End of Life Care
May 2003

1: Acta Anaesthesiol Scand 2003 May;47(5):499-500
End-of-life care in intensive care units Save lives that can be saved, offer the dying a peaceful and dignified death.
Klepstad P, Gisvold SE.
Department of Circulation and Medical Imaging, Norwegian University of Science and Technology, Trondheim, Norway.
PMID: 12699504 [PubMed - in process]

2: Adv Gerontol 2002;10:131-5
New challenges and old problems: end of life care and the dilemma of prognostic accuracy.
Tanneberger KS, Pannuti F, Malavasi I, Mariano P, Strocchi E.
Associazione Nazionale Tumori (ANT), Istituto di Ricerca, di Studio e di Formazione ANT, IST-ANT, Bologna, Italy. tanneberger@antnet.it Dignity of the natural end of life for everybody is one of the new great challenges of medicine and social care for the beginning 21st century. However, many end of life care providing doctors are confused about how to categorize the help they give. One of the central problems is predicting the life expectancy of an individual patient. Difficulties in this field can become ethical dilemmas when physicians are obliged to predict accurately a patient's prognosis as the basis for a certain care strategy. Clinical estimation of the duration of life for patients with end of life cancer needs experience and training. Education programmes in the field should include this topic much more until now. Prognosis should be based more on proven indices and less on intuition. However, there is no doubt that daily clinical practice limits the use of highly sophisticated computer-based score models. Even maximal accuracy of prognosis will not exclude the risk of errors in a great part of patients. This limits their classification in care categories too strictly defined. Health care systems should avoid models for care with standards and budgets based on prognostic estimates and the medical community should avoid claim by disciplines of certain categories of patients defined by their prognoses. What we need is a network of assistance for incurable patients with single parts defined by patients needs and not by predicted life expectancy. Separating palliative and terminal care is artificial and often in contrast to the needs of the patients.
PMID: 12577701 [PubMed - indexed for MEDLINE]

3: Age Ageing 1998 Sep;27(5):656-7
Comment on:
Age Ageing. 1997 Nov;26(6):429-34.

Considering the 'do not resuscitate' decision.
Page N, Morris D.
Publication Types:
Comment
Letter
PMID: 12675110 [PubMed - indexed for MEDLINE]

4: Aging Clin Exp Res 2002 Aug;14(4):300-6
Clinical challenges in the care of frail older persons.
Kane RL.
Minnesota Chair in Long-term Care and Aging, Division of Health Services Research and Policy, University of Minnesota School of Public Health, Minneapolis 55455, USA. kanex001@umn.edu
The clinical challenges of meeting the needs of frail older persons are essentially those encompassed by chronic disease multiplied by the special problems presented by aging, namely the presentation and management of disease and the special syndromes associated with geriatrics. The need to develop an approach to the care of frail older persons reflects a more general need to address system reform for chronic disease. The steps include new roles for patients and their families, the use of information technology to monitor changes in patients' status more continuously and to intervene in a more timely way, and a re-evaluation of the use of personnel at all levels. At present, we know more about how to deliver effective chronic care than we practice. The barriers to implementation include both a general reluctance to change and negative financial incentives to implement what has been shown to be effective.
Publication Types:
Review
Review, Tutorial
PMID: 12462376 [PubMed - indexed for MEDLINE]

5: Aging Ment Health 2002 Nov;6(4):402-12
Psychosocial issues near the end of life.
Werth JL Jr, Gordon JR, Johnson RR Jr.
Department of Psychology, The University of Akron, OH 44325-4301, USA. jwerth@uakron.edu
End-of-life care has received increasing attention in the last decade; however, the focus continues to be on the physical aspects of suffering and care to the virtual exclusion of psychosocial areas. This paper provides an overview of the literature on the intra- and interpersonal aspects of dying, including the effects that psychosocial variables have on end-of-life decision-making; common diagnosable mental disorders (e.g., clinical depression, delirium); other types of personal considerations (e.g., autonomy/control, grief); and interpersonal/environmental issues (e.g., cultural factors, financial variables). Six roles that qualified mental health professionals can play (i.e., advocate, counselor, educator, evaluator, multidisciplinary team member, and researcher) are also outlined. Because psychosocial issues are ubiquitous and can have enormous impact near the end of life, properly trained mental health professionals can play vital roles in alleviating suffering and improving the quality of life of people who are dying.
Publication Types:
Review
Review, Academic
PMID: 12425774 [PubMed - indexed for MEDLINE]

6: Am J Cardiol 2003 Mar 1;91(5):583-4

Using implantable devices to improve end-of-life care.
Martin D.
Publication Types:
Editorial
PMID: 12615265 [PubMed - indexed for MEDLINE]

7: Am J Hosp Palliat Care 2003 Mar-Apr;20(2):114-20
Complicated bereavement: a national survey of potential risk factors.
Ellifritt J, Nelson KA, Walsh D.
Hospice of the Cleveland Clinic, The Cleveland Clinic Foundation, Cleveland, Ohio, USA.
We developed a Bereavement Risk Questionnaire to rate 19 possible factors for assessing complicated bereavement. A four-point scale was used (0 = no risk, 3 = significant risk). The questionnaire was mailed nationwide in the United States to 508 hospice bereavement coordinators, and 262 responded. Most rated the following as significant risks: perceived lack of caregiver social support (70 percent), caregiver history of drug/alcohol abuse (68 percent), caregiver poor coping skills (68 percent), caregiver history of mental illness (67 percent), and patient is a child (63 percent). Overall, 61 percent chose perceived lack of social support, and 47 percent chose poor coping skills, as one of the top three risk factors. There was no relationship between professional discipline and responses. We found a consensus among bereavement professionals regarding important indicators in assessing bereavement risk. We conclude that it is possible to assess bereavement risk in caregivers of seriously ill patients, prior to the death of the patient. This would allow palliative care teams to allocate resources and services to those at the greatest risk for complicated bereavement.
PMID: 12693643 [PubMed - indexed for MEDLINE]

8: Am J Hosp Palliat Care 2003 Mar-Apr;20(2):105-13
Predictors of six-month survival among patients with dementia: an evaluation of hospice Medicare guidelines.
Schonwetter RS, Han B, Small BJ, Martin B, Tope K, Haley WE.
Department of Internal Medicine, University of South Florida College of Medicine, LifePath Hospice and Palliative Care, Inc., Tampa, Florida, USA.
The goal of the present study was to assess the validity of the Medicare hospice eligibility guidelines for dementia patients, as well as identify predictors that could more accurately identify prognosis in dementia patients referred to hospice. A retrospective chart review was conducted, including initial assessment and longitudinal follow-up of patients until the time of death. In addition, a second validation cohort was also followed. Participants consisted of 245 patients admitted to a large community-based hospice with a diagnosis of dementia, including a validation sample of 80 patients. The Kaplan-Meier estimation of survival and a Cox regression analysis ($p > 0.05$) revealed no significant relationship between the Medicare guidelines or any component of the guidelines and survival at six months for the initial and validation samples. Significant multivariate predictors of shorter survival in both the initial and validation sample include greater age ($p = 0.02$) and anorexia ($p < 0.001$), as well as a combination of anorexia and greater functional impairment ($p = 0.005$).
Overall, the results indicated that the Medicare guidelines were not valid predictors of survival in hospice patients with dementia and should be altered to include empirically valid predictors. Advanced age, as well as impaired nutritional and functional status, was associated with shortened survival in these patients. The predictor variables identified are an initial step toward providing improved prognoses for advanced dementia patients, their families, and practitioners. Broader issues in improving access to hospice care for dementia patients are discussed.

Publication Types:
Validation Studies
PMID: 12693642 [PubMed - indexed for MEDLINE]

9: Am J Hosp Palliat Care 2003 Mar-Apr;20(2):99-104
A longitudinal study of attitudes toward physician-assisted suicide and euthanasia among patients with noncurable malignancy.
Pacheco J, Hershberger PJ, Markert RJ, Kumar G.
Dayton VA Medical Center and Department of Medicine, Wright State University School of Medicine, Dayton, Ohio, USA.
This longitudinal study investigated whether attitudes toward physician-assisted suicide (PAS) and euthanasia (E) are stable among patients with noncurable malignancy, and whether depression and various coping strategies were related to such attitudes. Thirty patients with noncurable malignancies completed questionnaires measuring attitudes toward PAS and E, depression, and coping. Three months later, and subsequently at six-month intervals, repeated measures were obtained from 24 patients. There was a trend for patients to become less supportive of legalizing PAS and E from the initial to last attitude measurement. Depression was unrelated to attitude change. There were significant changes on two coping dimensions: use of social support for emotional reasons and use of religious resources. Our findings should be considered in clinical,legislative, and ethical debates.
PMID: 12693641 [PubMed - indexed for MEDLINE]

10: Am J Hosp Palliat Care 2003 Mar-Apr;20(2):95-6
Hospice care should be initiated sooner.
Strauch CE.
Publication Types:
Letter
PMID: 12693639 [PubMed - indexed for MEDLINE]

11: Am J Hosp Palliat Care 2003 Mar-Apr;20(2):90-2
Comment on:
Am J Hosp Palliat Care. 2003 Mar-Apr;20(2):135-9.
Spirituality in hospice and palliative care.
Baumrucker SJ.
Academy of Hospice and Palliative Medicine, USA.
Publication Types:
Comment
PMID: 12693637 [PubMed - indexed for MEDLINE]

12: Am J Hosp Palliat Care 2003 Mar-Apr;20(2):88-9
Comment on:
Am J Hosp Palliat Care. 2003 Mar-Apr;20(2):135-9.
Connecting the medical and spiritual models in patients nearing death.
Enck RE.
Publication Types:
Comment
Editorial
PMID: 12693636 [PubMed - indexed for MEDLINE]

13: Am J Hosp Palliat Care 2003 Mar-Apr;20(2):121-8

The contextual nature of decision making near the end of life: hospice patients' perspectives.
Gauthier DM, Swigart VA.
University of Louisiana at Lafayette, College of Nursing and Allied Health Professions, Lafayette, Louisiana, USA.
Mr. C. was diagnosed with lung cancer seven months ago. The cancer then spread to his brain. He was fully aware that the physicians were treating his symptoms, not the disease, however, discussions regarding the goals of treatment did not occur. He continued the treatment regimen of chemotherapy and radiation therapy. While at home one evening, he fell and fractured his femur. His mobility and independence were at once greatly compromised. While recovering in the hospital,
he made the decision to opt out of curative treatment. He stated, "I want to go home, play with my cat, smoke cigarettes, and be with my friends when they can visit." What are the processes by which adults with life-threatening conditions make decisions about their care? What is the context of these decisions? The purpose of this study was to describe the process of decision making for adults with a terminal illness.
PMID: 12693644 [PubMed - indexed for MEDLINE]

14: Am J Hosp Palliat Care 2003 Mar-Apr;20(2):129-34
Music therapy with imminently dying hospice patients and their families: facilitating release near the time of death.
Krout RE.
Conservatorium of Music, Massey University, Mt. Cook, Wellington, New Zealand.
Hospice care seeks to address the diverse needs of terminally ill patients in a number of physical, psychosocial, and spiritual areas. Family members of the patient often are included in the care and services provided by the hospice team, and hospice clinicians face a special challenge when working with families of patients who are imminently dying. When loved ones are anticipating the patient's impending death, they may find it difficult to express feelings, thoughts, and last wishes. Music therapy is a service modality that can help to facilitate such communication between the family and the patient who is actively dying, while also providing a comforting presence. Music therapy as a way to ease communication and sharing between dying patients and their loved ones is discussed in this article. The ways in which music therapy can facilitate a means of release for both patients and family members in an acute care unit of a large US hospice organization are specifically described. Case descriptions illustrate how music therapy functioned to allow five patients and their families to both come together and let go near the time of death. Elements to consider when providing such services to imminently dying patients and their families are discussed.
PMID: 12693645 [PubMed - indexed for MEDLINE]

15: Am J Hosp Palliat Care 2003 Mar-Apr;20(2):155-6
Lessons from Lisa.
Rousseau PC.
Geriatrics and Extended Care, VA Medical Center, Phoenix, Arizona, USA.
PMID: 12693649 [PubMed - indexed for MEDLINE]

16: Am J Hosp Palliat Care 2003 Mar-Apr;20(2):135-9
Comment in:
Am J Hosp Palliat Care. 2003 Mar-Apr;20(2):88-9.
Am J Hosp Palliat Care. 2003 Mar-Apr;20(2):90-2.
Hospice patients' attitudes regarding spiritual discussions with their doctors.
Hart A Jr, Kohlwes RJ, Deyo R, Rhodes LA, Bowen DJ.
Department of Medicine, University of Washington, Seattle, Washington, USA.

The purpose of this study was to assess hospice patients' attitudes regarding the discussion of spiritual issues with their physicians. We conducted in-depth interviews using open-ended questions on living with illness, spirituality and religion, and physician-patient relationships. The interviews were audiotaped, transcribed, and analyzed for dominant themes. The following dominant themes were identified: (1) treating the whole person, (2) treating with sensitivity,(3) favorable attitudes toward religious or spiritual discussions with doctors, and (4) no "preaching." Our findings suggest that patients do not expect physicians to be their primary spiritual advisors; however, physicians should be aware of and comfortable communicating with patients about religious or spiritual issues. More training in this topic may enhance the care physicians provide to patients near the end of life.
PMID: 12693646 [PubMed - indexed for MEDLINE]

17: Ann Intern Med 2003 Apr 15;138(8):639-43
Summary for patients in:
Ann Intern Med. 2003 Apr 15;138(8):I1.
Chemotherapy use among Medicare beneficiaries at the end of life.
Emanuel EJ, Young-Xu Y, Levinsky NG, Gazelle G, Saynina O, Ash AS.
Department of Clinical Bioethics, Warren G. Magnuson Clinical Center, National Institutes of Health, Building 10, Room 1C118, Bethesda, Maryland 20892-1156,USA.
BACKGROUND: Although many observers believe that cancer chemotherapy is overused at the end of life, there are no published data on this. OBJECTIVE: To determine the frequency and duration of chemotherapy use in the last 6 months of life stratified by type of cancer, age, and sex. DESIGN: Retrospective cohort analysis. SETTING: Administrative databases from Massachusetts and California. PATIENTS: All Medicare patients who died of cancer in Massachusetts and 5% of Medicare cancer decedents in California in 1996. MEASUREMENTS: Use of intravenous chemotherapy agents, chemotherapy administration, or medical evaluation for chemotherapy from Medicare billing data for each patient in 30-day periods from the date of death backward. RESULTS: In Massachusetts, 33% of cancer decedents older than 65 years of age received chemotherapy in the last 6 months of life, 23% in the last 3 months, and 9% in the last month. In California, the percentages were 26%, 20%, and 9%, respectively. Chemotherapy use greatly declined with age. Chemotherapy use was similar for patients with breast, colon, and ovarian cancer and those with cancer generally considered unresponsive to chemotherapy, such as pancreatic, hepatocellular, or renal-cell cancer or melanoma. Patients with types of cancer that are unresponsive to chemotherapy had shorter duration of chemotherapy use. CONCLUSION: Among patients who died of cancer, chemotherapy was used frequently in the last 3 months of life. The cancer's responsiveness to chemotherapy does not seem to influence whether dying patients receive chemotherapy at the end of life.
PMID: 12693886 [PubMed - indexed for MEDLINE]

18: Ann Intern Med 2003 Apr 15;138(8):I1
Original report in:
Ann Intern Med. 2003 Apr 15;138(8):639-43.
Summaries for patients. Chemotherapy use in the last 6 months of life among Medicare patients with cancer.
Publication Types:
Patient Education Handout
PMID: 12693915 [PubMed - indexed for MEDLINE]

19: Appl Nurs Res 2003 Feb;16(1):65-9
Could lack of clarity in written advance directives contribute to their

ineffectiveness? A study of the content of written advance directives.
Nolan MT.
School of Nursing, The Johns Hopkins University, Beltsville, MD 20705, USA.
mnolan@son.jhmi.edu
Since 1991, advance directives have failed to have a significant impact on end of life care. One reason is that despite widespread interest in these documents, few individuals have chosen to issue advance directives. Another reason reported in several studies is that the conditions under which the patient intended the directives to apply are unclear as are some of the treatments requested or declined. The purpose of this study was to describe instructions commonly included in written advance directives concerning the conditions under which the directives should apply and the treatments that are requested or declined. Five hundred consecutive closed medical records were reviewed from the medical and surgical departments of an urban hospital. These records produced 40 (8%) advance directive documents. Patient instructions indicating when the directives should take effect and which treatments should be declined or provided were summarized. Nurses and other health professionals can use this information to assist in patients in making their advance directives as clear as possible and to make patients more aware of the potential limitations of these types of written instructions. Copyright 2003, Elsevier Science (USA). All rights
reserved.
PMID: 12624865 [PubMed - indexed for MEDLINE]

20: Ariz Law Rev 1999;41(2):329-73
End-of-life decision making, therapeutic jurisprudence, and preventive law: hierarchical v. consensus-based decision-making model.
Hafemeister TL.
Chicago-Kent College of Law, Illinois Institute of Technology, USA.
PMID: 12666690 [PubMed - indexed for MEDLINE]

21: Br J Nurs 2003 Mar 27- Apr 9;12(6):391
Advance directives are challenging for nurses.
Castledine G.
University of Central England, Birmingham, and Dudley Group of Hospitals NHSTrust.
Publication Types:
Review
Review, Tutorial
PMID: 12682591 [PubMed - indexed for MEDLINE]
22: Br J Nurs 2003 Mar 27- Apr 9;12(6):344
Comment on:
Br J Nurs. 2003 Mar 13-26;12(5):268.
Elderly patients and the making of living wills.
Publication Types:
Comment
Letter
PMID: 12691096 [PubMed - indexed for MEDLINE]

23: Can Nurse 2003 Mar;99(3):27-31
Primer. End-of-life care.
McGoey A.
Pain and Symptom Management Team, Community Care Access Centre, Thunder Bay, Ontario.
PMID: 12696201 [PubMed - in process]

24: Cancer Nurs 2003 Apr;26(2):105-12

Voices of oncology nurses: What is needed to assist patients with advance directives.
Jezewski MA, Meeker MA, Schrader M.
School of Nursing, University at Buffalo, State University of New York, 14214-3079, USA. Jezewski@buffalo.edu
The process of completing and executing advance directives (ADs) is not without problems and issues that need to be studied. Nurses, by the nature of their practice, are in a unique position to help patients complete ADs. The findings reported in this article focus on an open-ended question that was part of a larger quantitative survey. The open-ended question, "What do oncology nurses need to increase their ability to assist patients with ADs?" was asked of a random sample of Oncology Nursing Society members. The Knowledge, Attitudinal,Experiential Survey on Advance Directives instrument was used to survey a random sample of oncology nurses in four states: California, Illinois, New York, and Texas. Of the 900 nurses who responded to the survey, 677 (75%) wrote responses to the open-ended question. Grounded theory was used to analyze data to establish and saturate categories. The four topics discussed most often by the nurses were time, education, support, and the nurse's role. Nurses also wrote about philosophical issues related to dying, end-of-life issues, and ADs, as well as institutional issues that have an impact on the assistance they can give patients completing ADs. In addition, the category "communicating" was frequently discussed by nurses. The importance of communication was a thread woven throughout their responses.
PMID: 12660559 [PubMed - indexed for MEDLINE]

25: Cancer Nurs 2003 Apr;26(2):113-8
Hospice patient and caregiver congruence in reporting patients' symptom intensity.
McMillan SC, Moody LE.
College of Nursing, University of South Florida, Tampa, 33612, USA. smcmilla@hsc.usfl.edu
As healthcare increasingly moves out of hospitals, the care of patients with cancer is provided in the community with the help of family caregivers. In many cases, nurses depend on family caregivers to provide assessment data about patients. This makes the accuracy and dependability of the data given by caregivers particularly important. However, it is not clear whether caregivers can accurately and dependably report such subjective data as symptom intensity. The purpose of this project was to evaluate the ability of the primary caregiver to report the symptom intensity of hospice patients with cancer. The sample consisted of 264 newly admitted adult patients with advanced cancer in hospice home care and their primary caregivers. These subjects were part of a large National Institutes of Health (NIH)-funded randomized clinical trial focused on symptom management and quality of life. The patients were alert and oriented. Among the questionnaires completed by both patients and caregivers on admission were numeric rating scales for pain and dyspnea and the Constipation Assessment Scale. All of these scales were designed to describe the patient's symptom intensity. The patient sample was predominantly white (83%) and male (57%), with a mean age of 71.6 years. The caregiver sample was predominantly white (85%) and female (78%), with a mean age of 62 years. The results indicated that caregivers significantly overestimated symptom intensity for all three symptoms (P =.000). Furthermore, the limited variance accounted for by the two sets of scores for each of the symptoms (R2 =.16-.26) indicated much more error in the scores than agreement between patient and caregiver. It appears that family caregivers cannot reliably report patient symptom intensity. Healthcare providers need to train family caregivers in conducting systematic assessments instead of assuming that they understand patient symptoms.
PMID: 12660560 [PubMed - indexed for MEDLINE]

26: Clin J Oncol Nurs 2003 Mar-Apr;7(2):131-2
The first state-by-state report card on end-of-life care: how did your state do?
Schulmeister L.
Publication Types:
Editorial
PMID: 12696207 [PubMed - indexed for MEDLINE]

27: Clin J Oncol Nurs 2001 Jul-Aug;5(4):177-8
Supporting alternative families.
Dahlin CM.
Massachusetts General Hospital, Boston, USA.
PMID: 12690621 [PubMed - indexed for MEDLINE]

28: Clin Med 2003 Mar-Apr;3(2):149-52
'If only someone had told me . . .' A review of the care of patients dying in hospital.
Edmonds P, Rogers A.
Department of Palliative Care and Policy, King's College, Weston Education Centre, London. polly.edmonds@kcl.ac.uk
Approximately half of all patients who die do so in hospital. Despite the advent of palliative care in the UK, there is evidence that the care that many patients receive in the final phase of their illness in hospital is poor. Building on a study of bereaved relatives' views of the information provided by an inner city hospital trust during an admission in which a patient died, this article explores the factors that may contribute to sub-optimal care for patients dying in hospital. In particular, a lack of open communication, difficulties in accurate prognostication and a lack of planning of end-of-life care can all result in poor care. Strategies to improve care, such as the use of integrated care pathways, advance directives and education initiatives, are discussed.
PMID: 12737372 [PubMed - in process]

29: Crit Care 2003 Feb;7(1):11-2
Beyond ethical dilemmas: improving the quality of end-of-life care in the intensive care unit.
Rubenfeld GD, Curtis JR.
Assistant Professor of Medicine, Division of Pulmonary and Critical Care Medicine, Harborview Medical Center, University of Washington, Seattle, Washington, USA. nodrog@u.washington.edu
PMID: 12617732 [PubMed - indexed for MEDLINE]

30: Crit Care Med 2003 Apr;31(4):1263-70
Surgeons, intensivists, and the covenant of care: administrative models and values affecting care at the end of life.
Cassell J, Buchman TG, Streat S, Stewart RM, Buchman TG.
Departments of Surgery, Washington University School of Medicine, St. Louis, MO, USA.
CONTEXT: End-of-life care remains a challenging and complex activity in critical care units. There is little information concerning the influence of administrative models of care delivery on end-of-life care. OBJECTIVE: To compare and contrast end-of-life care delivery in intensive care units using "semiclosed," "open," and "closed" administrative models. DESIGN: Ethnographic study of three critical care units. SETTING: University hospitals in the United States and New Zealand. SUBJECTS: Approximately 600 physicians, nurses, allied health personnel, patients, family members, and friends. MEASUREMENTS AND MAIN RESULTS: Ethnographic

observations were made at three sites for 75, 3, and 10 wks, respectively. Eighty end-of-life care episodes were observed. The interactions among care personnel and families varied according to the administrative model, depending on whether surgeons or intensivists had primary patient responsibility. This led to differential timing on the shift from "cure" to "comfort," and differential decision-making power for families.
CONCLUSIONS:
End-of-life care varies according to the administrative model. When surgeons have primary responsibility for the patient, the most important goal is defeating death. When intensivists have sole patient responsibility, scarce resources are considered and quality of life is a significant variable. Discussions about improving the way end-of-life decisions are carried out in intensive care units rarely consider the administrative models and personal, professional, and national values affecting such decisions. To improve care at the end of life, we must critically examine these features.
PMID: 12682502 [PubMed - indexed for MEDLINE]

31: Curr Cardiol Rep 2003 May;5(3):223-8
Management of heart failure in the elderly.
Kerzner R, Rich MW.
Washington University School of Medicine, 660 South Euclid Avenue, Box 8086, St. Louis, MO 63110, USA. mrich@im.wustl.edu
Chronic heart failure is an epidemic disorder in the elderly population. The frequent coexistence of comorbid illnesses and psychosocial issues in older persons often makes diagnosis and management difficult. Physicians must be aware of the current diagnostic modalities and proven therapies as they apply to
elderly patients in order to achieve optimal outcomes. This article reviews new approaches to the diagnosis of heart failure, and discusses the latest evidence for both pharmacologic and nonpharmacologic treatment for this condition. Multidisciplinary strategies for the management of heart failure and end-of-life care are also briefly discussed.
PMID: 12691641 [PubMed - in process]

32: Dimens Crit Care Nurs 2003 Jan-Feb;22(1):35-8
Palliative care services.
Hurst S, Whitmer M.
Critical Care Service, Good Samaritan Regional Medical Center, 1111 E. McDowell Road #118, Phoenix, AZ 85006, USA.
This article presents a program developed at one facility to help provide palliative care services to patients in the intensive care units.
PMID: 12548100 [PubMed - indexed for MEDLINE]

33: Fam Pract 2003 Jun;20(3):304-10
Organizing palliative care for rural populations: a systematic review of the evidence.
Evans R, Stone D, Elwyn G.
Department of Primary Care, University of Wales Swansea Clinical School, Swansea SA2 8PP and Ceredigion and Mid Wales NHS Trust, Bronglais Hospital, Aberystwyth, Ceredigion SY23 1ER, UK.
BACKGROUND: Palliative care services have developed mostly in urban areas. Rural areas typically are characterized by the lack of well-organized services, with primary care professionals, specifically GPs and community nurses, having to undertake most of the palliative care. Little is known, however, either of their views or of how best to organize palliative care in rural areas. OBJECTIVE: The aim of this study was to conduct a systematic literature review of studies that have examined the organization of rural palliative care and the views of professionals in rural areas.

METHOD: Six electronic databases were searched for published studies between 1991 and 2001. Articles had to match against (i) MeSH or keyword terms relating to palliative, terminal or end of life care; and (ii)MeSH or keyword terms relating to rural. A data extraction framework was designed and used systematically by two reviewers to consider research question and method, sample characteristics, selection and size, study quality, summary results and implications. RESULTS: Twenty-six studies were identified. These were mostly questionnaire surveys and reports, and three qualitative studies. No randomized controlled studies or cohort studies were identified. Education and strategic issues were dominant research questions. Both the sample numbers and response rates in the surveys were variable. The qualitative studies had methodological strengths and elicited important views from nurses, carers and families. GPs were, however, unrepresented. Whilst the role of primary care emerged as an important theme, primary care professionals reported difficulties in obtaining education and training. There were also reported problems in symptom control and in the management of emotional issues such as bereavement counselling. Difficulties were also described in accessing specialist services such as hospices, and families were reported as having problems in accessing information. Developments in information technology such as telemedicine were seen as possible solutions to some of the problems. CONCLUSIONS: There is little published work on this topic. Most of the work identifies problems in the delivery of palliative care in rural areas. Whilst primary care professionals are seen as having a key role, there is a need to discover both their views and their needs in this field.
PMID: 12738700 [PubMed - in process]

34: Gerontologist 2003 Apr;43 Spec No 2:76-84

Factors that influence end-of-life care in nursing homes: the physical environment, inadequate staffing, and lack of supervision.
Kayser-Jones J, Schell E, Lyons W, Kris AE, Chan J, Beard RL.
Department of Physiological Nursing, University of California-San Francisco, 2 Kirkham Street, Room N631, San Francisco, CA 94143-0610, USA. jeanie.kayser-jones@nursing.ucsf.edu
PURPOSE: This study investigated the physical environment and organizational factors that influenced the process of providing care to terminally ill nursing home residents. DESIGN AND METHODS: Participant observation, interviews, and event analysis were used to obtain data in two proprietary facilities. RESULTS: The physical environment was not conducive to end-of-life care. The rooms were crowded, there was little privacy, and the facilities were noisy. Inadequate staffing and lack of supervision were among the most significant organizational factors that influenced care. Often, residents did not receive basic care, such as bathing, oral hygiene, adequate food and fluids, and repositioning. A consequence of inadequate staffing was the development of pressure ulcers; 54% of the residents had pressure ulcers; 82% of these residents died with pressure ulcers. IMPLICATIONS: Findings suggest that the nursing home environment in these two facilities, as now structured, is an inappropriate setting for end-of-life care.
PMID: 12711727 [PubMed - in process]

35: Int J Palliat Nurs 2003 Feb;9(2):86; author reply 86-7
Comment on:
Int J Palliat Nurs. 2003 Jan;9(1):39.
An integrated care pathway for the last two days of life.
Smith J, Taylor A, Jones A.
Publication Types:

Comment
Letter
PMID: 12674094 [PubMed - indexed for MEDLINE]

36: Issues Ment Health Nurs 2003 Jan-Feb;24(1):45-57
Nurse-assisted suicide: not an answer in end-of-life care.
King P, Jordan-Welch M.
University of Tennessee, Knoxville, Tennessee, USA. pking@milligan.edu
PMID: 12735074 [PubMed - in process]

37: J Adv Nurs 2002 Dec;40(6):701-9
Pain management problems in patients' terminal phase as assessed by nurses in Finland.
Kuuppelomaki M.
Docent, Research and Development Centre for Social Welfare and Health, Seinajoki, Finland. merja.kuuppelomaki@seamk.fi
BACKGROUND: This study is part of a larger questionnaire survey concerned with the views of nursing staff on physical, emotional and spiritual support for terminally ill patients and decision making on the transition to the terminal phase of treatment. AIM: This article discusses the results concerning the prevalence of physical pain in patients and with problems in pain management. METHODS: A total of 328 nurses working on the inpatient wards of 32 municipal health centres in finland took part. Data were collected with multiple-choice items and one open-ended question, which were part of a larger structured questionnaire. The data were analysed by means of the SPSS statistical software and content analysis. FINDINGS: Dying patients often suffered from pain, which was most commonly because of cancer. Intractable pain was common. The problems of pain management concerned attitudes and qualifications related to treating pain, the assessment of the pain, pain management per se and the organization of pain management. CONCLUSION: The study highlights the need to increase pain education, discussion and agreement on the principles of pain management in municipal health centres in Finland.
Publication Types:
Multicenter Study
PMID: 12473050 [PubMed - indexed for MEDLINE]

38: J Am Coll Surg 2003 Apr;196(4):621-51
When do we stop, and how do we do it? Medical futility and withdrawal of care.
Hinshaw DB, Pawlik T, Mosenthal AC, Civetta JM, Hallenbeck J.
University of Michigan School of Medicine and VA Medical Center, 2215 Fuller Road, Ann Arbor, MI 48105, USA.
PMID: 12691944 [PubMed - indexed for MEDLINE]

39: J Appl Soc Psychol 2002 Jan;32(1):60-85
Individualism, authoritarianism, and attitudes toward assisted death: cross-cultural, cross-regional, and experimental evidence.
Kemmelmeier M, Wieczorkowska G, Erb HP, Burnstein E.
Department of Sociology, Mail Stop 300, Unviersity of Nevada, Reno, NV 89557. markusk@unr.edu
We hypothesized that in individualistic cultures, individualism predicts positive attitudes toward assisted death, whereas authoritarianism is negatively associated with favorable views of this issue. Study 1 confirmed this hypothesis in a Polish sample (n=100). Study 2, using a German sample (n=102), found the predicted relationships for forms of assisted death that involved the individual self-determination of a terminally ill patient. In Study 3 (n=72), we found experimental evidence that priming individualistic aspects of the self-concept results in more

favorable views of physician-assisted suicide. Using a representative sample (n=1158), Study 4 found that across the United States, regional levels of individualism are reflected in corresponding patterns of support for assisted suicide. The discussion focuses on assisted suicide as a cultural phenomenon and explores the implications of growing levels of individualism for public opinion and policy on assisted suicide.
PMID: 12680373 [PubMed - indexed for MEDLINE]

40: J Clin Oncol 2003 Apr 1;21(7):1412-5
Simultaneous care: disease treatment and palliative care throughout illness.
Meyers FJ, Linder J.
PMID: 12663735 [PubMed - indexed for MEDLINE]

41: J Cult Divers 2002 Winter;9(4):118-28
End of life issues in a palliative care framework for a critically ill adult African American with cystic fibrosis: a case study.
McNeal GJ.
School of Nursing, University of Medicine and Dentistry of New Jersey, USA.
The purpose of this investigation, using case study methodology, was to explore the end of life issues and to give meaning to the biopsychosocial experiences of the study participant, an adult African American female patient diagnosed with Cystic Fibrosis. Two theoretical frameworks were used to guide the investigation of the study: Kubler-Ross Model of the Stages of Dying and the Conceptual Framework for Palliative Care Practice. Data analysis included review of medical records and patient journals, interviews, observations and clinical assessment. The findings indicated that end of life issues can be articulated within the context of a palliative care framework and that the biopsychosocial experiences of the dying person acquire meaning when situated within life history, ethical values and metaphysical belief systems.
Publication Types:
Review
Review, Tutorial
PMID: 12674889 [PubMed - indexed for MEDLINE]

42: J Med Ethics 2003 Feb;29(1):10-5
Consent and end of life decisions.
Harris J.
Institute of Medicine, Law and Bioethics, School of Law, University of Manchester, UK. john.m.harris@man.ac.uk
This paper discusses the role of consent in decision making generally and its role in end of life decisions in particular. It outlines a conception of autonomy which explains and justifies the role of consent in decision making and criticises some misapplications of the idea of consent, particular the role of fictitious or "proxy" consents. Where the inevitable outcome of a decision must be that a human individual will die and where that individual is a person who can consent, then that decision is ethical if and only if the individual consents. In very rare and extreme cases such a decision will be ethical in the absence of consent where it would be massively cruel not to end life in order to prevent suffering which is in no other way preventable. Where, however, the human individual is not a person, as is the case with abortion, the death of infants like Mary (one of the conjoined twins in a case discussed in the paper), or in the very rare and extreme cases of those who have ceased to be persons like Tony Bland, such decisions are governed by the ethics of ending the lives of non-persons.
PMID: 12569187 [PubMed - indexed for MEDLINE]

43: J Pain Symptom Manage 2003 May;25(5):438-43
Antimicrobial use in patients with advanced cancer receiving hospice care.
White PH, Kuhlenschmidt HL, Vancura BG, Navari RM.
Walther Cancer Research Center, University of Notre Dame, Notre Dame, IN, USA
Patients with advanced cancer receiving hospice and palliative care are highly susceptible to infections. The decision whether to treat an active or suspected infection in end-of-life care may be difficult. In order to develop guidelines for the use of antimicrobials (antibiotics and antifungals) in palliative care, we discussed antimicrobial options with 255 patients with advanced cancer at the time they entered a community-based hospice and palliative care program. We subsequently documented the use and effectiveness of the antimicrobials employed during the palliative care period. Most patients (79.2%) chose either no antimicrobials or symptomatic use only. Choices were influenced by age, the desire for symptom control, life-prolongation issues, and the condition of the patient. After admission, 117 patients had a total of 129 infections, with the most common sites being urinary tract, respiratory tract, mouth/pharynx, and skin/subcutaneous tissues. The use of antimicrobials controlled symptoms in the majority of the urinary tract infections, but were less effective in controlling symptoms in the other sites of infection. Survival was not affected by the patients' choice of whether to use antimicrobials, the prevalence of infections, or the actual use of antimicrobials. Symptom control may be the major indication for antimicrobial use for patients receiving hospice and palliative care.
PMID: 12727041 [PubMed - in process]

44: J Pain Symptom Manage 2003 Apr;25(4):S53-62
Maximizing benefits and minimizing risks in palliative care research that involves patients near the end of life.
Fine PG.
Department of Anesthesiology, Salt Lake City, UT, USA
Research in end-of-life care is constrained more by pragmatic, social, cultural, and financial constraints than ethical issues that preclude the application of typical research methodologies. When normally accepted and ethically sound protections for subjects (especially for those who lack independent decision-making) are in place, exclusion of patients with far advanced disease from research is in and of itself unethical. Involvement in research may have a therapeutic, anticomiogenic effect on dying patients and their families. Institutional review boards must be educated to evaluate research protocols involving this group of vulnerable patients with an eye toward assuring that ethical safeguards are in place, conflicts of interest are transparent and minimized, and that the proposed methodology has duly considered all practical exigencies so that resources and peoples' time and emotional investments are not squandered. Investigators and research review committees must be knowledgeable about placebo effects and under what types of circumstances their use is justifiable, preferred or requisite to fulfill both ethical and scientific imperatives. Examples of investigations using various research methodologies, along with their respective ethical considerations are provided.
PMID: 12691697 [PubMed - in process]

45: J Palliat Med 2003 Feb;6(1):19-31
Issues in end-of-life care: patient, caregiver, and clinician perceptions.
Farber SJ, Egnew TR, Herman-Bertsch JL, Taylor TR, Guldin GE.
Department of Family Medicine, University of Washington, School of Medicine, Seattle, Washington 98195-6390, USA. sfarber@u.washington.edu
CONTEXT: Review of published research indicates the need to better incorporate patient and caregiver perceptions when providing end-of-life (EOL) care. Although considerable research regarding patient and caregiver experience of EOL has been

done, little research has studied patients, caregivers, and clinicians as a connected system. OBJECTIVE: To study the perceptions of patients, caregivers, and physicians who are already connected with one another in an EOL care experience. DESIGN: Qualitative study consisting of in-depth, open-ended, face-to-face interviews and content analysis. SETTING: Community family practice residency programs in rural and urban settings in the Affiliated Family Practice Residency Network of the Department of Family Medicine, University of Washington School of Medicine. PARTICIPANTS: Forty-two patients and 39 caregivers facing EOL were interviewed either alone or together after referral by their physicians. Additionally, results of previously published findings from interviews with 39 family practice faculty were included. OUTCOME MEASURES: Perceptions of participants on EOL issues. RESULTS: Participants identified four primary issues related to their experience of EOL care: awareness of impending death, management/coping with daily living while attempting to maintain the management regimen, relationship fluctuations, and the personal experiences associated with facing EOL. Participants expected their physicians to be competent and to provide a caring relationship. CONCLUSIONS: Awareness of these crucial patient and caregiver EOL issues and expectations and how they differ from clinician perspectives can assist clinicians to appropriately explore and address patient/caregiver concerns and thereby provide better quality EOL care.
PMID: 12710572 [PubMed - in process]

46: J Palliat Med 2003 Feb;6(1):37-44
Medical residents' perceptions of end-of-life care training in a large urban teaching hospital.
Schwartz CE, Goulet JL, Gorski V, Selwyn PA.
Department of Medicine, Montefiore Medical Center, Albert Einstein College of Medicine, Bronx, New York 10467, USA. chschwar@montefiore.org
BACKGROUND: Contemporary medicine has begun to reemphasize the importance of palliative and end-of-life-care. This shift requires a commensurate change in physician education to provide adequate palliative care training. The present research assessed medical residents' perceptions of their clinical and educational experiences in palliative care training as provided by a large urban teaching hospital. METHODS: All graduating third-year residents in internal medicine, family medicine, and social pediatrics at Montefiore Medical Center were asked to participate in a brief telephone survey. The survey assessed residents' experiences in caring for patients who were dying or had died, and their evaluation of faculty supervision, clinical rotations, and academic activities. RESULTS: Fifty-five residents (90%) were surveyed. They reported caring for few patients at the end of life over their 3 years of training (median of 10 inpatients who died, one outpatient who died, and three outpatients who were potentially terminally ill). Furthermore, the majority of residents gave poor ratings to clinical supervision and to clinical rotations where they were likely to evaluate dying patients (intensive care units and oncology), with only 16% of residents reporting that they had received very good or outstanding palliative care training. IMPLICATIONS: In order to provide adequate palliative care education to future physicians, residency programs must strategically target hospital training units, enhance the quality of palliative care supervision and training that residents receive, and increase the number of dying patients they care for in ambulatory care and nonhospital settings. Recommendations for change are discussed.
PMID: 12710574 [PubMed - in process]

47: J Palliat Med 2003 Feb;6(1):45-57
The challenges and opportunities in providing end-of-life care in nursing homes.
Ersek M, Wilson SA.

Pain Research Department, Swedish Medical Center, and Department of Biobehavioral Nursing and Health Systems, School of Nursing, University of Washington, Seattle, Washington 98122, USA.
Approximately 20% of deaths in the United States occur in nursing homes. That percentage is expected to increase as the population continues to age. As a setting for end-of-life care, nursing homes provide both challenges and opportunities. This article examines factors that impede the delivery of high-quality end-of-life care in nursing homes, such as inadequate staff and physician training, regulatory and reimbursement issues, poor symptom management, and lack of psychosocial support for staff, residents, and families. In addition to discussing hindrances to providing end-of-life care, this article explores characteristics of nursing homes and their staff that support the care of terminally ill residents. Also included is an overview of models for delivering end-of-life care in nursing homes, including provision of hospice services, specialized palliative care units, and consultation services. Finally, this article discusses educational programs and current educational initiatives to enhance end-of-life care in nursing homes.
PMID: 12710575 [PubMed - in process]

48: J Palliat Med 2003 Feb;6(1):86-91
A student-initiated elective on end-of-life care: a unique perspective.
Taylor L, Hammond J, DiCarlo R, Karabatsos G, Deblieux P.
Internal Medicine/Pediatrics Residency Program, Medical College of Wisconsin, Milwaukee, Wisconsin, USA.
Traditionally, curriculum change is a faculty responsibility. However, a first-year medical student, inspired by previous interactions with cancer patients and disillusioned with her education on the physician's role at the end of life, successfully initiated and sustained an end-of-life curriculum change. This article briefly describes the Preceptorship on End of Life Care and then shifts focus to five key dilemmas associated with student-led curriculum change. These dilemmas include articulating the benefits of student-initiated curriculum change, securing resources for curriculum change, the use of peer versus faculty facilitators, determining whether to create an elective or required curriculum, when to offer the course, and how to transition to new student leadership. Recommendations for students/residents seeking to initiate curriculum change are provided, highlighting the need for a collaborative approach of faculty, community affiliates, and students for sustained success.
PMID: 12710581 [PubMed - in process]

49: J Palliat Med 2002 Dec;5(6):843-8
Reflections of physician-authors on death: literary selections appropriate for teaching rounds.
Donohoe M.
Old Town Clinic, Center for Ethics in Health Care, Oregon Health and Science University, Lake Oswego, Oregon 97034, USA. adamsk@ohsu.edu
Physicians constantly confront to death and respond in a variety of ways to the many deaths that they witness and to their own sense of mortality. Student-doctors should be exposed, prior to and during their clinical training, to these different types of responses, so that they can prepare for their encounters with the "ultimate mystery" and realize that their own reactions, uncertainties and fears are neither unique or unnatural. Writings of physician-authors provide an ideal medium for this exposure. Despite improvements in death education in medical schools, studies have described trainees' desire for more education and have documented deficits in the care of dying patients. This paper briefly describes the responses of physician-authors and their fictional characters to death, in hopes of interesting students in reading and stimulating educators to use these and other literary selections in the classroom and on teaching rounds, in order to facilitate introspection and discussion.

Examples of brief readings, which can be used on ward rounds, incorporated into discussions of critical incidents, or read during teachable moments in the outpatient clinic are provided.
PMID: 12685530 [PubMed - indexed for MEDLINE]

50: J Palliat Med 2002 Dec;5(6):849-55
Correlates of health status for family caregivers in bereavement.
Brazil K, Bedard M, Willison K.
Department of Clinical Epidemiology and Biostatistics, Faculty of Health Sciences, McMaster University, Hamilton, Ontario, Canada. brazilk@mcmaster.ca

The purpose of this retrospective cohort study was to identify aspects of caregiving associated with health status among family caregivers in bereavement. Study participants included 151 family caregivers of terminally ill patients who had died, on average, 294 days prior to the study telephone interview. The interview covered two main areas: patient characteristics and caregiver characteristics. Multivariate linear regressions revealed that as the age of the care recipient (regression coefficient [b] = -0.32; 95% confidence interval [CI] -0.48,-0.15) and caregiver (b = -0.14; 95% CI = -0.25, -0.02) increased, caregivers experienced a decline in their physical health during bereavement. Furthermore, caregivers who reported that caregiving interrupted their usual activities (b = -5.97; 95% CI = -9.79, -2.15) had a decline in physical health during bereavement. A poorer mental health status during bereavement was seen in caregivers who reported poor physical health during caregiving (b = -4.31; 95% CI = -8.17, -0.45); and that they received insufficient family support in caregiving (b = -6.01; 95% CI = -9.75, -2.27). It was also revealed that a home death was associated with higher mental health of the caregiver (b = 3.55; 95% CI = 0.26, 6.84). The practice implications of these findings are discussed in this paper.
PMID: 12685531 [PubMed - indexed for MEDLINE]

51: J Palliat Med 2002 Dec;5(6):903-8
Prison hospice and pastoral care services in California.
Linder JF, Knauf K, Enders SR, Meyers FJ.
Department of Internal Medicine and the West Coast Center for Palliative Education, University of California, Davis, Sacramento 95817, USA. Hospice at the California Medical Facility (CMF) Vacaville dates back to the mid-1980s, when the acquired immune deficiency syndrome (AIDS) epidemic began to be felt throughout California's Department of Corrections. Vacaville has served for decades as the principal location for delivering health services to California's incarcerated men. Informal hospice-like services were inspired by Elisabeth Kubler-Ross and through inmate and community calls for more humane care for dying inmates. By 1990, efforts to formally establish a hospice were under way. In 1996, a 17-bed, state-licensed hospice began caring for dying inmates. An interdisciplinary team plans and delivers the care, meeting weekly to admit and review patients. The Pastoral Care Services (PCS) inmate volunteer program, with more than 50 trained participants, provides care and comfort to dying patients in hospice and to ill patients on the general medicine service. PCS volunteers perform many duties, including sitting vigil with actively dying inmates. Inmates enrolling in hospice have to forgo further curative therapy, consent to the program in writing, and have a 6-month or less survival prognosis; patients are not required to have a do-not-resuscitate (DNR) order, but are encouraged to consider one. Training for physicians, staff and PCS volunteers is provided by the University of California, Davis faculty of the West Coast Center for Palliative Education. Bereavement services are provided for PCS volunteers, other inmate "family" and staff. Family and friends of the deceased in the

free community are followed by phone, mail, and primarily through referral to resources in their local area.
PMID: 12685537 [PubMed - indexed for MEDLINE]

52: J Palliat Med 2002 Dec;5(6):819-27
The 107th Congress' legislative proposals concerning end-of-life care.
Goldstein NE, Lynn J.
The Robert Wood Johnson Clinical Scholars Program, Yale University, New Haven, Connecticut, USA.

PURPOSE: The current health care system cannot reliably meet the needs of patients with eventually fatal chronic illnesses near the end-of-life. Enduring change requires improved public policy, in part because most paid care for serious illness at the end of life now relies on federal programs. This project reviews the legislation proposed in the 107th Congress (2001-2002) related to improving end-of-life care. METHODS: We searched THOMAS, the search engine of the Library of Congress, to identify all bills relating to end-of-life care introduced in either house of the U.S. Congress during the 2001/2002 legislative period. Using explicit criteria intended to find any that received serious attention and incorporating recommendations of political consultants, the initial 563 bills narrowed to 22. We summarize their status as of October 24, 2002. RESULTS: The 22 bills identified dealt with the following topics: demonstration or research projects (9), palliative care or hospice (8), caregivers (7), chronic illness generally (5), care coordination (2), and long-term health care (3). Dementia, graduate medical education, nursing, and pain appeared in 1 bill each. Congress enacted only 1 of the bills. Only 7 bills had more than 10% of either house as sponsors. CONCLUSIONS: While Medicare reform and health care costs are prominent topics among policymakers, Congress is considering essentially no fundamental changes that would remedy the problems associated with health care for the elderly who are seriously ill near the end-of-life. The mismatch between the urgency of policy reform and the lack of vehicles and momentum to achieve reform calls for consensus and leadership from those concerned with hospice and palliative care.
Publication Types:
Review
Review Literature
PMID: 12685528 [PubMed - indexed for MEDLINE]

53: J Palliat Med 2002 Dec;5(6):877-82
Development of a bereavement program in a tertiary medical center.
Snyder D, Ellison NM, Neidig N.
Palliative Medicine Program, Geisinger Health System, Danville, Pennsylvania 17822-0140, USA.
Despite the fact that our institution has approximately 40 inpatient deaths per month, until recently virtually no support was provided to families/friends of the deceased. We developed and implemented a comprehensive bereavement program to prepare individuals for the loss and also to support them through the grieving process.
PMID: 12685534 [PubMed - indexed for MEDLINE]

54: J Palliat Med 2002 Dec;5(6):813-4
Comment in:
J Palliat Med. 2002 Dec;5(6):807-11.
End-of-Life care: the death of palliative medicine?
Davis MP, Walsh D, LeGrand SB, Lagman R.
Publication Types:

Editorial
PMID: 12685526 [PubMed - indexed for MEDLINE]

55: J Palliat Med 2002 Dec;5(6):895-901
Needs of the dying in nursing homes.
Reynolds K, Henderson M, Schulman A, Hanson LC.
Program on Aging, Center for Health Ethics and Policy, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina 27599-7110, USA.
OBJECTIVE: To describe the palliative care needs of dying nursing home residents during the last 3 months of life. METHODS: Nurses, aides, and family members completed structured interviews after all deaths of residents in two nursing homes during a 1-year study period. For each resident who died, family and staff caregivers answered parallel questions on the presence of physical and emotional symptoms, unmet needs for treatment of these symptoms, and the quality of the dying experience. RESULTS: Of 259 eligible respondents 176 completed interviews (68%). Decedents' average age was 82, and 90% died in the nursing home rather than in a hospital. Most deaths were preceded by orders to withhold resuscitation (79%) and other treatments (39%). The most common physical symptoms were pain (86%), problems with personal cleanliness (81%), dyspnea (75%), incontinence (59%), and fatigue (52%). Depressed mood (44%), anxiety (31%), and loneliness (21%) were common emotional symptoms. Respondents believed residents needed more treatment than they received for emotional symptoms (30%), personal cleanliness (23%) and pain (19%). Fifty-eight percent of respondents believed the resident experienced a "good death," as they would have wanted it to be. CONCLUSIONS: Dying nursing home residents need improved emotional and spiritual care, help with personal cleanliness, and treatment for pain. Efforts to improve end-of-life care in nursing homes should combine traditional palliative care services with increased attention to emotional symptoms and personal care services.
Publication Types:
Multicenter Study
PMID: 12685536 [PubMed - indexed for MEDLINE]

56: J Palliat Med 2002 Dec;5(6):916-9
Improving knowledge and communication through an advance directives objective structured clinical examination.
Aronson SG, Kirby RW.
Department of Psychiatry, University of Illinois College of Medicine at Urbana-Champaign, Urbana, Illinois, USA. saronson@uiuc.edu
Many physicians and patients do not discuss care at the end of life and most practicing physicians have had little formal education concerning end-of-life discussions. To address this deficiency, our internal medicine residency faculty participated in the National End of Life Residency Education Project and implemented a series of educational initiatives including an advance directives Objective Structured Clinical Examination (OSCE). The 20-minute station assessed knowledge about the key issues that differentiate types of advance directives; and communication issues that arise when discussing advance directives. OSCE results revealed that most residents readily learned to differentiate types of advance directives, appreciated fear and psychosocial factors as barriers to communication, and emphasized that do-not-resuscitate (DNR) orders did not mean a lack of treatment. Residents had difficulty discussing the influence of coping style and psychological defensiveness on behavior, and recognizing that patient's thoughts and concerns about dying or DNR orders might influence end of life wishes and behavior. The Advance Directives OSCE is a useful initial assessment of knowledge and ability to address basic end of life issues.

PMID: 12685540 [PubMed - indexed for MEDLINE]

57: J Palliat Med 2002 Dec;5(6):909-10
Tube feed or not tube feed?
Hallenbeck J.
VA Palo Alto HSC, California 94304, USA. james.hallenbeck@med.va.gov
Tube feeding should always be considered relative to patient goals. Physicians should be prepared to discuss tube feeding as an option bearing in mind what evidence (or lack thereof) exists that tube feeding will help reach such goals.
PMID: 12685538 [PubMed - indexed for MEDLINE]

58: J Palliat Med 2002 Dec;5(6):911-3
On the day that hairy died.
Hensel WA.
Moses Cone Family Practice Center, Greensboro, NC 27401-1007, USA. bill.hensel@mosescone.com
PMID: 12685539 [PubMed - indexed for MEDLINE]

59: JAMA 2003 Apr 23-30;289(16):2113-9
Practical considerations in dialysis withdrawal: "to have that option is a blessing".
Cohen LM, Germain MJ, Poppel DM.
Department of Psychiatry, Baystate Medical Center, Springfield, Mass 01199, USA. lewis.cohen@bhs.org
Cessation of life-support treatment is an appropriate option for situations in which the burdens of therapy substantially outweigh the benefits. Decisions to withdraw dialysis now precede 1 in 4 deaths of patients who have end-stage renal disease. Guidelines have been recently published to assist clinicians in making these complex and emotionally charged determinations, and they include: relying on shared decision making by all participants, obtaining informed consent, estimating the prognosis on dialysis, adopting a systematic approach for conflict resolution of disagreements, honoring advance directives, and ensuring the provision of palliative care. These principles are discussed in relation to an elderly man with dementia whose family decided to terminate maintenance hemodialysis.
PMID: 12709469 [PubMed - indexed for MEDLINE]

60: Med Care 2003 Apr;41(4):458-66
Factors associated with the time nurses spend at the bedsides of seriously ill patients with poor prognoses.
Sulmasy DP, Sood JR.
John J. Conley Department of Ethics, St. Vincent's Manhattan, New York, New York 10011, USA. daniel_sulmasy@nymc.edu
BACKGROUND: Little is known about the time health professionals spend with inpatients that are close to the end of life. SUBJECTS AND METHODS: We asked day-shift nurses to use a standardized log sheet to record how much time they spent in various categories of activity for 146 seriously ill medical inpatients with poor prognoses at 2 teaching hospitals. RESULTS: The mean patient age was 68, and the mean APACHE-III physiology score 28; 59% were white, 56% were women, 41% had cancer or HIV, and 81% had do not resuscitate (DNR) orders. The mean amount of time nurses spent with patients per 12-hour day shift was 53 min. In bivariate analyses, sex, religion, diagnosis and insurance status were not associated with nursing bedside time. In an ANOVA model, patients with DNR orders received more time than those without DNR orders (56 vs. 39 min, P = 0.04), and white patients received more bedside time than nonwhites (57 vs. 46 min, P = 0.01), even

after controlling for severity of illness and DNR status. Among the 47 mentally alert patients who could be interviewed, symptom severity, quality of care, and satisfaction ratings were not associated with nursing bedside time. CONCLUSIONS: In this population, nurses spent less time with nonwhite patients and more time with patients with DNR orders. That patients with DNR orders received more time may be reassuring. However, further investigation will be required to confirm these results, to understand why nonwhite patients appear to have received less bedside nursing time, and to investigate further the relationship between time, satisfaction, and quality of care.
PMID: 12665710 [PubMed - indexed for MEDLINE]

61: Mo Med 2003 Jan-Feb;100(1):82-6
The burden of caregiving at the end-of-life.
Fleming DA.
Center for Health Ethics, Department of Health Management and Informatics, University of Missouri-Columbia School of Medicine, USA.
Nonprofessional caregiving is crucial to effective end-of-life care for patients who wish to die at home. The burden of caregiving may lead to physical illness, emotional distress, financial hardship, and early mortality in the caregiver. Unmet caregiver needs have historically been poorly recognized and incompletely studied. Early recognition of caregiver distress, validation of the caregiver role, and effective communication by physicians may ease the burden of caregiving and help to secure a trusting partnership between the physician and the patient-caregiver unit at the end of life.
PMID: 12664710 [PubMed - indexed for MEDLINE]

62: Mo Med 2003 Jan-Feb;100(1):76-81
Relieving non-pain suffering at the end-of-life.
Cravens DD, Anderson CM.
University of Missouri Columbia-School of Medicine, USA.
We discuss non-pain problems at end-of-life in this paper. Management of these problems is key to ensuring relief of suffering. Much of this paper is a reiteration of the material on common physical symptoms, which is presented in module 10 of the Education for Physicians on End-of-life Care (EPEC) project of the American Medical Association in conjunction with the Robert Wood Johnson Foundation.
PMID: 12664709 [PubMed - indexed for MEDLINE]

63: Mo Med 2003 Jan-Feb;100(1):69-75
Cultural sensitivity in end-of-life discussions.
Fleming DA.
Center for Health Ethics, Department of Health Management and Informatics, University of Missouri-Columbia School of Medicine, USA.
Cultural origins influence the way patients and health care providers think about care and treatment at the end-of-life. With increasing ethnic diversity there is greater chance that clinical encounters will occur between individuals of different backgrounds, therefore there is greater risk of misunderstanding. Health care providers should be mindful of cultural differences when informing patients, discussing advance care planning, responding to requests for assistance in dying, and responding to requests for limiting treatment.
PMID: 12664708 [PubMed - indexed for MEDLINE]

64: Mo Med 2003 Jan-Feb;100(1):62-8
Helping older patients and their families decide about end-of-life care.
Zweig S, Mehr DR.

Department of Family and Community Medicine, University of Missouri Columbia-School of Medicine, USA.
Three-fourths of those who die in America are 65 or older. In all but the cases where death is sudden and unexpected, decisions frequently must be made about whether to limit treatment. In this paper, we provide a framework and specific tools that may help physicians in talking to older patients and their family members about end-of-life care. After briefly reviewing the demography of dying and methods of advance care planning, we propose a four-step process for deciding about end-of-life care: 1. Identifying patient preferences. 2. Communicating about medical prognosis. 3. Defining goals of care. 4. Implementing a management plan consistent with those goals. The paper concludes with special considerations about four common experiences of dying as an older person: chronic diseases with acute exacerbations (e.g. congestive heart failure or chronic obstructive lung disease), cancer, end stage dementia, and unexpected catastrophic decline.
PMID: 12664707 [PubMed - indexed for MEDLINE]

65: Mo Med 2003 Jan-Feb;100(1):15
Comment on:
Mo Med. 2002 Nov-Dec;99(10):571-6.
Spirituality and end-of-life care.
Davis TN 3rd.
Publication Types:
Comment
Letter
PMID: 12664704 [PubMed - indexed for MEDLINE]

66: Mo Med 2003 Jan-Feb;100(1):6-8
The opportunities of caring at the end-of-life.
Fleming DA.
Publication Types:
Editorial
PMID: 12664701 [PubMed - indexed for MEDLINE]

67: Nephrol News Issues 2003 Feb;17(3):43-5, 49-50
Palliative care in ESRD.
PMID: 12655998 [PubMed - indexed for MEDLINE]

68: Nurs Ethics 2003 Mar;10(2):175-85
Ethical issues after the disclosure of a terminal illness: Danish and Norwegian hospice nurses' reflections.
Lorensen M, Davis AJ, Konishi E, Bunch EH.
Institute for Nursing Science, University of Oslo, Blindern, Norway. margarethe.lorensen@sykepleievit.uio.no
This research explored the ethical issues that nurses reported in the process of elaboration and further disclosure after an initial diagnosis of a terminal illness had been given. One hundred and six hospice nurses in Norway and Denmark completed a questionnaire containing 45 items of forced-choice and open-ended questions. This questionnaire was tested and used in three countries prior to this study; for this research it was tested on Danish and Norwegian nurses. All respondents supported the ethics of ongoing disclosure to terminally ill patients based on ethical principles embedded in their country's Patients' Rights Acts. Truth, as an intrinsic value, proved foundational to patient autonomy, the most frequent ethical principle these nurses reported to justify their ethical position on information disclosure to terminally ill people. Telling the truth about a diagnosis was not the end of ethics in hospice care, but rather the beginning because what occurs ethically in dealing with prognosis

issues became central to these hospice nurses, the patients and their families. Coupled with truth-telling, compassionate interaction and care become extensions of patients' rights.
PMID: 12659488 [PubMed - indexed for MEDLINE]

69: Nurs J India 2002 Nov;93(11):249-51
Management of physical symptoms in terminal illness.
Gopalkrishnan S.
Bharati Vidyapeeth Deemed University, College of Nursing, Pune-43.
PMID: 12718112 [PubMed - indexed for MEDLINE]

71: Nurs Stand 2003 Mar 5-11;17(25):14
You only die once. Interview by Judy Czylok.
Polack F.
PMID: 12674005 [PubMed - indexed for MEDLINE]

72: Nurs Stand 2003 Mar 5-11;17(25):40-4
Euthanasia: a need for reform.
Moody J.
Napier University, School of Acute and Continuing Care Nursing, Edinburgh.
j.moody@napier.ac.uk
Recent high profile right-to-die cases have served to heighten the confusion surrounding euthanasia, particularly in relation to active and passive euthanasia. It is apparent that the underlying philosophical basis of the active-passive distinction has led to distortions in the law surrounding this issue, which further compounds the confusion. It is time for a more honest approach to assistance in dying. In the long-term, reform is inevitable and may involve reclassifying passive and active euthanasia as life-terminating acts. Nurses need to have an understanding of the ethical and legal basis of euthanasia to acknowledge and define their possible future role in relation to the provision of life-terminating acts.
Publication Types:
Review
Review, Tutorial
PMID: 12674013 [PubMed - indexed for MEDLINE]

73: Nurs Stand 2003 Mar 5-11;17(25):13
Where there's a will....
Duffin C.
PMID: 12674004 [PubMed - indexed for MEDLINE]

74: Nurse Educ 2003 Mar-Apr;28(2):71-6
Strategies for teaching loss, grief, and bereavement.
Matzo ML, Sherman DW, Lo K, Egan KA, Grant M, Rhome A.
Union Institute and University, Cincinatti, Ohio, USA. mmatzo@tui.edu
Teaching loss, grief, and bereavement to nursing students should be an interactive process to stimulate critical thinking and address the affective domain of learning. Lecture as a teaching methodology may be the easiest to prepare and deliver; however, used alone, it is ineffective in identifying perceptions, fears, and issues related to dying and death. Personal and professional experiences of loss, grief, and bereavement are central to student's learning of effective and compassionate care of the dying patient and their family. Strategies that explore such experiences allow students to move forward and focus on the cognitive retention of content related to loss, grief, and bereavement, as well as the ability to learn related psychomotor skills. The authors discuss pedagogical methods for

teaching student nurses about loss, grief, and bereavement utilizing the End of Life Nursing Education Consortium (ELNEC) curriculum training materials.
PMID: 12646826 [PubMed - indexed for MEDLINE]

75: Oncol Nurs Forum 2003 Jan-Feb;30(1):E1-E11
The role of oncology nursing to ensure quality care for cancer survivors: a report commissioned by the National Cancer Policy Board and Institute of Medicine.
Ferrell BR, Virani R, Smith S, Juarez G; National Cancer Policy Board and Institute of Medicine.
Department of Nursing Research and Education, City of Hope National Medical Center, Duarte, CA, USA. bferrell@coh.org
PURPOSE: To examine the roles of oncology nurses in improving quality care for cancer survivors. DATA SOURCES: A content analysis of textbooks, journals, and key documents; surveys of graduate oncology nursing programs and the Oncology Nursing Society's Survivorship Special Interest Group; review of the nursing licensure examination and oncology nursing certification; review of undergraduate and graduate nursing standards; and review of currently funded nursing research. DATA SYNTHESIS: Ten critical content areas of cancer survivorship were used for the analysis: description of population of cancer survivors, primary care, short- and long-term complications, prevention of secondary cancer, detecting recurrent and secondary cancers, treatment of recurrent cancer, quality-of-life issues, rehabilitative services, palliative and end-of-life care, and quality of care. Although findings within each source indicated significant information related to the roles of nurses in caring for cancer survivors, deficits also were identified. CONCLUSIONS: Review of key literature and resources suggests significant contributions by oncology nursing over the past two decades to the area of cancer survivorship. IMPLICATIONS FOR NURSING: Support is needed to expand education and research to ensure quality care for future cancer survivors.
Publication Types:
Review
Review, Tutorial
PMID: 12515992 [PubMed - indexed for MEDLINE]

76: Oncol Nurs Forum 2003 Jan-Feb;30(1):35-50
Palliative and end-of-life care: policy analysis.
Reb AM.
College of Nursing, University of Maryland, Baltimore, MD, USA. amrreb@aol.com
PURPOSE/OBJECTIVES: To present an overview of policy issues affecting hospice and palliative care focusing on the nursing home and hospital settings and to discuss factors affecting end-of-life care, policy initiatives, recent legislation, and nursing implications. DATA SOURCES: Published articles; technical, advisory, and research reports (from government, professional, and private organizations); newsletters; textbooks; meeting minutes; online references; and legislative documents. DATA SYNTHESIS: Improvements are needed in end-of-life care, especially with regard to access, delivery, and financing of such services. Legal, organizational, and reimbursement policies, as well as healthcare professional education, have been identified as areas that need improvement. The nursing shortage and variable reimbursement policies for nursing services have a significant impact on access to quality end-of-life care, especially for underserved populations. CONCLUSIONS: A need exists for further research, including demonstration projects to test new ways to deliver and integrate hospice and palliative care throughout the illness continuum. Education and research are needed regarding symptom management, communication and decision making, caregiver support, and other end-of-life issues. Nursing interventions, palliative care networks, and other models that promote a coordinated approach to care delivery have been shown to decrease costs and

improve quality of care. IMPLICATIONS FOR NURSING: Nurses play a key role in advancing improvements in palliative and end-of-life care through their involvement in educational, quality improvement, research, and legislative initiatives. Nursing activities in these areas may contribute to improved access, lower costs, and improved quality of care in advanced illness.
Publication Types:
Review
Review, Academic
PMID: 12515982 [PubMed - indexed for MEDLINE]

77: Oncol Nurs Forum 2003 Jan-Feb;30(1):123-9
Methodologic issues in collecting data from debilitated patients with cancer near the end of life.
McMillan SC, Weitzner MA.
College of Nursing, University of South Florida, Tampa, FL, USA. smcmilla@hsc.usf.edu
PURPOSE/OBJECTIVES: To report the experience of a group of researchers who have had a year of experience in a clinical trial with homecare hospice patients. SAMPLE: 150 hospice patients with cancer and their primary caregivers who were accrued to a National Cancer Institute-funded clinical trial focusing on quality of life. METHODS: The investigative team kept careful records of the numbers of patient/caregiver dyads accrued to the study and the reasons for nonaccrual as well as reasons for attrition. Data were analyzed using descriptive statistics. FINDINGS: During a nine-month period, the hospice admitted 2,517 patients; 75% had cancer and 95% had caregivers, making them eligible for the study. However, after further screening, only 19% were eligible for contact and only 5% finally were accrued to the study. For the 125 patient/caregiver dyads actually accrued to the study, baseline data were obtained on only 50% and evaluable follow-up data on only 50%. CONCLUSIONS: Accruing patients to clinical trials and retaining them when they are critically ill and near death are extraordinarily difficult tasks. The inability to recruit and retain subjects for clinical trials has implications for integrity of data, data analysis, success of the project, and the cost of conducting such projects in the future.
Publication Types:
Clinical Trial
Randomized Controlled Trial
PMID: 12515990 [PubMed - indexed for MEDLINE]

78: Physician Exec 2003 Mar-Apr;29(2):44-6
Two hospice patients and the roles of the physician and the physician executive.
Olds JW.
Cahaba GBA Midwest, Des Moines, Iowa, USA. jolds@cahabagba.com
Hospice care is available nearly everywhere. Yet some physicians aren't aware of its role in end-of-life care. Explore what hospice care provides and how patients and their families may benefit.
PMID: 12685270 [PubMed - indexed for MEDLINE]

79: Swiss Med Wkly 2002 Nov 2;132(39-40):562-5
Quality of life of Do-Not-Resuscitate (DNR) patients: how good are physicians in assessing DNR patients' quality of life?
Junod Perron N, Morabia A, de Torrente A.
Service de medecine interne, Hopital de la Ville, La Chaux-de-Fonds, Switzerland. noelle.junod@hcuge.ch
QUESTIONS UNDER STUDY: To assess 1) the impact of quality of life evaluation on the implementation of Do-Not-Resuscitate (DNR) orders by physicians, 2) the accuracy of physicians' estimation of DNR patients' quality of life. METHODS: A 10-

month prospective clinical study in a community hospital including 255 DNR patients and 9 physicians in postgraduate training. Outcomes of interest were the influence of quality of life on the DNR decision and the assessment from patients and physicians of five different components related directly or indirectly to quality of life: mental (the Mini Mental State Examination), physical (the Activities of Daily Living) and social (Framingham Disability), degree of pain (visual analogical scale of pain) and of depression (Geriatric Depression Scale). RESULTS: Quality of life intervened in more than 70% of the DNR decisions. However, physicians underestimated quality of life components of DNR patients (Kappa <0.4 for each functionality). Severe depression, social isolation and physical dependence influenced negatively patients' perception of their quality of life (p <0.01). CONCLUSION: Physicians often (71%) rely on the assumed quality of life of their patients in their DNR decision but unfortunately tend to underestimate it. Greater involvement of patients in the DNR decision could improve quality of care.
PMID: 12571762 [PubMed - indexed for MEDLINE]