

From: Code A
 Sent: 11 May 2003 12:01
 To: richard.baker@Code A
 Subject: Ovid Citations

Ovid Technologies, Inc. Email Service

 Search for: 2 and 5
 Citations: 2-48

Database: MEDLINE <1996 to April Week 4 2003>
 Search Strategy:

 1 exp PALLIATIVE CARE/ or exp Terminal Care/ (15664)
 2 limit 1 to (human and english language) (12165)
 3 Aged/ (407050)
 4 1 and 3 (4102)
 5 exp DEMENTIA/ (24069)
 6 4 and 2 (3368)
 7 exp Heroin/ (823)
 8 6 and 7 (2)
 9 exp GUIDELINES/ (26756)
 10 2 and 5 (145)
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 61,65,68,72,75,79-80,82,87,89,93,95,107,109,113-114,121-122,125-126,131,134-
 135,140,144 (47)

Citation <1>

Unique Identifier

12571827

Medline Identifier

22458848

Authors

Coetzee RH. Leask SJ. Jones RG.

Institution

Division of Psychiatry, University of Nottingham, A Floor, South Block, Queens Medical Centre, Nottingham, NG7 2UH, UK.

Title

The attitudes of carers and old age psychiatrists towards the treatment of potentially fatal events in end-stage dementia.

Source

International Journal of Geriatric Psychiatry. 18(2):169-73, 2003 Feb.

Abstract

BACKGROUND: Deciding how to treat patients with end-stage dementia developing potentially fatal events has long been contentious. Under expected new legislation the role of carers is likely to increase. Old age psychiatrists frequently have to decide between active or palliative approaches to such patients. Little is known concerning the comparative attitudes of carers and old age psychiatrists. This research examined how their attitudes differed.

METHODS: A Likert scale attitudinal questionnaire was designed following a literature review and was initially distributed to a pilot group of medical students to aid in establishing reliability and validity. Subsequently it was sent to all members of the local Alzheimer's

Society Branch and all the old age psychiatrists in the health region. Its validity and reliability were investigated using factor analysis and test-retest reliability. Between group comparisons were then made using the students t-test and analysis of variance. R!

ESULTS: 148 carers and 34 clinicians responded. Factor analysis and test-retest analysis of students' responses validated six questions, which grouped into two factors, relating to active treatment and patient-centred ethics. Between group comparisons revealed significant differences between carers' and clinicians' attitudes in these areas. Clinicians favoured active treatment of potentially fatal events in end-stage dementia less than carers who more significantly valued patient-centred issues such as dying with dignity, the patient's best interests and the patient's wishes. CONCLUSIONS: Old age psychiatrists and carers significantly differed in their attitudes towards treatment of potentially fatal events in end-stage dementia and this may impact on decision-making. Considerably more clinician/carer debate and dialogue seems needed. Copyright 2003 John Wiley & Sons, Ltd.

Citation <2>

Unique Identifier

12569925

Medline Identifier

22456143

Authors

Owen JE. Goode KT. Haley WE.

Institution

University of Alabama at Birmingham, USA.

Title

End of life care and reactions to death in African-American and white family caregivers of relatives with Alzheimer's disease.

Source

Omega - Journal of Death & Dying. 43(4):349-61, 2001.

Abstract

Family caregivers for relatives with Alzheimer's Disease (AD) often experience significant stress-related problems in mental and physical health. Patients with AD often survive for protracted periods of time, placing an extensive burden of care on the caregiver prior to the patient's death. The present study addresses ethnic differences in the experience of AD caregivers around the time of their loved one's death, including life-sustaining treatment decisions and reactions to death. The results showed that, in our sample, more patients died in their homes than has been reported for deaths in the United States. African-American and White caregivers differed substantially in their reports of end of life care and subjective reactions to the death. Compared with White caregivers, African-American caregivers were less likely to make a decision to withhold treatment at the time of death, less likely to have their relative die in a nursing home, and reported less acceptance of the ! relative's death and greater perceived loss. Results suggest that death after AD caregiving deserves further study, and that ethnic differences in end of life care and bereavement may be of particular importance.

Citation <3>

Unique Identifier

12569923

Medline Identifier

22456141

Authors

Gessert CE. Forbes S. Bern-Klug M.

Institution

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Title

Planning end-of-life care for patients with dementia: roles of families and health professionals.

Source

Omega - Journal of Death & Dying. 42(4):273-91, 2000.

Abstract

We examined families' end-of-life decision making and their interactions with health professionals. Twenty-eight family members of institutionalized dementia patients participated in four focus groups. We found that participating family members were not well prepared for their decision-making roles, and that they: 1) experienced substantial burdens and loss in caring for institutionalized elders; 2) had limited understanding of the natural progression of dementing conditions; 3) were uncomfortable in setting goals for their relatives' end-of-life care; 4) had little experience with death, and were ambivalent about the anticipated death of their relative; and (5) reported that they had little substantive communication with health professionals regarding end-of-life care planning. We concluded that many of the needs of such families could be addressed through improved application of the principles of advance care planning, including regular structured discussions, involvement of surrogate decision-makers, and anticipation of clinical decisions. Health professionals should take the lead in 'normalizing' the discussion of death.

Citation <4>

Unique Identifier

12544465

Medline Identifier

22431668

Authors

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Institution

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Title

Palliative care for persons with dementia. [Review] [11 refs]

Source

Home Healthcare Nurse. 21(1):53-60; quiz 61, 2003 Jan.

Abstract

Home care and hospice nurses provide invaluable care for patients with Alzheimer's Disease and related disorders. Often these patients have advanced disease and may be approaching the end of life. This article describes a palliative care approach to providing comprehensive assessment, care planning, and interventions enhancing the functioning and quality of life for both the patient and family coping with this illness. [References: 11]

Citation <5>

Unique Identifier

12442969

Medline Identifier

22330133

Authors

Kirchhoff M.

Title

Lack of knowledge and training affects quality of hospice care for persons with dementia. [comment].

Comments

Comment on: Am J Hosp Palliat Care. 2002 Jul-Aug;19(4):263-6; PMID: 12141791

Source

American Journal of Hospice & Palliative Care. 19(6):372, 2002 Nov-Dec.

Citation <6>

Unique Identifier

12366622

Medline Identifier

22254762

Authors

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Title

Pneumonia: the demented patient's best friend? Discomfort after starting or withholding antibiotic treatment.

Source

Journal of the American Geriatrics Society. 50(10):1681-8, 2002 Oct.

Abstract

OBJECTIVES: To assess suffering in demented nursing home patients with pneumonia treated with antibiotics or without antibiotics. This study should provide the first empirical data on whether pneumonia is a "friend" or an "enemy" of demented patients and promote a debate on appropriate palliative care. **DESIGN:** Prospective cohort study. **SETTING:** Psychogeriatric wards of 61 nursing homes in the Netherlands. **PARTICIPANTS:** Six hundred sixty-two demented patients with pneumonia treated with (77%) or without (23%) antibiotics. **MEASUREMENTS:** Using an observational scale (Discomfort Scale-Dementia of Alzheimer Type), discomfort was assessed at the time of the pneumonia treatment decision and periodically thereafter for 3 months or until death. (Thirty-nine percent of patients treated with antibiotics and 93% of patients treated without antibiotics died within 3 months.) Physicians also offered a retrospective judgment of discomfort 2 weeks before the treatment decision. In addition,!

pneumonia symptoms were assessed at baseline and on follow-up. Linear regression was performed with discomfort shortly before death as an outcome. **RESULTS:** A peak in discomfort was observed at baseline. Compared with surviving patients treated with antibiotics, the level of discomfort was generally higher in patients in whom antibiotic treatment was withheld and in nonsurvivors. However, these same patients had more discomfort before the pneumonia. Breathing problems were most prominent. Shortly before death from pneumonia, discomfort increased. Discomfort was higher shortly before death when pneumonia was the final cause of death than with death from other causes.

CONCLUSION: Irrespective of antibiotic treatment, pneumonia causes substantial suffering in demented patients. Adequate symptomatic treatment deserves priority attention.

Citation <7>

Unique Identifier

12418367

Medline Identifier

22306234

Authors

Albinsson L. Strang P.

Institution

Department of Public Health and Caring Science, Uppsala University, Uppsala.

Title

A palliative approach to existential issues and death in end-stage dementia care.

Source

Journal of Palliative Care. 18(3):168-74, 2002 Fall.

Abstract

The aim of this study was to investigate how, in relation to the palliative philosophy of care, municipal staff caring for patients with dementia deal with existential issues, the dying process, and bereavement follow up with next of kin. **METHODS:** Thirty-one semi-structured interviews were performed and analyzed using a modified phenomenographic method. **RESULTS:** Those interviewed experienced existential issues as difficult to handle, and they felt lost. Three patterns of answers emerged: 1) attempting to minimize or ignore the issue, 2) pleading, in relation to the patient, that no one has control over issues concerning life and death, and 3) showing affection for the patient. When faced with dying patients, they made things easier for the family, and their goal was that the patient should not be left alone. No systematic bereavement follow up of next of kin occurred. **DISCUSSION:** Suggestions are made for improving municipal care, and applying palliative care principles for patients dying of dementia.

Citation <8>

Unique Identifier

12425711

Medline Identifier

22313785

Authors

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Institution

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Title

Alzheimer Disease: "It's okay, Mama, if you want to go, it's okay".

Source

JAMA. 288(18):2324-31, 2002 Nov 13.

Abstract

About 4 million people in the United States have Alzheimer disease (AD) and the number of incident cases is expected to more than double from 377,000 in 1995 to 959,000 in 2050. Patients, their families, and health care professionals struggle with a relentless and irreversible neurological syndrome that can last from 2 to 20 years. Alzheimer disease causes both cognitive and functional impairments that predispose the patient to behavioral symptoms, destroy intellectual capacity and personality, erase the ability to communicate one's wishes for care, and lead to life-threatening consequences. At the close of life, family members and clinicians face decisions regarding degrees of intensive medical care to be provided for treatment of the late-stage consequences of AD, including withdrawal of invasive interventions, initiation of hospice, and treatment of a range of progressive medical conditions. Physicians can assist patients with AD and their loved ones through the terminal phases of the illness by preparing them for the relentless progression of the disease and by supporting them through the intellectual and emotional conflicts accompanying the end of life.

Citation <9>

Unique Identifier

12401040

Medline Identifier

22288120

Authors

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Institution

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Title

How physicians approach advance care planning in patients with mild to moderate Alzheimer's disease.

Source

Journal of the American Osteopathic Association. 102(10):541-4, 2002 Oct.

Abstract

Decision-making ability regarding end-of-life issues is often compromised by dementia in patients with Alzheimer's disease. This study assessed physicians' discussions of advance care planning with patients with mild to moderate Alzheimer's disease. Data were collected by a survey of full-time faculty in the departments of Medicine and Family Medicine and the Center for Aging at the University of Medicine and Dentistry of New Jersey-School of Osteopathic Medicine, as well as physicians in private practice affiliated with the Kennedy Health System. Data consisted of questions that assessed whether advance care planning was provided, what specific topics were discussed, and what actions were taken if advance care planning was not offered. Of the 271 physicians to whom the survey was sent, 63 responded, for a return rate of 23%. Of those responding, 81% indicated that they counseled their patients regarding advance care planning issues, while 19% did not. Of those who provided ! advance care planning for their patients (N = 51), 88% discussed living wills; 53%, the durable power of attorney for healthcare; 47%, end-of-life care; and 35%, financial planning issues. Thirty-seven percent recommended an elder law attorney, and 31% made a referral to the Alzheimer's Association. Of those who provided advance care planning for their patients' caregivers (N = 51), 86% discussed living wills; 78%, nursing home care; 69%, driving issues; and 47%, end-of-life care. Twenty-five percent referred their patients to an elder law attorney. Results indicate that physicians need to be more knowledgeable and proactive in their approaches to advance care planning for patients with mild to moderate Alzheimer's disease.

Citation <10>

Unique Identifier

12242316

Medline Identifier

22226788

Authors

Michel JP. Pautex S. Zekry D. Zulian G. Gold G.

Institution

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Title

End-of-life care of persons with dementia. [Review] [60 refs]

Source

Journals of Gerontology Series A-Biological Sciences & Medical Sciences. 57(10):M640-4, 2002 Oct.

Abstract

Many clinicians with different training and practice are involved in the care of persons with dementia. Whereas neurologists and psychiatrists focus their attention on the early phase of dementia, geriatricians and palliative care specialists are particularly involved at the end of demented patients' lives. To summarize the progress of knowledge in this field, it seems possible to answer four fundamental questions. When? Several longitudinal studies of cohorts of demented and nondemented patients showed clearly that dementia is a risk factor for early death. There are no survival differences between Alzheimer's and Lewy body disease patients. Patients with vascular dementia have the worst prognosis. These results need to be analyzed with consideration of associated comorbidity, types and intensity of care, and dementia treatment. Why? Studies conducted on the basis of death certificates appear to be biased. A large autopsy study performed in the geriatric department of Geneva! a University Hospital showed no difference existed in immediate causes of death between demented and nondemented hospitalized old patients. On the other hand, cardiac causes are significantly more frequent in vascular dementia than in Alzheimer's disease or mixed dementia patients. How? Deaths of demented patients raise a lot of ethical considerations. It is always difficult to know demented patients' awareness of the end of life. It is really difficult to accompany these patients, with whom communication is essentially nonverbal. During this delicate phase of the end of life, how can formal health professionals help the family members who are afraid of both death and dementia? And after? Suffering of family members and caregivers has to be strongly considered. This goal includes the improvement of our communication skills with the patient, and the facilitation of interdisciplinary exchanges with the caregiver's team and with the family members to allow acceptance of the death!

. [References: 60]

Citation <11>

Unique Identifier

12271257

Medline Identifier

22231547

Authors

Lloyd-Williams M. Payne S.

Institution

Community Studies Unit, Department of Primary Care, University of Liverpool, UK.

Title

Can multidisciplinary guidelines improve the palliation of symptoms in the terminal phase of dementia?.

Source

International Journal of Palliative Nursing. 8(8):370-5, 2002 Aug.

Abstract

Dementia is a progressive terminal disease. More than 95% of patients will require 24-hour care either in long-stay hospital wards or in nursing homes at the end of life. There are many issues in the care of patients with dementia that parallel palliative cancer care, but relatively few patients with dementia currently access palliative care. Following an initial audit that found that many patients dying with dementia had symptoms that were not palliated, multidisciplinary guidelines were developed jointly by medical and nursing staff working in psychiatry for older people, together with pharmacy and palliative care staff. Following the implementation of guidelines, there was a significant decrease in the prescribing of antibiotics in the last 2 weeks of life and patients were much more likely to be prescribed analgesia,

including opiates. This small study suggests that when developed collaboratively, multidisciplinary guidelines can have a positive impact on palliative care! for non-oncology patients.

Citation <12>

Unique Identifier

12046995

Medline Identifier

22041922

Authors

Hinkka H. Kosunen E. Lammi EK. Metsanoja R. Puustelli A. Kellokumpu-Lehtinen P.

Institution

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Title

Decision making in terminal care: a survey of finnish doctors' treatment decisions in end-of-life scenarios involving a terminal cancer and a terminal dementia patient.

Source

Palliative Medicine. 16(3):195-204, 2002 May.

Abstract

GOALS: The physicians' decision-making process in terminal care is complex: medical, ethical, legal and psychological aspects are all involved, particularly in critical situations. Here, a study was made of the association of personal background factors with end-of-life decisions. **METHODS:** A questionnaire was sent to 300 surgeons, 300 internists, 500 health centre practitioners (GPs) and all 82 Finnish oncologists. The response rate was 62%. Two scenarios were presented: one involving a terminal cancer patient, the other a dementia patient. Sociodemographic factors, general life values and attitudes related to end-of-life care were asked. **MAIN RESULTS:** In the cancer case (Scenario 1) 17%, and in the dementia case (Scenario 2) 43% of all the respondents chose active treatment. In a logistic regression analysis of treatment decisions in Scenario 1, physician's age, specialty, marital status and attitudes to assisted suicide and withdrawal of life-sustaining treatment (LST) entered the model. In Scenario 2, the variables were physician's age, physician's own experience of severe disease in the family, attitude to withdrawal of LST and opinion of advanced directives. **CONCLUSIONS:** Doctors' end-of-life decisions vary widely according to personal background factors. The findings underline the importance of advance communication, making these decisions in accordance with the patient's wishes.

Citation <13>

Unique Identifier

12040307

Medline Identifier

22034849

Authors

Casarett D. Takesaka J. Karlawish J. Hirschman KB. Clark CM.

Institution

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Title

How should clinicians discuss hospice for patients with dementia? Anticipating caregivers' preconceptions and meeting their information needs.

Source

Alzheimer Disease & Associated Disorders. 16(2):116-22, 2002 Apr-Jun.

Abstract

This study was designed to determine whether Alzheimer disease (AD) caregivers view the benefits of hospice as more relevant to themselves or to patients, to identify the features of hospice care that are most important to caregivers, and to determine how often these features are described in hospice promotional materials. Telephone interviews were conducted with AD caregivers from a Memory Disorders Clinic of an urban academic medical center (N = 45). A nationwide mail survey of randomly selected hospices was also conducted (N = 66). Caregivers were twice as likely to say that hospice would benefit them than they were to say it would benefit the patient (26 vs. 13; $p = 0.002$). The features of hospice that were most important to caregivers were continued follow-up evaluation by the patient's primary care provider and hospice's emphasis on helping patients to avoid hospital admission. The least important was the availability of a chaplain. There was moderate agreement between the importance of various hospice features to caregivers, and the representation of that feature in hospice promotional materials. AD caregivers have generally positive opinions about hospice's benefits for themselves. In discussing hospice with AD caregivers, clinicians may want to emphasize selected features of hospice that are particularly important to caregivers.

Citation <14>

Unique Identifier

11986512

Medline Identifier

21982971

Authors

Evers MM. Purohit D. Perl D. Khan K. Marin DB.

Institution

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Title

Palliative and aggressive end-of-life care for patients with dementia.

Source

Psychiatric Services. 53(5):609-13, 2002 May.

Abstract

OBJECTIVES: The goals of this study were to establish the frequency of palliative and aggressive treatment measures among patients with and without dementia during the last six months of life, to identify relationships between the severity of dementia and aggressive and palliative care, and to determine whether treatment patterns have changed over time.

METHODS: Antemortem data for 279 patients with dementia and 24 control patients who were brought for autopsy in chronic care facilities between 1985 and 2000 were reviewed. The severity of dementia was defined by scores on the Clinical Dementia Rating scale. Data on use of systemic antibiotics (designated as an aggressive treatment measure) and on use of narcotic and nonnarcotic pain medications and nasal oxygen (defined as palliative measures) were collected from medical charts. **RESULTS:** Fifty-three percent of the patients with dementia and 46 percent of those without dementia had received systemic antibiotics.

Fourteen perc!

ent of the patients with dementia and 38 percent of those without dementia had received narcotic pain medications. The prevalence of aggressive and palliative measures did not vary significantly with the severity of dementia. Eleven percent of the patients with dementia who died between 1991 and 1995 and 18 percent of those who died between 1996 and 2000 had received narcotic pain medications in the last six months of their lives. **CONCLUSIONS:** Use of systemic antibiotics is prevalent in the treatment of patients with end-stage dementia, despite the limited utility and discomfort associated with the use of these agents. That patients with severe dementia and those with milder cognitive impairment received similar treatment may be contrary to good clinical practice, given the poor prognosis of patients with severe dementia.

Citation <15>

Unique Identifier

11746659

Medline Identifier

21610981

Authors

Lambourne P. Lambourne A.

Title

Do not resuscitate policies - what do staff and relatives want for patients with severe dementia?.

Source

International Journal of Geriatric Psychiatry. 16(11):1107-8, 2001 Nov.

Citation <16>

Unique Identifier

11522928

Medline Identifier

21413389

Authors

Whitehouse PJ.

Institution

University Alzheimer Center, Case Western Reserve University, Cleveland, Ohio, USA.

Title

The end of Alzheimer disease II: commentary on "Decisions to treat or not to treat pneumonia in demented psychogeriatric nursing home patients".[comment].

Comments

Comment on: Alzheimer Dis Assoc Disord. 2001 Jul-Sep;15(3):119-28; PMID: 11522929

Source

Alzheimer Disease & Associated Disorders. 15(3):118, 2001 Jul-Sep.

Citation <17>

Unique Identifier

11506347

Medline Identifier

21397167

Authors

Salib E. Tadros G.

Institution

Liverpool University, Hollins Park Hospital, Winwick.

Title

Passive euthanasia in dementia: killing ... or letting die?.

Source

Medicine, Science & the Law. 41(3):237-40, 2001 Jul.

Abstract

A sample of carers was asked to complete a self-administered questionnaire designed to collect information about carers' characteristics and obtain their views on passive euthanasia. Each carer was given an information sheet about the study, which included a detailed and clear account for the different types of euthanasia. The study showed a strong support for passive euthanasia from the non-professional carers of dementia patients. The strongest support was for the idea of a 'Living Will'. Having previous experience in looking after other people with dementia would appear to influence carers' perception of passive euthanasia. The

subject of passive euthanasia and its ramifications for sufferers, carers and professionals warrants further exploration.

Citation <18>

Unique Identifier

11444665

Medline Identifier

21337566

Authors

Levine B. King T. Pestaner JP. Smialek JE.

Institution

Office of the Chief Medical Examiner, Baltimore, Maryland 21201, USA.

Title

Palliative pain therapy at the end of life and forensic medicine issues. [Review] [17 refs]

Source

American Journal of Forensic Medicine & Pathology. 22(1):62-4, 2001 Mar.

Abstract

An 83-year-old woman with a history of Alzheimer's disease and breast cancer died at home while receiving palliative pain therapy with oral morphine from her family for metastatic breast cancer. Allegations of mistreatment were made, and this case was ultimately referred to the Office of the Chief Medical Examiner, State of Maryland. An autopsy failed to identify any injuries or residual cancer, leaving no anatomic explanation for the pain that had been presumed to be metastatic breast carcinoma involving bone. The blood free morphine concentration was 5,200 ng/ml, and the total morphine concentration was 15,000 ng/ml. This case demonstrates the challenges and difficulties in forensic medicine when faced with the interpretation of toxicologic results at the end of life. [References: 17]

Citation <19>

Unique Identifier

11417027

Medline Identifier

21310699

Authors

Richter J. Eisemann M. Zgonnikova E.

Institution

Clinic for Psychiatry and Psychotherapy, University of Rostock, Germany.

Title

Doctors' authoritarianism in end-of-life treatment decisions. A comparison between Russia, Sweden and Germany.

Source

Journal of Medical Ethics. 27(3):186-91, 2001 Jun.

Abstract

OBJECTIVES: The study was performed in order to investigate how end-of-life decisions are influenced by cultural and sociopolitical circumstances and to explore the compliance of doctors with patient wishes. **PARTICIPANTS AND MEASUREMENT:** Five hundred and thirty-five physicians were surveyed in Sweden (Umea), Germany (Rostock and Neubrandenburg), and in Russia (Arkhangelsk) by a questionnaire. The participants were recruited according to availability and are not representative. The questionnaire is based on the one developed by Molloy and co-workers in Canada which contains three case vignettes about an 82-year-old Alzheimer patient with an acute life-threatening condition; the questionnaire includes different levels of information about his treatment wishes. We have added various questions about attitudes determining doctors' decision making process (legal

and ethical concerns, patient's and family wishes, hospital costs, patient's age and level of dementia and physician's religion). RESULTS: Swedish physicians chose fewer life-prolonging interventions as compared with the Russian and the German doctors. Swedish physicians would perform cardiopulmonary resuscitation (CPR) in the event of a cardiac arrest less frequently, followed by the German doctors. More than half the Russian physicians decided to perform CPR irrespective of the available information about the patient's wishes. Level of dementia emerged as the most powerful determining attitude-variable for the decision making in all three countries. CONCLUSIONS: The lack of compliance with patient wishes among a substantial number of doctors points to the necessity of emphasising ethical aspects both in medical education and clinical practice. The inconsistency in the treatment decisions of doctors from different countries calls for social consensus in this matter.

Citation <20>

Unique Identifier

11375141

Medline Identifier

21269050

Authors

Volicer L.

Institution

Geriatric Research Education Clinical Center, E. N. Rogers Memorial Veterans Hospital, Bedford, Massachusetts 01730, USA.

Title

Management of severe Alzheimer's disease and end-of-life issues. [Review] [29 refs]

Source

Clinics in Geriatric Medicine. 17(2):377-91, 2001 May.

Abstract

The quality of life of individuals with severe Alzheimer's disease requires attention to three main factors: (1) availability of meaningful activities, (2) optimal management of medical issues, and (3) appropriate treatment of psychiatric symptoms. Preservation of ambulation and comfort and avoidance of depression are significant interfaces between these three main factors. Formulation of an advance proxy plan is important for ensuring that the patient's previous wishes or best interests are considered when decisions about treatment strategies are made. Decisions regarding treatment strategies should take into consideration decreased effectiveness of several therapeutic approaches in this patient population. Hospice care is appropriate for the terminal stage of Alzheimer's disease, but palliative care also can be provided in other settings. [References: 29]

Citation <21>

Unique Identifier

11252920

Medline Identifier

21147137

Authors

Spike J.

Institution

Ethics Consultation Service, Strong Memorial Hospital, Rochester, New York, USA.

Title

Narrative unity and the unraveling of personal identity: dialysis, dementia, stroke, and advance directives.

Source

Journal of Clinical Ethics. 11(4):367-72, 2000 Winter.

Citation <22>

Unique Identifier

11113979

Medline Identifier

20566320

Authors

Potkins D. Bradley S. Shrimanker J. O'Brien J. Swann A. Ballard C.

Institution

Specialist Registrar in Psychiatry, Newcastle General Hospital, Newcastle upon Tyne, UK.

Title

End of life treatment decisions in people with dementia: carers' views and the factors which influence them.

Source

International Journal of Geriatric Psychiatry. 15(11):1005-8, 2000 Nov.

Abstract

OBJECTIVE: Treatment decisions in life threatening situations (TD) are poorly studied in people with dementia. **METHOD:** The carers of people with dementia were asked four TD 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 TD were evaluated. **RESULTS:** Fifty carers participated, 46% 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 TD. **CONCLUSION:** 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. Copyright 2000 John Wiley & Sons, Ltd.

Citation <23>

Unique Identifier

11074773

Medline Identifier

20528576

Authors

Hurley AC. Volicer L. Blasi ZV.

Title

End-of-life care for patients with advanced dementia.

Source

JAMA. 284(19):2449-50, 2000 Nov 15.

Citation <24>

Unique Identifier

11018000

Medline Identifier

20473178

Authors

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Institute for Research in Extramural Medicine (EMGO) Vrije Universiteit Amsterdam Van der Boechorststraat 7 1081 BT Amsterdam, The Netherlands.

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Title

When should physicians forgo curative treatment of pneumonia in patients with dementia? Using a guideline for decision-making.

Source

Western Journal of Medicine. 173(4):274-7, 2000 Oct.

Citation <25>

Unique Identifier

10872012

Medline Identifier

20332183

Authors

Morrison RS. Siu AL.

Institution

Department of Geriatrics, Box 1070, Mount Sinai School of Medicine, One Gustave L. Levy Pl, New York, NY 10029, USA. sean.morrison@mssm.edu

Title

Survival in end-stage dementia following acute illness.[comment].

Comments

Comment in: JAMA. 2000 Jul 5;284(1):87-9; PMID: 10872019, Comment in: JAMA. 2000 Nov 15;284(19):2447-8; PMID: 11074770, Comment in: JAMA. 2000 Nov 15;284(19):2447; discussion 2448; PMID: 11074769, Comment in: JAMA. 2000 Nov 15;284(19):2447; discussion 2448; PMID: 11074768

Source

JAMA. 284(1):47-52, 2000 Jul 5.

Abstract

CONTEXT: Little is known about the prognosis of acutely ill patients with end-stage dementia or about the type of care that these patients receive. If their prognosis is poor, then emphasis should be placed on palliative care for these patients rather than on curative interventions. OBJECTIVES: To examine survival for patients with end-stage dementia following hospitalization for hip fracture or pneumonia and to compare their care with that of cognitively intact older adults. DESIGN: Prospective cohort study with 6 months of follow-up. SETTING AND PATIENTS: Patients aged 70 years or older who were hospitalized with hip fracture (cognitively intact, n=59; with end-stage dementia, n=38) or pneumonia (cognitively intact, n=39; with end-stage dementia, n=80) in a large hospital in New York, NY, between September 1, 1996, and March 1, 1998. MAIN OUTCOME MEASURES: Mortality, treatments directed at symptoms, and application of distressing and painful procedures in cognitively intact

t patients vs those with end-stage dementia. RESULTS: Six-month mortality for patients with end-stage dementia and pneumonia was 53% (95% confidence interval [CI], 41%-64%) compared with 13% (95% CI, 4%-27%) for cognitively intact patients (adjusted hazard ratio, 4.6; 95% CI, 1.8-11.8). Six-month mortality for patients with end-stage dementia and hip fracture was 55% (95% CI, 42%-75%) compared with 12% (95% CI, 5%-24%) for cognitively intact patients (adjusted hazard ratio, 5.8; 95% CI, 1.7-20.4). Patients with end-stage dementia received as many burdensome procedures as cognitively intact patients and only 8 (7%) of 118 patients with end-stage dementia had a documented decision made to forego a life-sustaining treatment other than cardiopulmonary resuscitation. Only 24% of patients with end-stage dementia and hip fracture received a standing order for analgesics.

CONCLUSIONS: In this study, patients with advanced dementia and hip fracture or pneumonia had a very poor prognosis. Given the limited life expectancy of patients with end-stage dementia following these illnesses and the burdens associated with their treatment, increased attention should be focused on efforts to enhance comfort in this patient population. JAMA. 2000;284:47-52

Citation <26>

Unique Identifier

10783434

Medline Identifier

20247122

Authors

Shuster JL Jr.

Institution

Departments of Psychiatry and Medicine, University of Alabama School of Medicine, Birmingham, Alabama, USA.

Title

Palliative care for advanced dementia. [Review] [38 refs]

Source

Clinics in Geriatric Medicine. 16(2):373-86, 2000 May.

Abstract

Dementia is a common, devastating, and ultimately fatal illness. Although no cure exists for most causes of dementia, palliative interventions for the predictable complications of the illness can effectively reduce the suffering of patients and families. Care of patients with end-stage dementia is clinically and conceptually consistent with hospice and palliative care, and this approach to care for patients with terminal dementia is preferred. Although the 6-month risk for mortality can be predicted (to satisfy current American hospice eligibility requirements), palliative care interventions are appropriate much earlier in the course of deterioration from dementia. [References: 38]

Citation <27>

Unique Identifier

10770128

Medline Identifier

20230897

Authors

Hensel WA.

Title

The old man's friend.

Source

JAMA. 283(14):1793-4, 2000 Apr 12.

Citation <28>

Unique Identifier

10451307

Medline Identifier

99375703

Authors

Armstrong-Esther CA. Browne KD. McAfee JG.

Institution

School of Nursing, University of Lethbridge, Alberta, Canada.

Title

Investigation into nursing staff knowledge and attitude to dementia.

Source

International Journal of Psychiatric Nursing Research. 4(3):489-97, 1999 Jan.

Abstract

The knowledge and attitudes to the concept of dementia of nurses working within the general (N = 70) and psychiatric (N = 236) hospital settings were investigated by questionnaire. The study shows that knowledge was good regardless of type of level of training for basic facts. Nurses also report positive attitudes towards the elderly but there were significant differences when the questions became more controversial. A significant number of nursing in psychiatric units ($x^2 p < 0.01$) favoured euthanasia for demented patients compared with their colleagues in acute general units.

Citation <29>

Unique Identifier

10372952

Medline Identifier

99300167

Authors

Berghmans RL.

Institution

Institute of Bioethics and Department of Health Ethics and Philosophy, University of Maastricht, The Netherlands.

Title

Ethics of end-of-life decisions in cases of dementia: views of the Royal Dutch Medical Association with some critical comments.[comment].

Comments

Comment in: Alzheimer Dis Assoc Disord. 1999 Apr-Jun;13(2):63-5; PMID: 10372947

Source

Alzheimer Disease & Associated Disorders. 13(2):91-5, 1999 Apr-Jun.

Abstract

Some of the views of the Royal Dutch Medical Association on end-of-life decisions in cases of people suffering from Alzheimer disease and related disorders are presented. The focus of the present report is on the views of the commission regarding active life termination of demented patients with or without an actual and explicit request from the patient. Some comments on these views are made, particularly regarding the notion of "loss of human dignity" (ontluistering) with respect to dementia.

Citation <30>

Unique Identifier

10366374

Medline Identifier

99242207

Authors

Karlawish JH. Quill T. Meier DE.

Institution

Institute on Aging, University of Pennsylvania, Philadelphia 19104, USA.

Title

A consensus-based approach to providing palliative care to patients who lack decision-making capacity. ACP-ASIM End-of-Life Care Consensus Panel. American College of Physicians-American Society of Internal Medicine.

Source

Annals of Internal Medicine. 130(10):835-40, 1999 May 18.

Abstract

Making palliative care decisions for a patient who lacks decision-making capacity presents several challenges. Other people, such as family and caregivers, must choose for the patient. The goals and values of these decision makers may conflict with those of each other and with those of the patient, who now lacks the capacity to participate in the decision. This paper presents a case study of a patient with severe Alzheimer disease who has two common clinical problems: neurogenic dysphagia and aspiration pneumonia. The case study describes a consensus-based decision-making strategy that keeps what is known about the patient's wishes and values in the foreground but also expects guidance from the physician and elicits input from family members and other people who care for and have knowledge about the patient. The steps of this process, including key clinical prompts and potential transition statements, are outlined and described. The overall goal of the case commentary is to demonstrate that physicians can guide a highly emotional and personal process in a structured manner that has meaning for the patient, family, physician, and other caregivers.

Citation <31>

Unique Identifier

10078909

Medline Identifier

99176795

Authors

Van Nes MC. Michel JP.

Title

Palliative care and severe dementia.[comment].

Comments

Comment on: J Am Geriatr Soc. 1998 Mar;46(3):287-90; PMID: 9514373

Source

Journal of the American Geriatrics Society. 47(3):378-9, 1999 Mar.

Citation <32>

Unique Identifier

10068357

Medline Identifier

99150008

Authors

Hamel MB. Teno JM. Goldman L. Lynn J. Davis RB. Galanos AN. Desbiens N. Connors AF Jr. Wenger N. Phillips RS.

Institution

Beth Israel Deaconess Medical Center, Boston, Massachusetts 02215, USA.

Title

Patient age and decisions to withhold life-sustaining treatments from seriously ill, hospitalized adults. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment.

Source

Annals of Internal Medicine. 130(2):116-25, 1999 Jan 19.

Abstract

BACKGROUND: Patient age may influence decisions to withhold life-sustaining treatments, independent of patients' preferences for or ability to benefit from such treatments. Controversy exists about the appropriateness of using age as a criterion for making treatment decisions. **OBJECTIVE:** To determine the effect of age on decisions to withhold life-sustaining therapies. **DESIGN:** Prospective cohort study. **SETTING:** Five medical centers participating in the Study to Understand Prognoses and Preferences for Outcomes and Risks

of Treatments (SUPPORT). PATIENTS: 9105 hospitalized adults who had one of nine illnesses associated with an average 6-month mortality rate of 50%. MEASUREMENTS: Outcomes were the presence and timing of decisions to withhold ventilator support, surgery, and dialysis. Adjustment was made for sociodemographic characteristics, prognoses, baseline function, patients' preferences for life-extending care, and physicians' understanding of patients' preferences for life-extending care. RESULTS: The median patient age was 63 years; 44% of patients were women, and 53% survived to 180 days. In adjusted analyses, older age was associated with higher rates of withholding each of the three life-sustaining treatments studied. For ventilator support, the rate of decisions to withhold therapy increased 15% with each decade of age (hazard ratio, 1.15 [95% CI, 1.12 to 1.19]); for surgery, the increase per decade was 19% (hazard ratio, 1.19 [CI, 1.12 to 1.27]); and for dialysis, the increase per decade was 12% (hazard ratio, 1.12 [CI, 1.06 to 1.19]). Physicians underestimated older patients' preferences for life-extending care; adjustment for this underestimation resulted in an attenuation of the association between age and decisions to withhold treatments. CONCLUSION: Even after adjustment for differences in patients' prognoses and preferences, older age was associated with higher rates of decisions to withhold ventilator support, surgery, and dialysis.

Citation <33>

Unique Identifier

10787947

Medline Identifier

20166226

Authors

Whitney PJ.

Title

Role of hospice in Alzheimer's care.

Source

Provider. 25(9):87, 89-91, 1999 Sep.

Citation <34>

Unique Identifier

10542528

Medline Identifier

20010241

Authors

Nazarko L.

Institution

South Bank University.

Title

A duty to protect.

Source

Elderly Care. 11(3):25, 1999 May.

Citation <35>

Unique Identifier

9288027

Medline Identifier

97434141

Authors

Volicer L.

Title

Hospice care for dementia patients.[comment].

Comments

Comment on: J Am Geriatr Soc. 1997 Sep;45(9):1054-9; PMID: 9288011, Comment on: J Am Geriatr Soc. 1997 Sep;45(9):1104-7; PMID: 9288019

Source

Journal of the American Geriatrics Society. 45(9):1147-9, 1997 Sep.

Citation <36>

Unique Identifier

9288011

Medline Identifier

97434125

Authors

Luchins DJ. Hanrahan P. Murphy K.

Institution

University of Chicago, Dept. of Psychiatry, IL 60637, USA.

Title

Criteria for enrolling dementia patients in hospice.[comment].

Comments

Comment in: J Am Geriatr Soc. 1997 Sep;45(9):1147-9; PMID: 9288027

Source

Journal of the American Geriatrics Society. 45(9):1054-9, 1997 Sep.

Abstract

OBJECTIVE: Because survival time varies greatly, it is difficult for dementia patients to meet a key criterion for eligibility for the Medicare hospice benefit: a 6-month survival time. We have developed criteria for the Medicare hospice benefit that include the characteristics of advanced dementia and related medical complications. The purpose of the study was to determine survival time among dementia patients who met these criteria. Additionally, because the National Hospice Organization (NHO) developed its own guidelines while the study was in progress, we retrospectively examined the application of these guidelines to our sample. **DESIGN:** Two cohorts of hospice patients were studied longitudinally, each for 2 years. **SETTING:** Nine Midwestern hospice programs. **PARTICIPANTS:** Forty-seven patients were enrolled in home hospice and institutional hospice settings.

MEASUREMENTS: Survival time consisted of the number of days between enrollment in the hospice program and death or t!

he end of the study. Other measures included Activities of Daily Living, ratings of Appetite, Nourishment, and Mobility, Functional Assessment Staging (FAST), a Medical Complications Checklist, and a care plan concerning the use of medications for acute illness.

RESULTS: Our hospice enrollment criteria predicted a median survival time of 4 months and a mean survival time of 6.9 months; 38% of patients survived for more than 6 months. FAST scores and Mobility ratings were significantly related to survival time. However, 41% could not be scored on the FAST as their disease progression was not ordinal. Among patients who could be scored on the FAST and who had reached Stage Seven C, their mean survival time was 3.2 months compared with 18 months among those who could be scored and had not reached this stage and 8.6 months among patients whose disease progression was not ordinal, $P < .001$. When the palliative care plans were examined, less aggressive care plans resulted in shorter!

survival times, $P < .01$. **CONCLUSION:** Our hospice enrollment criteria identified a group with a median survival time of 4 months and a mean survival time of 6.9 months. Using NHO criteria relying on the FAST allows the identification of a subgroup with very high mortality and a short time until death. Although the FAST can identify a subgroup of appropriate

candidates for hospice, sole reliance on this measure might decrease access to hospice care for many dementia patients.

Citation <37>

Unique Identifier

9158595

Medline Identifier

97302234

Authors

Post SG.

Institution

Center for Biomedical Ethics, School of Medicine, Case Western Reserve University, Cleveland, Ohio 44106, USA.

Title

Physician-assisted suicide in Alzheimer's disease.

Source

Journal of the American Geriatrics Society. 45(5):647-51, 1997 May.

Abstract

This paper takes up the question of physician-assisted suicide (PAS) in Alzheimer's disease (AD), reviewing arguments for and against in a broad interdisciplinary context. Preemptive PAS-AD involving competent patients raises the further question of AD-euthanasia. The author concludes, after thorough assessment of the literature, that caution in moving toward AD-PAS is necessary. However, where PAS is legalized, it may be difficult to justify precluding people with AD from access.

Citation <38>

Unique Identifier

9152728

Medline Identifier

97297259

Authors

McCarthy M. Addington-Hall J. Altmann D.

Institution

Department of Epidemiology and Public Health, University College London, UK.

Title

The experience of dying with dementia: a retrospective study.

Source

International Journal of Geriatric Psychiatry. 12(3):404-9, 1997 Mar.

Abstract

OBJECTIVE: To describe the last year of life of people with dementia, their symptoms, care needs, use of and satisfaction with health services and the bereavement state of the respondent. **METHODS:** The study is drawn from the Regional Study of Care for the Dying, a retrospective sample survey of the carers, family members or others who knew about the last year of life of a random sample of people age 15 and over dying in the last quarter of 1990. The samples were drawn in 20 English health districts which, although self-selected, were nationally representative. There was a total of 3696 patients (response rate of 69%) dying from all causes. Within this sample, 170 dementia patients were identified and compared with 1513 cancer patients. **RESULTS:** The symptoms most commonly reported in the last year were mental confusion (83%), urinary incontinence (72%), pain (64%), low mood (61%), constipation (59%) and loss of appetite (57%). Dementia patients saw their GP less often than ca!

ncer patients and their respondents rated GP assistance less highly. Dementia patients needed more help at home compared with cancer patients, and received more social services; 78% of respondents for dementia patients and 64% for cancer said they had come to terms with the patient's death. CONCLUSION: Patients dying from dementia have symptoms and health care needs comparable with cancer patients. Greater attention should be given to these needs.

Citation <39>

Unique Identifier

9081557

Medline Identifier

97110872

Authors

Filley CM. Chapman MM. Dubovsky SL.

Institution

Department of Neurology, University of Colorado School of Medicine, Denver 80262, USA.

Title

Ethical concerns in the use of palliative drug treatment for Alzheimer's Disease.[comment].

Comments

Comment in: J Neuropsychiatry Clin Neurosci. 1996 Summer;8(3):361-2; PMID: 8854311

Source

Journal of Neuropsychiatry & Clinical Neurosciences. 8(2):202-5, 1996 Spring.

Abstract

The cases of 3 patients with Alzheimer's disease (AD) who had varied outcomes from treatment with tacrine or other palliative drugs illustrate the need to consider the benefits of such agents for each case on an individual basis. In the absence of a cure, the most important factor in the care of AD patients may be the physician's attitude that irreversibility does not imply untreatability.

Citation <40>

Unique Identifier

8919497

Medline Identifier

97078573

Authors

Gura C.

Institution

Benjamin B. Green-Field National Alzheimer's Library and Resource Center, Chicago, USA.
greenfld@class.org

Title

The ethics of end-of-life care.

Source

Alzheimer Disease & Associated Disorders. 10(1):57-8, 1996 Spring.

Citation <41>

Unique Identifier

8919490

Medline Identifier

97078566

Authors

Whitehouse PJ. Post SG. Sachs GA.

Institution

Alzheimer Center, University Hospitals of Cleveland, Ohio, USA.

Title

Dementia care at the end of life: empirical research and international collaboration.[comment].

Comments

Comment on: Alzheimer Dis Assoc Disord. 1996 Spring;10(1):11-9; PMID: 8919492,

Comment on: Alzheimer Dis Assoc Disord. 1996 Spring;10(1):5-10; PMID: 8919491

Source

Alzheimer Disease & Associated Disorders. 10(1):3-4, 1996 Spring.

Citation <42>

Unique Identifier

8909347

Medline Identifier

97065866

Authors

Gillick MR. Mendes ML.

Institution

Hebrew Rehabilitation Center for Aged, Department of Gerontology, Beth Israel Hospital, Boston, Massachusetts, USA.

Title

Medical care in old age: what do nurses in long-term care consider appropriate?.

Source

Journal of the American Geriatrics Society. 44(11):1322-5, 1996 Nov.

Abstract

OBJECTIVES: To determine whether nurses working in a long-term care institution, who are knowledgeable about the full range of conditions common among older people, favor limitations of treatment in old age; and to study whether the level of intensity of care they regard as appropriate varies with the overall health status of the older individual. **DESIGN:** Participants were asked to complete an intervention-specific advance directive for themselves, with scenarios representing terminal illness, dementia plus chronic illness, chronic illness in a nursing home resident, chronic illness in a community-dwelling older person, and a robust, community-dwelling older person. **SETTING:** A 725-bed long-term care institution, with residents having a mean age of 88 years and a wide range of physical and cognitive deficits. **PARTICIPANTS:** Full-time nurses at the long-term care facility were eligible and were given survey instruments; 102 of the 145 eligible nurses completed the questionnaire!

MEASUREMENTS: The unit of analysis is the refusal rate, defined as the mean number of refusals of interventions for each respondent. **MAIN RESULTS:** The overall refusal rate for all five scenarios taken together was 72.1%. The refusal rate in the case of terminal illness was 90.9%, in the case of dementia plus chronic illness 81.8%, in the case of dementia in a nursing home 69.1%, for a homebound older person with chronic illness 70.9%, and for a previously healthy 85-year-old person living in the community, 50.0% ($P < .001$).

CONCLUSIONS: Nurses working in a long-term care institution have strong preferences about limiting a variety of interventions in old age. The greater the degree of physical and cognitive impairment, the more limitations they favor. This suggests the necessity of expanding advance planning to include a discussion of what constitutes appropriate treatment in a broad range of circumstances.

Citation <43>

Unique Identifier

8799352

Medline Identifier

96392564

Authors

von Gunten CF. Twaddle ML.

Institution

Department of Medicine, Northwestern University Medical School, Chicago, Illinois, USA.

Title

Terminal care for noncancer patients. [Review] [32 refs]

Source

Clinics in Geriatric Medicine. 12(2):349-58, 1996 May.

Abstract

The hospice approach to terminal care will benefit patients with advanced chronic illnesses other than cancer. This article describes general criteria that will help clinicians assess when patients may be appropriately referred for hospice care. Common illnesses, such as dementia, heart disease, lung disease, and renal failure for which terminal care in advanced stages is appropriate, are discussed. Specific palliative management issues regarding these advanced disease states also are addressed. [References: 32]

Citation <44>

Unique Identifier

8715471

Medline Identifier

96360896

Authors

Lloyd-Williams M.

Title

An audit of palliative care in dementia.

Source

European Journal of Cancer Care. 5(1):53-5, 1996 Mar.

Abstract

A retrospective case note audit was conducted in order to determine the most prevalent symptoms in terminal dementia and to assess the palliation given. Seventeen case notes were audited. Pain and dyspnoea were the most common symptoms. The palliation and treatment of constipation and oral candidiasis was within current accepted practice. Palliation of other symptoms were inadequate compared to current accepted practice. There appears to be a reluctance to prescribe opiate analgesia, and when this was prescribed the doses were not modified to achieve full pain or symptomatic relief. Many patients were unable to take medication orally, but syringe drivers were not used. The conclusions include the need for education of both nursing and medical staff as to the current principles of palliative care.

Citation <45>

Unique Identifier

8707146

Medline Identifier

96345332

Authors

Wilson SA. Kovach CR. Stearns SA.

Title

Hospice concepts in the care of end-stage dementia.

Source

Geriatric Nursing. 17(1):6-10, 1996 Jan-Feb.

Citation <46>

Unique Identifier

8764531

Medline Identifier

96321521

Authors

Cusveller B. Jochemsen H.

Institution

Lindeboom Instituut, Centre for Medical Ethics, Ede, The Netherlands.

Title

Life-terminating actions with severely demented patients: critical assessment of a report of the Royal Dutch Society of Medicine.

Source

Issues in Law & Medicine. 12(1):31-45, 1996 Summer.

Citation <47>

Unique Identifier

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Medline Identifier

96234779

Authors

Weber LJ. Campbell ML.

Institution

Ethics Institute, University of Detroit Mercy, Michigan 48219, USA.

Title

Medical futility and life-sustaining treatment decisions.[comment].

Comments

Comment in: J Neurosci Nurs. 1996 Aug;28(4):212-3; PMID: 8880593

Source

Journal of Neuroscience Nursing. 28(1):56-60, 1996 Feb.

Abstract

By focusing our attention on the questions of "what are we trying to achieve" and "are we able to do it", the discussion of medical futility has contributed an important dimension to the ethics of treatment decision making near the end of life. It is not simply enough to ask and answer the question of what the patient wants. Healthcare professionals have a responsibility to offer only those life-sustaining efforts that have a reasonable chance of being beneficial. Futility policies should permit treatment-limiting decisions to be made without the agreement of the patient or surrogate at times, but such policies should also provide opportunities to challenge a judgement of futility. Above all, such policies should not be used as a reason to avoid communication. Patients or surrogates need to be informed about what treatments are options and what are not. The futility criterion for limiting treatment should be recognized as a means of contributing to communication and discussion! on regarding benefits, harms and medical goals. It should not be permitted to bypass such discussions. The recognition of the significance of the concept of futility means that discussion needs to continue at another level as well. The questions of "what are we trying to achieve" and "are we able to do it" are not easily answered. It is especially important, we think, that those who are experienced in working with patients with neurological impairments contribute to the on-going reflection on what constitutes benefit or what is the appropriate use of life-sustaining interventions for such patients.