasing. The views of health professionals, patients and their carers differ widely about the perceived benefits, which makes decision-making difficult and stressful. The palliative care approach of facilitating better communication and end-of life care planning can help avoid inappropriate gastrostomy tube placements. A case of an elderly male with dementia and two malignancies is described, and the place of the palliative care approach is explored.

**Source:** Medline

Available in fulltext from Palliative Medicine at EBSCOhost

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31. Expectations and outcomes of gastric feeding tubes.

**Author(s)** Carey TS, Hanson L, Garrett JM, Lewis C, Phifer N, Cox CE, Jackman A

**Citation:** American Journal of Medicine, June 2006, vol./is. 119/6(527.e11-6), 0002-9343;1555-7162 (2006 Jun)

**Publication Date:** June 2006

**Abstract:** PURPOSE: To compare expected outcomes with actual outcomes from tube feeding in adult patients.SUBJECTS AND METHODS: This prospective cohort study was conducted in two North Carolina hospitals. Surrogates were interviewed shortly after feeding tube insertion and at 3- and 6-month follow-up; chart abstraction and death certificate review also were carried out. Participants were surrogate decision-makers for consecutive adult patients who received new feeding tubes.RESULTS: There were 288 patients with surrogate decision-makers enrolled. Mean age was 65 years; 30% had a primary diagnosis of stroke, 16% neurodegenerative disorder, 20% head and neck cancer, and 30% other diagnoses. At 3 months, 21% of patients had died, and 6-month mortality was 30%. At 3 months, 38% of survivors were residing in a nursing home, and 27% had the feeding tube removed. Patients were impaired in most activities of daily living (ADLs) with little change over time. Medical complications were common: 25% of patients had decubitus ulcers at 3 months, and 24% had at least one episode of pneumonia. Perceived global quality of life was poor at 4.6 (on a 0-10 scale) at baseline, and surrogates anticipated this would improve to 8.0 with tube feeding. Family surrogates' expectations for improvement from the feeding tube were very high at baseline and remained so at 3 and 6 months.CONCLUSIONS: Families' high expectations of benefit from tube feeding are in contrast to clinical outcomes. Providers and families need better information about the outcomes of this common procedure.

**Source:** Medline

Available in print at

32. [Amyotrophic lateral sclerosis--when planning is almost too late]. [German] Amyotrope Lateralsklerose--wenn die Planung fast zu spat kommt.

**Author(s)** Praxmarer V, Lahrmann H

**Citation:** Wiener Medizinische Wochenschrift, May 2006, vol./is. 156/9-10(297-301), 0043-
Amyotrophic lateral sclerosis (ALS) is a disease with progressive muscle weakness, also affecting respiratory muscles. In the terminal phase most patients experience a progression. Nutrition, speech and breathing capacity decrease. It is important to inform the patient and relatives in time and to give them a chance to decide. "Care Planning" and "Advance Directives" especially concerning ventilation reduces fear and helps the doctors and carers to decide, following the will of the patient. Nobody knows the speed of the progression. The patient in this case had few subjective symptoms at the time of the family conference. Progression till death lasted one month only. Treatment of his dyspnoe was not optimised, but during care all decisions were based on the actual will of the patient. Generally nocturnal hypoventilation, for instance non-invasive ventilation by BiPAP-mode, can relieve symptoms of dyspnoe in ALS patients. Low-dose morphine and/or benzodiazepine relieve respiratory discomfort and remove the negative spiral of dyspnoe-fear-dyspnoe. Oxygen therapy is usually not needed (only in the very last stages of the disease) and is not recommended especially during the night. Hypercapnia can occur because of hypoventilation. This can cause growing unconsciousness and maybe death during sleep. Prolonging life is only possible by invasive long-term ventilation with all the problems of intensive care measures. The patient could have been given low dose morphine from the time of the family conference. Ventilation by CPAP-mode was insufficient for him.

Source: Medline

33. A patient with dementia and cancer: To feed via percutaneous endoscopic gastrostomy tube or not?

Author(s) Shah S.H.

Citation: Palliative Medicine, 2006, vol./is. 20/7(711-714), 0269-2163 (2006)

Abstract: Despite the lack of clear benefits of feeding via gastrostomy tube in dementia patients, its use has been increasing. The views of health professionals, patients and their carers differ widely about the perceived benefits, which makes decision-making difficult and stressful. The palliative care approach of facilitating better communication and end-of-life care planning can help avoid inappropriate gastrostomy tube placements. A case of an elderly male with dementia and two malignancies is described, and the place of the palliative care approach is explored. 2006 Sage Publications.

Source: EMBASE

Available in fulltext from Palliative Medicine at EBSCOhost

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34. The problem of futile treatments. Practical theoretical considerations in the dementia patient [Spanish] El problema de los tratamiento inutiles. Consideraciones teoricopracticas en el paciente con demencia

Author(s) Ara J.R.

Citation: Neurologia Suplementos, December 2005, vol./is. 1/4(32-39), 1695-5374 (December 2005)

Abstract: Treatment possibilities of diseases have increased greatly due to the scientific medicine advances, and the limits that point out the irreversibility of the end of life have become blurred. This situation has led to the use of treatments that can be considered unnecessary from the technical or patient point of view. We can define a treatment as futile when it will have no beneficial effect on the patient. This could be because the biological effect or action attributed to the treatment will not be effective due to clinical conditions of
the patient, either because the patient considers that such treatment is not beneficial enough for him/her or he/she rejects it. Among patients who suffer from advanced dementia, it is frequently discussed if intercurrent infections should be treated with antibiotics and if we should feed them artificially in case of dysphagia. In both cases, with greater evidence in the case of artificial feeding, available studies suggest their inefficiency, so that the neurologist should consider them optional treatments, not clearly indicated, and make an agreement with the patient's representative on the decision to make. Since possible conflicts may arise between the patient's family and neurologist about what kind of treatments should be considered futile, it is necessary to establish explicit guidelines, promoted from hospitals, scientific societies or similar institutions.

Source: EMBASE
Available in print at

35. The Terri Schiavo case: legal, ethical, and medical perspectives.

Author(s) Perry JE, Churchill LR, Kirshner HS
Citation: Annals of Internal Medicine, November 2005, vol./is. 143/10(744-48), 0003-4819:1539-3704 (2005 Nov 15)
Publication Date: November 2005
Abstract: Although tragic, the plight of Terri Schiavo provides a valuable case study. The conflicts and misunderstandings surrounding her situation offer important lessons in medicine, law, and ethics. Despite media saturation and intense public interest, widespread confusion lingers regarding the diagnosis of persistent vegetative state, the judicial processes involved, and the appropriateness of the ethical framework used by those entrusted with Terri Schiavo's care. First, the authors review the current medical understanding of persistent vegetative state, including the requirements for patient examination, the differential diagnosis, and the practice guidelines of the American Academy of Neurology regarding artificial nutrition and hydration for patients with this diagnosis. Second, they examine the legal history, including the 2000 trial, the 2002 evidentiary hearing, and the subsequent appeals. The authors argue that the law did not fail Terri Schiavo, but produced the highest-quality evidence and provided the most judicial review of any end-of-life guardianship case in U.S. history. Third, they review alternative ethical frameworks for understanding the Terri Schiavo case and contend that the principle of respect for autonomy is paramount in this case and in similar cases. Far from being unusual, the manner in which Terri Schiavo's case was reviewed and the basis for the decision reflect a broad medical, legal, and ethical consensus. Greater clarity regarding the persistent vegetative state, less apprehension of the presumed mysteries of legal proceedings, and greater appreciation of the ethical principles at work are the chief benefits obtained from studying this provocative case.

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36. The Terri Schiavo case: Legal, ethical, and medical perspectives

Author(s) Perry J.E., Churchill L.R., Kirshner H.S.
Citation: Annals of Internal Medicine, November 2005, vol./is. 143/10(744-748), 0003-4819 (15 Nov 2005)
Publication Date: November 2005
Abstract: Although tragic, the plight of Terri Schiavo provides a valuable case study. The conflicts and misunderstandings surrounding her situation offer important lessons in medicine, law, and ethics. Despite media saturation and intense public interest, widespread confusion lingers regarding the diagnosis of persistent vegetative state, the judicial processes involved, and the appropriateness of the ethical framework used by those entrusted with Terri Schiavo's care. First, the authors review the current medical
understanding of persistent vegetative state, including the requirements for patient examination, the differential diagnosis, and the practice guidelines of the American Academy of Neurology regarding artificial nutrition and hydration for patients with this diagnosis. Second, they examine the legal history, including the 2000 trial, the 2002 evidentiary hearing, and the subsequent appeals. The authors argue that the law did not fail Terri Schiavo, but produced the highest-quality evidence and provided the most judicial review of any end-of-life guardianship case in U.S. history. Third, they review alternative ethical frameworks for understanding the Terri Schiavo case and contend that the principle of respect for autonomy is paramount in this case and in similar cases. Far from being unusual, the manner in which Terri Schiavo's case was reviewed and the basis for the decision reflect a broad medical, legal, and ethical consensus. Greater clarity regarding the persistent vegetative state, less apprehension of the presumed mysteries of legal proceedings, and greater appreciation of the ethical principles at work are the chief benefits obtained from studying this provocative case. 2005 American College of Physicians.

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37. Who cares?: Contextual layers in end-of-life care for people with intellectual disability and dementia.

Author(s) Forbat, Liz, Service, Kathryn Pekala

Citation: Dementia: The International Journal of Social Research and Practice, October 2005, vol./is. 4/3(413-431), 1471-3012;1741-2684 (Oct 2005)

Publication Date: October 2005

Abstract: The complexity of the relationship between intellectual disability (ID) and dementia is increasingly acknowledged. In order to operationalize a route towards person-centred care, we introduce the hierarchy model (Pearce, 1999) as a tool to focus the attention of policy and practice on all aspects of caregiving. This tool, which is taken from the family therapy literature, enables practitioners to examine the broad systems that impact on the delivery and receipt of care. In this article, we focus on its utility in scrutinizing end-of-life and later stages of dementia by illustrating its use with three key areas in dementia care. These three areas provide some of the most challenging situations at the end stages, because of the possible treatment options, they are: nutrition, medical interventions, and the location of care provision. This model enables a focused approach to understanding how meaning is created within social interaction. The article draws out implications for practice and policy and has applications for practice internationally. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract)

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38. Tube feeding, antibiotics, and hospitalization of nursing home residents with end-stage dementia: Perceptions of key medical decision-makers.

Author(s) Lacey, Debra

Citation: American Journal of Alzheimer's Disease and Other Dementias, July 2005, vol./is. 20/4(211-219), 1533-3175;1938-2731 (Jul-Aug 2005)

Publication Date: July 2005

Abstract: This article discusses the literature supporting the limited use of tube feeding, antibiotics, and hospital transfers of nursing home residents with end-stage dementia. This article also presents the findings of a study that queried 138 nursing home social service staff members in New York State regarding positions taken by key medical decision makers regarding tube feeding, antibiotic use, and hospitalization of nursing home residents with end-stage dementia. Results are discussed in the context of positions taken by experts in palliative and dementia care. According to social service staff perceptions, the majority of
these key decision-makers (e.g., administrators, directors of nursing, and medical directors) take positions inconsistent with palliative care experts. Instead, a majority of them were perceived as more likely to encourage tube feeding, antibiotics, and hospitalization of nursing home residents with end-stage dementia. These findings indicate a strong need for educating administrative staff in state-of-the-art care of residents with end-stage dementia. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract)

Source: PsycINFO
Available in print at

39. The PEG "consult".

Author(s) Scott LD
Citation: American Journal of Gastroenterology, April 2005, vol./is. 100/4(740-3), 0002-9270:0002-9270 (2005 Apr)
Publication Date: April 2005
Source: Medline
Available in fulltext from American Journal of Gastroenterology at EBSCOhost

40. Events and decision-making in the long-term care of Dutch nursing home patients in a vegetative state.

Author(s) Lavrijsen J, van den Bosch H, Koopmans R, van Weel C, Froeling P
Citation: Brain Injury, January 2005, vol./is. 19/1(67-75), 0269-9052;0269-9052 (2005 Jan)
Publication Date: January 2005
Abstract: OBJECTIVE: To clarify characteristics of long-term care and treatment of patients in a vegetative state.DESIGN: Qualitative, descriptive study in a Dutch nursing home.METHODS: Review of clinical records of patients in a vegetative state after acute brain damage between 1978-2002.RESULTS: Five patients received intensive care of a multi-disciplinary team and showed considerable co-morbidity. There was no standard scenario for end-of-life decisions. Physicians play a more proactive role by evaluating the total medical treatment instead of withholding therapy in case of incidental complications. The families’ attitude is a crucial factor in their ultimate decision.CONCLUSIONS: There is no standard solution to alleviate the fate of patients in a vegetative state and their families. Withdrawing all medical treatment, including artificial nutrition and hydration, can be an acceptable scenario for letting the patient die. More research is needed to identify the factors that contribute to acceptance of the physician's decision by the family.

Source: Medline
Available in print at
Available in fulltext from Brain Injury at EBSCOhost

41. Artificial nutrition and the public guardian.

Author(s) Menkin E
Citation: Journal of Palliative Medicine, October 2004, vol./is. 7/5(723-6), 1096-6218;1557-7740 (2004 Oct)
Publication Date: October 2004
Source: Medline
Available in fulltext from Journal of Palliative Medicine at EBSCOhost
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42. Parenteral hydration and nutrition in the geriatric patient: clinical and ethical
A common ethical and legal issue in elder care involves the decision to withhold or withdraw parenteral hydration and nutrition (PHN) at the end of life and in the terminal stage of dementia. The aging of the population will impact the frequency with which nurses face this situation in their practices and with their families. The ethical, legal, and clinical issues involving PHN discussed in this article will assist the nurse in his or her practice.

43. Assessing the older person: is the MNA a more appropriate nutritional assessment tool than the SGA?.

OBJECTIVES: A study was undertaken to determine which nutritional assessment tool would be better in assessing changes in nutritional status over time in hospitalised older patients. The two tools used were the Mini Nutritional Assessment (MNA) and the Subjective Global Assessment (SGA). DESIGN: Single blind, prospective study conducted over a 60-day period. SETTING: Five regional hospitals within Southern New South Wales, Australia. SUBJECTS: There were 43 patients at the commencement of the study, then 28 patients at day 30 and 20 patients at day 60. METHODS: All patients over 65 years of age admitted to the five hospitals during May 2001 were eligible. The only exclusions were those patients admitted to palliative care or with severe dementia. Two dietitians saw each patient. Each dietitian assessed the patient using his or her assigned nutritional assessment tool either the SGA or the MNA. All dietitians were randomly assigned the tool at the commencement of the study. They were familiarised with the use of the tool by participating in a workshop prior to the start of the study. RESULT: The MNA was able to detect greater numbers of malnourished subjects when compared to the SGA. This finding was consistent across Day 0, 30 and 60 and statistically significant (p<0.05) at all time periods. CONCLUSIONS: This study has shown the MNA to be a more appropriate nutrition assessment tool for older patients when compared to the SGA. The MNA is better able to identify severely malnourished patients. This study illustrated the potential use of the MNA as an ongoing monitor of nutritional status and hence a measure of the impact of nutrition intervention.

44. Ethical conflicts in decision making [Spanish] Conflictos eticos en la toma de decisiones.

Given the progressive ageing of the population, we treat "older old" every day. In an acute hospital, whose purpose is cure, sanitary workers are not always prepared to face death and we tend to use all disposable means, omitting patient globality, his general conditions and his quality of life. From the point of view of geriatric attention, patient, is an holistic being, we think the impact of illness in functional capacity and we analyze each case individually, without forgetting quality of life, illness evolution and palliative care if...
necessary. Nutritional problems are frequent in advanced dementia, the discussion is that nutritional supplementation with nasogastrical probe (NGP) should be considered as a basic care or a treatment. When we decide to begin artificial nutrition by means of NGP we must consider if those patients are in terminal phases, of their illness. In those cases we should not ignore that this nutrition probably will not prolong life neither will improve its quality, but it can produce discomfort to the patient. Regarding the previous reasons, we discuss the convenience of placing a nasogastrical probe in the patient who is not able to take her own decisions, bearing in mind, her quality of life.

Source: EMBASE

45. Assessing the older person: Is the MNA a more appropriate nutritional assessment tool than the SGA?

Author(s) Barone L., Milosavljevic M., Gazibarich B.

Citation: Journal of Nutrition, Health and Aging, 2003, vol./is. 7/1(13-17), 1279-7707 (2003)

Publication Date: 2003

Abstract: OBJECTIVES: A study was undertaken to determine which nutritional assessment tool would be better in assessing changes in nutritional status over time in hospitalised older patients. The two tools used were the Mini Nutritional Assessment (MNA) and the Subjective Global Assessment (SGA). DESIGN: Single blind, prospective study conducted over a 60-day period. SETTING: Five regional hospitals within Southern New South Wales, Australia. SUBJECTS: There were 43 patients at the commencement of the study, then 28 patients at day 30 and 20 patients at day 60. METHODS: All patients over 65 years of age admitted to the five hospitals during May 2001 were eligible. The only exclusions were those patients admitted to palliative care or with severe dementia. Two dietitians saw each patient. Each dietitian assessed the patient using his or her assigned nutritional assessment tool either the SGA or the MNA. All dietitians were randomly assigned the tool at the commencement of the study. They were familiarised with the use of the tool by participating in a workshop prior to the start of the study. RESULT: The MNA was able to detect greater numbers of malnourished subjects when compared to the SGA. This finding was consistent across Day 0, 30 and 60 and statistically significant (p<0.05) at all time periods. CONCLUSIONS: This study has shown the MNA to be a more appropriate nutrition assessment tool for older patients when compared to the SGA. The MNA is better able to identify severely malnourished patients. This study illustrated the potential use of the MNA as an ongoing monitor of nutritional status and hence a measure of the impact of nutrition intervention.

Source: EMBASE

46. Gender differences in older adults’ preferences for life-sustaining medical treatments and end-of-life values.

Author(s) Bookwala, Jamila, Coppola, Kristen M, Fagerlin, Angela, Ditto, Peter H, Danks, Joseph H, Smucker, William D

Citation: Death Studies, March 2001, vol./is. 25/2(127-149), 0748-1187;1091-7683 (Mar 2001)

Publication Date: March 2001

Abstract: In the present study, the authors examined gender differences in preferences for life-sustaining treatments in response to various health state scenarios and the endorsement of end-of-life values in 99 older adults (mean age 73.2 yrs). Men preferred life-sustaining treatments more than women overall, for specific treatments (i.e., CPR, surgery, and artificial feeding), and in response to specific health scenarios (i.e., current health, Alzheimer's disease, coma with a slight chance of recovery). In terms of values, women indicated a greater desire for a dignified death than men. (PsycINFO Database Record (c) 2012 APA, all rights reserved)

Source: PsycINFO
47. End of life treatment decisions in people with dementia: Carers' views and the factors which influence them.

Author(s) Potkins, Dawn, Bradley, Sonia, Shrimanker, Jay, O'Brien, John, Swann, Alan, Ballard, Clive

Citation: International Journal of Geriatric Psychiatry, November 2000, vol./is. 15/11(1005-1008), 0885-6230;1099-1166 (Nov 2000)

Publication Date: November 2000

Abstract: Examined the wishes of carers regarding end of life treatment decisions and factors influencing these decisions. 50 carers of 50 people with dementia (mean age 81.4 yrs) were asked four treatment decision questions pertaining to cardiac resuscitation, intravenous fluids, oral antibiotics and intravenous antibiotics. The impact of key variables (age, dementia severity, psychiatric co-morbidity, physical illness, family relationship of carer) on treatment decisions was evaluated. 46% of the carers wanted cardiac resuscitation, 60% wanted treatment with intravenous fluids, 52% wanted treatment with intravenous antibiotics and 60% wanted treatment with oral antibiotics. Agreement between questions was high (76-89%), suggesting that relatives were either for or against intervention. There was an association between more severe dementia and a reduced wish for intravenous antibiotics. None of the variables significantly influenced other treatment decisions. It is concluded that the 'global' view of carers was not influenced greatly by key disease variables. There are potential implications for the way in which carers are used as proxy decision makers. (PsycINFO Database Record (c) 2012 APA, all rights reserved)

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48. Palliative Care in Advanced Dementia: A Randomized Controlled Trial and Descriptive Analysis.

Author(s) Ahronheim, Judith C, Morrison, R. Sean, Morris, Jane, Baskin, Shari, Meier, Diane E

Citation: Journal of Palliative Medicine, September 2000, vol./is. 3/3(265-273), 1096-6218;1557-7740 (Sep 2000)

Publication Date: September 2000

Abstract: Background: Few patients with end-stage dementia are enrolled in hospice care. A palliative care approach would nonetheless seem to be appropriate in various care settings, including the acute care hospital. Methods: We conducted a randomized controlled trial of palliative care in patients with advanced dementia (Functional Assessment Staging Tool [FAST] stage 6d-7f) who were hospitalized with acute illness. Intervention patients received recommendations by a palliative care team with the goal of enhancing patient comfort; control patients received usual care without these recommendations. Results: Among 99 patients enrolled over 3 years, groups were comparable at baseline in terms of gender, age, race, dementia stage, and advance directive status. Outcomes were similar in terms of mean number of hospitalizations, average length of stay, and mortality. Intervention patients were more likely than control patients to receive a palliative care plan (23% versus 4%; p = 0.008), usually on discharge, and more decisions were made to forgo certain medical treatments but the numbers were small. Fewer patients in the intervention group received intravenous therapy throughout the admission (66% vs. 81%, p = 0.025). Overall, additional interventions included daily
phlebotomy for at least half of the admission (41%), systemic antibiotics (75%), and new feeding tubes (44%). Including tubes present at the time of randomization, a total of 69% received long-term enteral feeding. Conclusion: It was difficult for a palliative care research team to influence the care of advanced dementia patients in the acute hospital setting. When patients have advanced dementia, there may be unique barriers, including perceived prognostic uncertainty, difficulty assessing comfort level, and perceptions about tube feeding. There must be a reexamination of treatment approaches for this severely impaired group of patients. Further study should attempt to identify patients prior to the need for acute hospitalization so goals can be established when there is less urgency to make life and death decisions. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract)

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49. Making decision about tube feeding for severely demented patients at the end of life: Clinical, legal, and ethical considerations.

**Author(s)** Hoefler, James M

**Citation:** Death Studies, April 2000, vol./is. 24/3(233-254), 0748-1187;1091-7683 (Apr-May 2000)

**Publication Date:** April 2000

**Abstract:** Notes that caregivers and family members are forced to deal with questions about tube feeding at the end of life for hundreds of thousands of patients suffering from severe dementia every year. But decisions about accepting or forgoing artificial nutrition and hydration (ANH) tend to be made in haste, late in the game, without benefit of full information. Oftentimes, this leads to increased patient suffering and the inefficient use of medical resources. Surviving family members and caregivers may experience a haunting sense of guilt, wondering if they made the right decision at the right time. The professional literature suggests that forgoing ANH is an entirely appropriate alternative at the end of life. The vast majority of Americans say they do not want to be tube fed if mortally ill and are no longer able to eat on their own. Nonetheless, the provision of aggressive nutrition and hydration support for the severely demented population at the end of life is the norm in America. If there were more awareness of (1) the burdens typically associated with ANH; (2) the pathogenesis of terminal dehydration, and; (3) the medical, legal, and ethical acceptability of terminal dehydration, then forgoing of ANH might become more commonly considered. (PsycINFO Database Record (c) 2012 APA, all rights reserved)

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Available in *fulltext* from *Death Studies* at *EBSCOhost*

50. Palliative care in advanced dementia: A randomized controlled trial and descriptive analysis

**Author(s)** Ahronheim J.C., Morrison R.S., Morris J., Baskin S., Meier D.E.

**Citation:** Journal of Palliative Medicine, 2000, vol./is. 3/3(265-273), 1096-6218 (2000)

**Publication Date:** 2000

**Abstract:** Background: Few patients with end-stage dementia are enrolled in hospice care. A palliative care approach would nonetheless seem to be appropriate in various care settings, including the acute care hospital. Methods: We conducted a randomized controlled trial of palliative care in patients with advanced dementia (Functional Assessment Staging Tool [FAST] stage 6d-7f) who were hospitalized with acute illness. Intervention patients received recommendations by a palliative care team with the goal of enhancing patient comfort; control patients received usual care without these
recommendations. Results: Among 99 patients enrolled over 3 years, groups were comparable at baseline in terms of gender, age, race, dementia stage, and advance directive status. Outcomes were similar in terms of mean number of hospitalizations, average length of stay, and mortality. Intervention patients were more likely than control patients to receive a palliative care plan (23% versus 4%; p = 0.008), usually on discharge, and more decisions were made to forgo certain medical treatments but the numbers were small. Fewer patients in the intervention group received intravenous therapy throughout the admission (66% vs. 81%, p = 0.025). Overall, additional interventions included daily phlebotomy for at least half of the admission (41%), systemic antibiotics (75%), and new feeding tubes (44%). Including tubes present at the time of randomization, a total of 69% received long-term enteral feeding. Conclusion: It was difficult for a palliative care research team to influence the care of advanced dementia patients in the acute hospital setting. When patients have advanced dementia, there may be unique barriers, including perceived prognostic uncertainty, difficulty assessing comfort level, and perceptions about tube feeding. There must be a reexamination of treatment approaches for this severely impaired group of patients. Further study should attempt to identify patients prior to the need for acute hospitalization so goals can be established when there is less urgency to make life and death decisions.

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J Hallenbeck - Journal of palliative medicine, 2002 - online.liebertpub.com
... “Fast Facts,” a project of the National Residency End-of-Life Curriculum Project ... A recent literature review using palliative care and enteral nutrition as search terms found no studies ... H: Relation between incidence of pneumonia and protective reflexes in post-stroke patients with ...
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ME Groher, TP Groher - Topics in Language Disorders, 2012 - journals.lww.com
... University of Redlands, Redlands, California (Dr Groher); and Palliative Care Consult Services, Saint Joseph's Hospital of Atlanta ... End-of-life disease often compromises swallowing safety. ... Hypodermal clysis is a form of parenteral nutrition that is given for hydration through the ...
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SM Dy, DR Feldman - Journal of general internal medicine, 2012 - Springer
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The difficulties of swallowing at the end of life
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... (Ask your health care provider if you have any questions regarding your loved one's
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D Lacey - American journal of Alzheimer's disease and other ... 2005 - aja.sagepub.com

... 8.33 In sum, research has not identified any appreciable benefits to tube feeding in end-stage dementia, but risks ... research can also help identify best practices for administrative staff in the implementation of improving palliative care for declining ...

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... There are particular challenges for developing and evaluating these tools in the context of end-of-life decisions. ... The scenarios in the feeding tube decision aid include: (1) an older woman in reasonably good health who suffered stroke impairing her ability to swallow. ...

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